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Information Needs Expressed During Patient-Oriented Oncology Consultations: Quantity, Variation, and Barriers

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Abstract

High-quality oncology consultation includes *patient-oriented communication* tailored to patients' individualized needs. Common methods used in studies to increase question-asking are prompt lists and coaching pre-consultations. However, our patients were encouraged to ask questions by the physician during their visit. We aimed to estimate the *quantity, nature, and variation* of their questions when they were invited to ask by their oncologist. During radiotherapy consultations from 2012 to 2016, patient's questions were deliberately elicited and physician-transcribed. We derived mean and median number of questions per patient, variance by patient factors, and a taxonomy of subjects using thematic analysis. Three hundred ninety-six patients asked 2386 questions, *median asked per patient* = 6 (interquartile range = 4). We found significant variance with *age* (mean = 6.9 questions for < 60 years, 5.4 for ≥ 70 years) $p = 0.018$, *insurance type* (mean = 4.7 for Medicaid, 7.2 for private insurance) $p = 0.0004$, and *tumor site* (mean number of questions: skin = 4.6, lymphoma = 5.2, lung = 5.8, breast = 6.1, prostate = 6.3, rectum = 6.7 head and neck = 6.9, brain = 7.0, bladder = 7.2, anus = 8.8, others = 5.8) $p = 0.0440$. Of the diverse set of 57 topics, the commonest were 1. logistics, 2. radiotherapy details, 3. side effects, 4. diagnosis, and 5. stage and prognosis. Only 17 topics were asked by more > 10% of patients and 40 topics were asked by < 10% of patients. With median of 6 questions, it is practicable to routinely elicit and address individualized information needs. Potential barriers may be older and underinsured patients. The wide variety of topics, often pertaining to individuals' case, suggests that cancer clinicians should take time-out during consultation to elicit patients' questions to accomplish best-practice communication.

Keywords Cancer · Oncology · Communication · Patient-oriented communication · Radiotherapy · Personalized medicine · Nature of information needs · Quantity of information need · Patient-reported information needs · Variation of information needs · Patient-centered communication · Frequently asked radiotherapy questions · Barriers to communication, question-asking

Introduction

We hypothesized that individualized patients' information needs are manageable but so diverse that information customization is necessary. The purposes of this study were to describe and analyze the quantity and spectrum of information needs of patients at initial radiotherapy consultation for a variety of cancers, and to find out if there were any differences in the quantity of information requested with variation in patient or tumor characteristics. We studied the questions that patients asked when they were prompted by their physician at the time when they could have answers to their questions. This contrasts to the commoner reported methods that are used to encourage patients to express their information needs: use of

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prompt lists or coaching; both of which are performed by *another member* of the care team and *prior* to consultation [1, 2].

Whether physicians meet the information needs of patients undergoing radiotherapy is ranked by patients as one of the top ten crucial elements of care [3]. The American College of Radiology and the American Society for Radiation Oncology recognize that high-quality consultation includes patient-oriented communication [4]. Care providers are unlikely to know what patients want to know unless they elicit their questions. Yet, this may not be routinely done in up to 45% of patients [5]. Physicians may be reluctant to enquire actively about patients' questions [6], use avoidance strategies such as focusing on medical information [7] or using closed questions [8], or may be unaware that patients may not understand the information that is provided [9] or may worry that it may consume too much time. This study, therefore, assessed the quantity of questions that were asked when the radiation oncologist dedicated unlimited time and effort to this portion of their initial consultation and deliberately invited each patient to ask all their questions as part of a validated communication technique [10].

Although cancer-specific websites often do not contain thorough answers to many questions even for common cancers [11], a common approved approach is to provide generic printed, graphic, or internet-based information without personalization. This study also evaluated the nature of patients' questions using a thematic analysis [12] to estimate whether generic information materials could be sufficient.

Payors are moving towards compensation of high-quality patient care, yet they have not coded this crucial communication element as a metric for high-quality care [13]. This study draws attention to the need for research to clarify the benefits and resource implications of patient-oriented communication that may enable a better course of therapy for both patients and healthcare providers [14–20].

Methods

With institutional review board approval, we retrospectively reviewed the medical records of 579 unselected consecutive patients who underwent consultation at a free-standing cancer center from August 2012 to September 2016 to extract and list all their questions.

These questions had been elicited and documented during each of their consultations. All the patient's questions had been deliberately prompted using a validated communication technique [10]. During history-taking, patients were asked to express what they knew about their illness and what they understood about the purpose of the consultation. After history-taking and physical examination, each patient and supporting companions had been instructed to state all their questions which were elicited exhaustively, i.e., after patients asked their questions, they were further prompted and encouraged until they verified that they had no further questions. Questions were requested up-front before any information was given to patients unless they requested information before asking their questions. All questions were transcribed by the interviewing physician as soon as they were stated and subsequently documented in the patients' record.

All patients' questions had been answered using language and tools that were appropriate to each patient. Patient understanding was routinely verified. This was done by asking patients to express what they understood about what was told to them. If they expressed a misunderstanding of the information or had not learnt the information, it was re-taught until their understanding was verified. They were also asked about how they felt about the information given. Patients were given other essential information if they had not requested it such as their options, risks, and benefits of radiotherapy, technique, logistics, side effects, and its management. This practice of the physician prompting and encouraging question-asking at the time when patients can get answers to their questions is unlike the commoner-reported methods: *use of prompt lists or coaching*. These two other methods are usually performed by another member of the care team and done *prior* to consultation [1, 2].

We excluded 183 patients from the analysis for the following reasons: 117 patients because their questions were not documented (unless it was specified that they had had no questions), 57 patients because their consultations were not for radiotherapy, 6 patients because they had benign disease, and 3 patients for other reasons that rendered their data irrelevant to the goal of the study.

Pilot Group to Define the Information Topics for Data Abstraction

To gather information on the topics that patients asked about, we created a checklist of topics. The list of topics was generated from the questions that had been asked by a sample of patients. This sample is referred to as the pilot group and consisted of all patients who presented for consultation during the 6-month period from January 2016 to June 2016. We studied the medical records of this pilot group. All *questions* that were asked by each patient of this pilot cohort were read and listed, totaling 175 questions. A thematic analysis of these 175 questions [12] was performed and they were classified into 53 clear concise information *topics*. To the topics of the pilot group, we added three topics on etiology and epidemiology that are commonly included in the educational materials offered to patients and one called "other" which would include questions that could not fit into any of the defined topics. Fifty-seven topics in total were therefore formulated and compiled into a checklist to be used for data abstraction from the entire study. They are listed in Table 2. The analysis of the entire cohort (patients who attended from August 2012 to September 2016) included the patients who were in the pilot group (patients who attended from January to June 2016).

Taxonomy of Topics for Data Reduction

Of the 57 topics on the checklist that was generated from the questions of the pilot group, those that were similar were grouped into themes and 34 information *themes* were identified. Each topic and theme were grouped into nine broader *subjects* and into two *overarching areas* as either disease-related or radiation modality-related. Examples of how questions were classified into topics, themes, and areas are depicted in Fig. 1.

Data Collection

A data collection sheet was designed for coding to capture data of the entire cohort that included the pilot group. The sheet contained a checklist of the 57 topics, their classification into the respective 34 themes, and fields to record the absolute number of questions asked by each patient and their characteristics: age, race, gender, insurance type, and Karnofsky performance status and their tumor characteristics (stage, primary cancer site, treatment goal, whether treatment was of an initial cancer or a recurrence, and treatment was of a primary or metastatic site).

The records of all 396 patients were read, and each of their questions was classified into 1 of the 57 information topics, 34 themes, 9 subjects, and 2 overarching areas. If patients asked a question that was classified as "other," we recorded the specific question. Their characteristics were recorded.

We calculated data the mean and median number of questions asked per patient, mean and median number of themes asked per patient, the relative frequency of each topic among all patients and among all questions, and the relative frequency of each theme, subject, and overarching area.

To test for variation of the volume of information asked with patient and tumor variables, the mean number of questions and mean number of themes asked according to each characteristic were calculated, and the difference of these means were evaluated by the Kruskal–Wallis analysis of variance (ANOVA). We used the SAS statistical software package (SAS Institute, Cary, NC).

Results

Patients' Characteristics

Characteristics of the 396 patients studied are given in Table 1. Their mean age was 65.1 years (median 65.3, range 27 to 94). Their median Karnofsky performance status was 90 (range 50 to 100).

Quantity of Questions and Themes According to Patients' Characteristics

A total of 2386 questions were asked. The most striking finding was that the median number of *questions asked per patient was only 6* (range 0 to 16, interquartile range 4). The mean number of questions and mean number of themes asked according to patients' characteristics are shown in Table 1. It shows an interesting finding: there is a statistically significant difference in the number of questions and number of themes asked according to age and type of health insurance. There is a statistically significant difference in the number of questions asked according to the anatomical site of the primary tumor.

The mean number of questions asked by patients *according to their age* was 6.9 for < 60 years, 6.2 for 60–69 years, and 5.4 for > 70 years old ($p = 0.0018$). The mean number of themes asked by patients *according to their age* was 6.8 for < 60 years, 6.1 for 60–69 years, and 5.4 for > 70 years ($p = 0.0049$).

The mean number of questions asked by patients *according to insurance coverage* was 7.2 for private insurers, 6.3 for Veterans Affairs/Tricare, 5.7 for Medicare, 5.4 for none/self-pay, and 4.7 for Medicaid ($p = 0.0004$). The mean *number of themes* asked according to insurance coverage was 7.1 for private insurers, 6.1 for Veterans Affairs/Tricare, 5.7 for Medicare, 5.5 for none/self-pay, and 4.4 for Medicaid ($p = 0.0008$).

The mean number of questions asked by patients *according to their primary tumor site* was 8.8 for anal canal, 7.2 for bladder, 7 for brain, 6.9 for head and neck, 6.7 for rectum, 6.3 for prostate, 6.1 for breast, 5.8 for lung, 5.8 for others, 5.2 for lymphoma, and 4.6 for skin ($p = 0.0440$).

There were slightly more questions asked if treatment was for a primary cancer (mean = 6.3 questions) versus treatment for a recurrence (mean = 5.3) ($p = 0.078$). We found no statistically significant difference in mean number of questions or themes asked according to race, gender, Karnofsky performance status, tumor stage, or treatment of a primary versus metastatic site.

Topics and Themes

Table 2 states the 57 question topics. They are ranked in order of frequency asked. The table states the number of patients and proportion of patients who asked each of the topics, the number of questions asked on each topic, and its respective proportion of all the questions. It is interesting to note that when we look at topics *as a proportion of patients who ask them*, only a few topics were asked by many patients while most topics were asked by only a few patients. As given in the

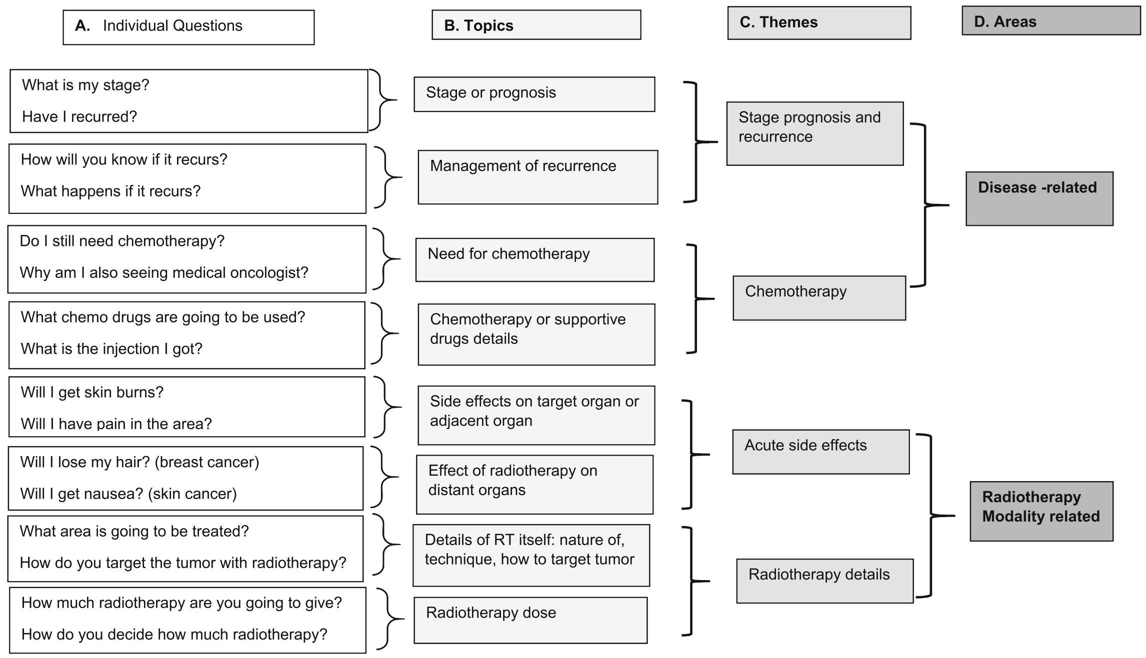


Fig. 1 Illustration of the method used to define and classify the questions that patients asked. Column A shows examples of 16 questions asked by pilot cohort and their classification into 8 topics (column B) and further classification into 4 themes (column C), and 2 overarching areas (column D) (Themes were grouped into subjects which is not shown here). Thematic analysis [12] yielded a taxonomy of 57 topics, 34 themes, 9 subjects, and 2 overarching areas

columns C and D, only 17 of topics (29.8% of topics) were asked by more than 10% of patients. The rest of the 40 topics (70.2% of topics) were each brought up by fewer than 10% of patients according to patients' own idiosyncratic needs and information gaps. Similarly, when taken as *a proportion of all questions asked*, there were a few topics that were asked frequently, and the vast number of topics was asked infrequently. As given in the columns E and F in Table 2, only 5 topics (8.8% of topics) each comprised more than 5% of all 2386 questions. The other 52 topics (91.2% of topics) each comprised less than 5% of all the questions asked, and furthermore, 42 topics (73.7% of topics) each comprised less than 2% of all the questions asked.

The proportion of patients who asked about each of *34 themes* is depicted Fig. 2.

Broad Areas and Subjects

We identified two *broad areas*: radiation modality-related questions which comprised 56.9% of all questions (1358 questions) and disease-related questions which comprised 36.7% of all questions (878 questions); 6.3% (150 questions) were classified as "other" (topics that did not fall in any of the defined topics that were derived from the pilot group, for example: "What will the effect of radiation be on my dog?". Their relative frequencies with which these broad areas as a percent of all questions asked are depicted in Fig. 3(a).

We identified nine *subjects.* Their relative frequencies as a percent of all questions asked are depicted in Fig. 3(b). They were as follows:

1. schedule and logistics
2. side effects, symptom control effect of treatment on life, and follow-up
3. radiotherapy details, effectiveness, and technique
4. disease characteristics: diagnosis, pathology, stage, results, biology, and symptoms
5. pertaining to other specialties
6. lifestyle, complementary subjects, nutrition, supplements, stress, physical activity, and quality of life
7. other topics
8. cost
9. epidemiology or etiology

Discussion and Conclusion

Discussion

This study focused on personalized communication, a factor that has been shown to lead to better outcomes: psychological functioning of patients [14], compliance with treatment [15], quality of life and satisfaction [16], less anxiety, and increased recall and understanding [17]. It also contributes to more valid and ethical

Table 1 Characteristics of 396 patients whose questions were studied with the mean number of themes and mean number of questions by each covariate and *p* values for difference of the means resulting from analysis of variance calculation

Characteristic		No. of pts.	%	Mean no. of *themes*	ANOVA *P* value	Mean no. of *questions*	ANOVA *P* value
Race	White	320	80.8	6.2	0.1771	6.2	0.1573
	Black	15	3.8	6.1		7.2	
	Hispanic	31	7.8	5.2		5.4	
	Other	2	0.5	9.5		9.5	
Gender	Male	231	58.3	6.2	0.3881	6.3	0.4926
	Female	165	41.7	5.9		6.0	
Age (years)	< 60	116	29.3	6.8	**0.0049**	6.9	**0.0018**
	60–69	158	39.9	6.1		6.2	
	≥ 70	122	30.8	5.4		5.4	
KPS	< 90	86	22.3	5.8	0.6396	5.8	0.4845
	90	138	35.8	6.2		6.4	
	100	157	40.7	6.1		6.2	
Health insurance	Medicare	214	54.0	5.7	**0.0008**	5.7	**0.0004**
	Medicaid	12	3.0	4.4		4.7	
	Private	119	30.1	7.1		7.2	
	VA/Tricare	33	8.3	6.1		6.3	
	None/self-pay	18	4.5	5.5		5.4	
Stage	0	10	2.5	6.1	0.1294	6.0	0.1521
	1	78	19.7	5.6		5.6	
	2	88	22.2	6.5		6.6	
	3	100	25.3	6.0		6.2	
	§4	109	27.5	6.0		6.1	
	N/A-brain	9	2.3	8.3		8.3	
Primary site	Breast	80	20.2	6.0	0.0775	6.1	**0.0440**
	Prostate	69	17.4	6.1		6.3	
	Head and neck	61	15.4	6.8		6.9	
	Lung	53	13.4	5.7		5.8	
	Skin	29	7.3	4.6		4.6	
	Bladder	13	3.3	7.2		7.2	
	Brain	9	2.3	7.0		7.0	
	Rectum	11	2.8	6.7		6.7	
	Anus	10	2.5	7.8		8.8	
	Lymphoma	9	2.3	5.2		5.2	
	*Other	52	13.1	5.8		5.8	
Treatment goal	Adjuvant	136	34.3	6.2	0.8738	6.2	0.9316
	Definitive	183	46.2	6.0		6.2	
	§Palliative	74	18.7	6.0		6.0	
Treatment site	Primary	337	85.1	6.1	0.6258	6.2	0.5800
	Metastatic	56	14.1	5.9		5.9	
Type of treatment	Primary tumor	358	90.4	6.2	0.0766	6.3	0.0783
	Recurrent	35	8.8	5.2		5.3	

No. number, *pts.* patients, *ANOVA* analysis of variance, *H&N* head and neck, *KPS* Karnofsky performance status, *VA* Veterans Affairs

A *p* value of 0.05 or less was considered significant and shown in bold where they were significant

§ Note that although 27.5% of patients were stage 4, only 18.7% of the cohort were treated with palliative intent because of the high proportion (15.4%) of patients with head and neck cancer. These patients are deemed stage 4 due to the presence of locoregionally advanced disease without distant metastases and are often curable

*"Other" cancer types include cancer of the pancreas, cervix, esophagus, unknown, liver and bile ducts, endometrium, vulva, stomach, kidney, colon, testis, and other, each of which comprised 2% or less of the total cohort

Table 2 The information topics of 2386 questions which were asked by 396 patients. Their ranks according to the number of patients who asked about each topic is listed in column A. The topic is stated in column B. The number patients who asked each topic is shown in column C along with the respective percentage in column D. The number of times each topic was asked by all patients in the cohort is shown in column E along with the respective percentage of total questions in column F

A Rank	B Topic	C No. of patients	D % of patients	E No. of questions	F % of questions
1	Logistics of RT: start, timing, duration, timeline, or number of treatments	215	54.3	337	14.1
2	Details of RT itself: nature of technique, how to target tumor	168	42.4	208	8.7
3	Side effects in general	152	38.4	154	6.5
4	Other questions	118	29.8	150	6.3
5	What is diagnosis or explanation of, or cancer status	100	25.3	127	5.3
6	Stage or prognosis	94	23.7	112	4.7
7	Nutrition or special diet	73	18.4	76	3.2
8	Necessity of RT or alternative options	70	17.7	72	3.0
9	Effectiveness of RT or consequence of omitting	66	16.7	78	3.3
10	RT causing tiredness debility, weakness, or disability	63	15.9	72	3.0
11	Results or necessity of radiology studies	52	13.1	60	2.5
12	Details of or necessity of surgery	51	12.9	55	2.3
13	Continuation of a usual physical activity	49	12.4	58	2.4
14	Details or results of pathology or laboratory studies	49	12.4	57	2.4
15	Pain or pain control	47	11.9	50	2.1
16	Details of chemotherapy, supportive drugs, side effects	45	11.4	44	1.8
17	Side effects to target organ or adjacent organ or tissue	40	10.1	46	1.9
18	Effect on work and work schedule or other usual or planned undertaking	39	9.8	46	1.9
19	Distinct types of RT such as brachytherapy, Gamma Knife, CyberKnife, or protons	37	9.3	36	1.5
20	Anatomic location to be treated	33	8.3	37	1.6
21	Explain symptoms or relation of symptoms to cancer	32	8.1	32	1.3
22	Long-term side effects or scarring	30	7.6	30	1.3
23	Effect of RT on distant organs	29	7.3	33	1.4
24	Need for chemotherapy or to see medical oncologist	29	7.3	25	1.0
25	Use of supplements or CAM	29	7.3	24	1.0
26	Cost or insurance	28	7.1	25	1.0
27	Sequencing of chemo/RT	26	6.6	24	1.0
28	Medications	24	6.1	25	1.0
29	Management of recurrence or whether RT or surgery can be repeated	22	5.6	19	0.8
30	Request for services not directly related to radiation treatment	22	5.6	17	0.7
31	Explanation or interpretation of something another doctor said	21	5.3%	19	0.8
32	Necessity or details of anti-hormonal therapy	21	5.3	20	0.8
33	Transportation, RT appointment arrangement, time or other coordination	19	4.8	14	0.6
34	Dying, hospice, anticipating or preparing for future	19	4.8	20	0.8
35	Capability of technical staff or equipment	19	4.8	16	0.7
36	Follow-up and after care	18	4.5	16	0.7
37	Effect or side effects of anti-hormonal therapy	18	4.5	13	0.5
38	RT dose	18	4.5	13	0.5
39	Explanation of chemotherapy or difference from RT	17	4.3	13	0.5
40	Dangers of RT and persistence in body afterwards	17	4.3	15	0.6
41	Burning of skin	17	4.3	13	0.5
42	How to prepare for RT	16	4.0	16	0.7
43	Advice on alcohol intake	15	3.8	10	0.4
44	Capability of doctor or direct involvement in treatment	14	3.5	9	0.4
45	Symptoms that were observed in another person who had RT	13	3.%	9	0.4
46	Cause of cancer by non-carcinogen or questionable carcinogen	12	3.0	7	0.3
47	Assessment of cure or RT response	11	2.8	8	0.3
48	Protection or normal organs	10	2.5	5	0.2
49	RT instead of chemotherapy	10	2.5	6	0.3
50	Quality of life	9	2.3	4	0.2
51	Protection from hair loss	8	2.0	3	0.1
52	Cause of cancer by carcinogen other than alcohol or tobacco smoking	7	1.8	2	0.1
53	Shielding normal organs using physical shields	7	1.8	2	0.1
54	Effect of stress	7	1.8	2	0.1
55	Cause of cancer by tobacco smoking	6	1.5	1	0.0
56	Effect of RT on others	6	1.5	1	0.0
57	Cause of cancer by alcohol or other epidemiology question	0	0.0	0	0.0

For each topic, the number of patients who ask that topic does not match the number of questions asked about the topic because a single patient may have asked more than one question pertaining to the topic

No. number, *RT* radiotherapy, *CAM* complementary or alternative medicine informed consent for patients contemplating radiotherapy treatment [18]. It may also benefit health care professionals by reducing malpractice claims rate [19], lessen clinician stress and emotional burnout, and increase job satisfaction [20].

Feasibility of Eliciting All Questions

Doctors often do not ask open-ended questions and address the concerns of each patient. They may fear that patients would express far too many questions, which would be impractical to answer in the allotted consultation time. Although this is the experience at a single center, our findings suggest that *this fear may be unfounded*: the median number of questions per patient was only 6 when they were encouraged and given adequate time to ask. We did not measure how oncologists felt about answering this volume of questions; however it seems that a median of 6 questions is reasonable number of questions to address and, in general, is quite easy to manage.

We detected intriguing variation in the volume of information requested according to patients' characteristics that may represent barriers to communication: (a) decreasing volume with increasing age, (b) variation with type of health insurance, and (c) significant variation with tumor site. A recent study on the information needs of women with breast cancer similarly found a wide range of information topics and variation of need with age [21]. Special attention may be needed in attending to information needs of groups who tend to ask fewer questions.

We did not find a correlation of question volume with race, gender, KPS, stage, treatment goal, or whether attending for treatment of a primary or metastatic site.

Quality of Questions and Personalization of Information

As Fig. 3 shows, almost 40% of questions were disease-related. Therefore, addressing only radiotherapy-related topics may leave patients with a significant knowledge gap. There were many questions about personalized details (results or necessity of their radiology, pathology or laboratory studies, their surgery, continuation of their specified physical activity, and details of chemotherapy or supportive drugs) which would safely be covered if discussion is based on customized patient need.

It was also noteworthy that only a few topics were frequently asked by many patients while most topics were each asked by only a few patients and asked infrequently. This diversity of topics suggests that generic materials may be insufficient and argues against a paternalistic approach to giving information: if physicians give the same content to all patients based only on what they believe patients need to know, many patients may have unanswered questions.

Even if we elected to satisfy patient-oriented communication by dealing with the ten most frequently asked questions (Table 2), we would still need to personalize it because these ten topics included patient-specific information.

Benefit to Patients

There is a dearth of evidence of the benefit to patients of physicians taking time-out to deliberately prompt patients to express their questions and concerns during consultations. There is need for quantitative study to examine whether patients benefit from the manner of patient consultation that is described in this study. The effect of encouraging patients to ask questions was calculated in a landmark study published in 1977 that is often sited in literature about patient-centered communications [1]. Roter tested the intervention of a 10-minute session with a health educator in the waiting room *prior* to patients' visit with the physician. The health educator worked through a question-asking protocol to identify questions that the patients may have. This significantly increased the number of direct questions asked by patients: mean number of questions asked when coached was 2.12 versus 1.21 among placebo patients.

There has been extensive study of other interventions designed to help patients address their information needs within consultations. The two common interventions that aim to increase question-asking among patients are *written prompt lists* and *patient-coaching* to ask their questions. The effects of these were summarized in a meta-analysis of 8244 patients in 33 controlled trials [2]. The results address effect on patient anxiety and patient satisfaction. Note that the studies in this meta-analysis were different than the current study in which patients were coached by their physician to express their question during their consultation. The meta-analysis showed significant effects:

- *Patient satisfaction*—There was a small and statistically significant increase in patient satisfaction. Interestingly, interventions performed immediately before the consultation significantly increased patient satisfaction whereas those interventions given some time before the consultation led to *no significant change.* Coaching significantly improved satisfaction while question prompting using written materials produced an insignificant increase.
- *Anxiety*—Analysis of this effect was complicated by the varying timing of its measurement. The meta-analysis showed a small statistically insignificant decrease in patient anxiety after consultations.

These studies may have failed to show a bigger effect on satisfaction and anxiety because both interventions (using question prompt lists and coaching to ask questions) incur a time gap between encouraging question-asking and the time of face-to-face consultation. Whether addressing patients own question list that is generated through *encouragement by the physician* reduces anxiety and increases satisfaction should be studied and perhaps compared against prompt lists, closed-ended invitations to express needs, and no specific intervention. None of the studies reported the effect of the simpler intervention of having the physician deliberately invite

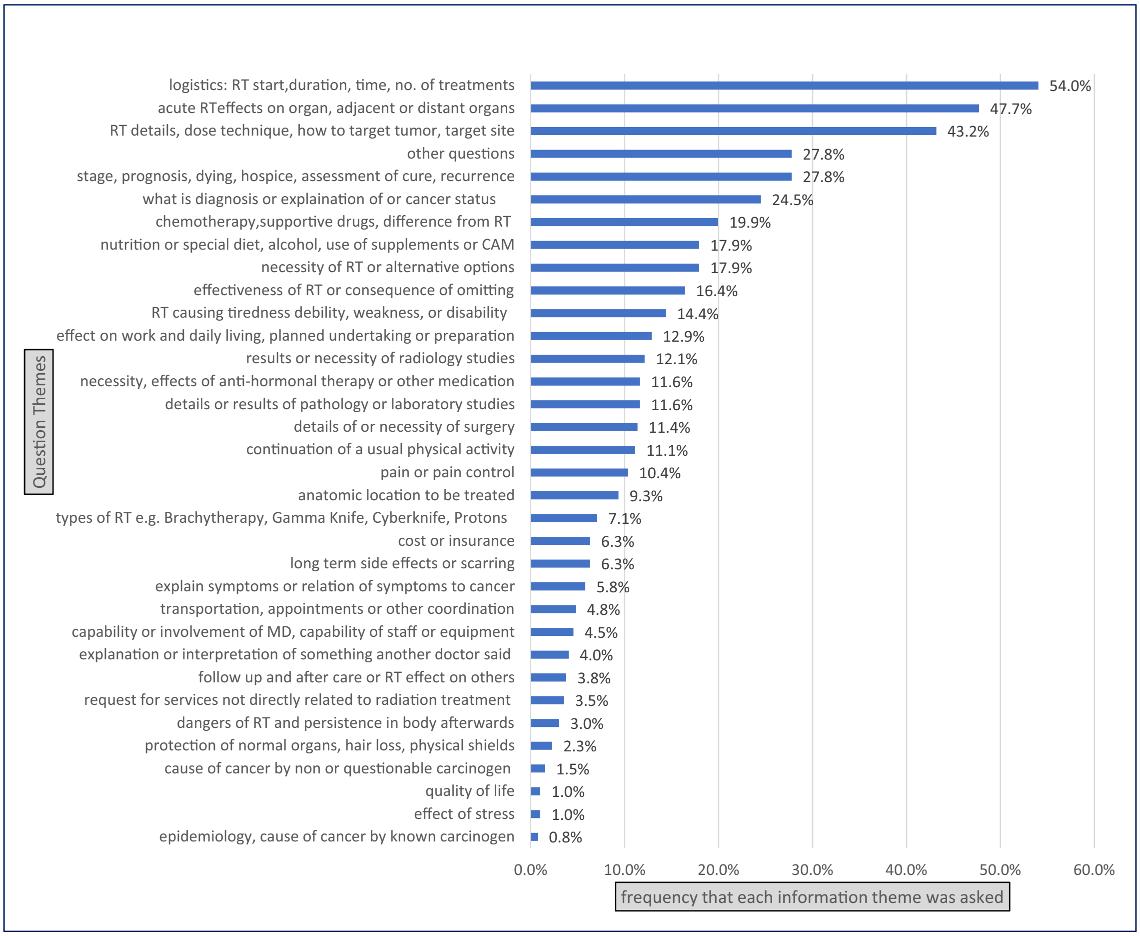
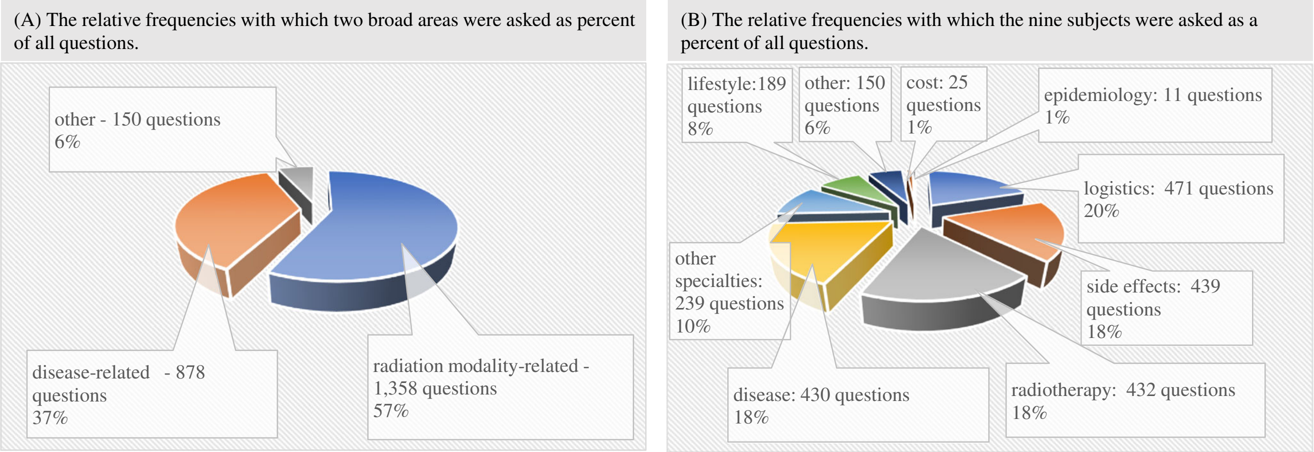


Fig. 2 The frequency that each information *theme* was asked expressed as percentage of patients who asked each theme. The themes are listed on the *y* axis. They are arranged by order of increasing proportion of patients that asked for information on the respective theme. The percent of patients who asked for information on each theme is shown on the *x* axis. *RT* radiotherapy, *No*. number, *CAM* complementary or alternative medicine, *MD* medical doctor


(A) The relative frequencies with which two broad areas were asked as percent of all questions.

(B) The relative frequencies with which the nine subjects were asked as a percent of all questions.

Fig. 3 The relative frequencies with which the two broad areas and nine subjects were asked as a percentage of all questions asked by the cohort. (a) The frequency of two broad areas: radiation modality-related and disease-related questions. (b) The frequency of questions that were asked about nine subjects: *logistics* = schedule and logistics; *side effects* = side effects, symptom control, effect of treatment on life, and follow-up; *radiotherapy* = radiotherapy details, effectiveness, and technique; *disease* = disease characteristics: diagnosis, pathology, stage, results, biology, and symptoms; *other specialties* = pertaining to other specialties; *lifestyle* = lifestyle, complementary subjects, nutrition, supplements, stress, physical activity, and quality of life; *other* = other topics; *cost* = pertaining to cost; *epidemiology* = epidemiology or etiology patients to express their questions during the consultation itself as described in this report.

Resource Implications

We did not measure how much time it took to complete the average consultation. Anecdotally, the process described did not seem to prolong the consultation and in fact allowed for a very focused approach. This is a small part of the consultation process which also includes review of patients' case details, complete history-taking, physical examination, information processing, staging, communication with other physicians, formulation of treatment plans and alternatives, communication of plans to patient and care team, writing orders and prescriptions, documentation, and coordination of care.

The meta-analysis, referred to in the previous section, of 8244 patients in 33 controlled trials that were designed to help patients address their information needs [2] also examined the effect on length of consultations. The studies used pre-written prompt lists or coaching of patients before their consultations. The meta-analysis did not show statistically significant increase in length. Written materials led to a small and statistically significant increase in consultation length whereas coaching did not lead to significant increase in consultation length. Their finding that coaching did not yield a significant increase in consultation length supports our suspicion that consultations described in this paper were neither unduly protracted nor made burdensome by answering patients' questions.

Conclusion and Study Limitations

The finding that the median number of questions per patient was only 6 suggests that it may be feasible and practical for healthcare professionals in oncology to elicit all the specific information needed by each patient. Increasing patient age, being underinsured, and having certain tumor types may be potential barriers to the amount of information that patients request.

Radiation oncologists need to address questions that are disease-related, radiotherapy-related, and details requested about patients' case. They may use generic materials but also need to provide customized information.

Results may differ for radiotherapy patients from more diverse backgrounds than this group. This is the experience of a relatively homogenous group of patients at a single cancer center only. The distribution of race was 80.8% White, 7.8% Hispanic, 3.8% Black, and other 0.5%. There is evidence that race/ethnicity significantly affects question-asking: in one study, Black patients asked fewer questions, a smaller proportion of direct questions, and were less likely to have companions present during the interaction than White patients [22]. Our group was also predominantly older than 60 years with only 29.3% of patients younger than 60 years. This group contained more curable patients with only 18.7% treated with palliative intent. Only 8.8% of patients were being treated for recurrent disease versus treatment of an initial cancer. There was better distribution of patients among gender, cancer primary site, and stage.

All patients resided in one geographic region and had care in a single setting: a free-standing radiotherapy center. Studies on management of information needs are needed using a larger number of practitioners and in different settings. Results may differ in other settings and systems where nurses, trainees, and other specialists may evaluate and manage information needs.

Another interesting question to study is the potential effect of satisfying patient information needs on efficiency: Does answering questions during initial consultation result in shorter follow-up visits? This is especially important for radiotherapy where patients may proceed to treatment over 3 to 8 weeks which requires a weekly physician visit. If they have their information needs addressed up-front, will patients spend less time in on-treatment weekly visits?

There may be potential bias which is inherent in qualitative thematic analysis method [12] that involves researchers reading and studying the raw data (patients' questions) and classifying them into overarching areas, subjects, themes, and topics. This classification was original and not anchored to a pre-existing classification of patients' questions.

Although this study was retrospective, it was not prone to selection bias since patients were unselected. It was also not prone to recall bias because all patients' questions were methodically transcribed by the physician as soon as they were expressed.

Practice Implications

It is quite reasonable to manage the information needs of patients with cancer when they are encouraged to ask questions during routine consultations. Review of the literature also suggests that it improves patient satisfaction, reduces anxiety, and may not lengthen the consultation [2]. The top ten most frequently asked topics (proportion of patients who ask each) were identified:

1. Logistics of radiotherapy, i.e., start, timing, duration, timeline, or number of treatments (54.3% of patients)
2. Details of radiotherapy itself, i.e., nature of radiation, technique, tumor targeting (42.4% of patients)
3. Side effects in general (38.4% of patients)
4. Nature or status of their cancer diagnosis (25.3% of patients)
5. Stage or prognosis (23.7% of patients)
6. Need for special nutrition or diet (18.4% of patients)
7. Necessity of radiotherapy or alternative options (17.7% of patients)
8. Effectiveness of radiotherapy or consequence of omission (16.7% of patients)
9. Whether radiotherapy will cause tiredness debility, weakness, or disability (15.9% of patients)

10. Results or necessity of radiology studies (13.1% of patients)

We may use these topics to create information materials but their wide variation and high proportion that are related to the individual's case argues that generic information material may not be sufficient for patient-oriented communication.

Patient-centered communication is recommended as a measure of quality [23]. We risk losing focus on this aspect of care as other competing obligations take precedence such as the requirement for cancer clinicians to enter extensive data into computers *during* consultations in the USA. As this paper was being written, the American Society of Clinical Oncology issued their consensus-based recommendations for best practices for cancer clinicians when communicating with patients and their loved ones [24]. Many of the recommended core skills contained in these guidelines may be accomplished by the simple modification of medical consultations that was described and audited in our study: cancer clinicians taking time-out to elicit patients' questions at the time when they can get answers during consultation. We should not just individualize care with molecular, genomic, or spatial targeting of tumors in oncology: personalized medicine is not just "biologically personalized therapeutics" [25].

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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