Informational needs of gastrointestinal oncology patients

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Abstract

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Objectives In response to the dearth of consumer health information for patients with gastrointestinal cancers, this study examined the informational needs of these patients to build a plan for future resource development. Although studies have examined informational needs of some such cancers, no published literature has investigated the comprehensive informational needs across all sites of gastrointestinal cancer.

Methods A cross-sectional needs assessment comprising a self-administered questionnaire was conducted at an ambulatory gastrointestinal oncology clinic in Toronto, Canada. Patient informational needs were measured, including importance of information, amount desired and preferred mode of delivery. Informational needs were grouped into six domains: medical, practical, physical, emotional, social and spiritual.

Results Eighty-two surveys were analysed. The majority of the respondents were male (53.8%), over the age of 50 (77.8%), and born outside of Canada (51.9%). While many did not speak English as a child (46.3%), and do not speak English at home (22.2%), nearly all indicated comfort with receiving health information in English (97.5%). The majority of respondents were college educated (79.3%) and married (73%). Multiple cancer types were reported; the most common being colorectal (39%), followed by pancreatic (12%) and cancers of the gallbladder or bile duct (12%). Overall, respondents placed highest importance on medical information ($P < 0.001$). Preferred education modalities were pamphlets, websites and one-on-one discussions with health-care professionals.

Conclusions This study highlights the principal informational needs of patients with gastrointestinal malignancies, along with preferred modality for information delivery. This information will guide the development of educational resources for future patients.

Introduction

With thousands of new diagnoses each year, patients with gastrointestinal cancers comprise a significant portion of the modern cancer survivor population. These cancers including: oesophageal, stomach, colorectal, liver and pancreatic are among the largest categories of cancers by incidence in the North American population.^{1,2} Colorectal cancer is a major cause of morbidity and mortality, and it is the third most common cancer worldwide and the fourth most common cause of death, effecting men and women almost equally. Colorectal accounts for over 9% of all cancer incidences. Incidence and prevalence studies in 2009 reported that Australia, New Zealand, Canada, the United States and parts of Europe had the highest incidence rates, and China, India, and parts of Africa and South America reported the lowest risk.³ Gastrointestinal cancers are responsible for more deaths from cancer than any other system in the body.⁴ However, improvement in survival rates translates into a significant number of gastrointestinal cancer survivors.⁵

Between managing the effects of cancer itself, the side-effects from treatments, and dealing with general lifestyle disruptions, individuals with gastrointestinal cancers face considerable challenges.⁵⁻⁹ Navigating these issues can be made increasingly difficult when there is insufficient information to meet patient needs.^{10,11}

Recent investigations show that individuals with cancer desire a significant amount of information about their condition.^{10,12} One such study indicated that 87% of patients wanted as much information as possible about their cancer, including both positive and negative information.¹⁰ Additionally, patients increasingly wish to partner in the decision-making process, and information provision is a

critical component of this partnership.¹³ These findings have held true for gastrointestinal cancers,¹⁴ with patients desiring more information than their doctors provide.¹⁵ Lacking sufficient information can have an impact on quality of life and hinder the patient's ability to cope and self-manage symptoms or side-effects.¹⁶ The need for patients to better understand their illness was highlighted by one study on breast and prostate cancer patients, which found a significant relationship between perceived quality of life and satisfaction with information received.¹⁷

Much of the current research on the informational needs of cancer patients has focused on interactions with clinicians and emphasized medical need.^{14,18} However, patient information needs extend beyond medical issues.¹⁹ Cancer patients have indicated that they are not only willing to receive information from multiple sources, including online material, they want this information to be easily accessible and accurate.²⁰ However, the specific information that patients with gastrointestinal cancers want, and the format that they prefer it in, is not well established.

The majority of current research has evaluated the cancer population as a whole, rather than at individual subpopulations with specific classes of malignancies, such as gastrointestinal cancers.^{10,21,22} To date, most of the interest in individual cancer subpopulations have been limited to breast and prostate cancer.²² Some investigations are beginning to address this gap in the literature. Recently, an informational needs assessment was conducted for gynecological patients²³ and a scoping review was conducted to examine the literature on colorectal cancer patient informational needs.²⁴ No similar studies have been published on the needs of gastrointestinal cancer patients. Where gastrointestinal cancer informational needs have been

investigated, it has been limited to the context of clinician interactions and medical information needs and these have largely focused on colorectal cancers.^{14,15,25,26}

The purpose of this investigation was to determine what information is desired by individuals with gastrointestinal cancers and in what format they would prefer to receive it. This investigation examined and identified variations in informational needs by demographic and clinical characteristics.

Methods

Participants

A cross-sectional observational study was conducted using a convenience sample. Patients visiting the Gastrointestinal Oncology Clinic at the Princess Margaret Cancer Centre in Toronto, Canada, between January and February 2010, were asked to complete a self-administered questionnaire. Upon registration at the clinic reception, patients were invited to participate in the study while they waited for their appointment. The questionnaire took between 15 and 25 min to complete. Consent was implied by completion of the questionnaire and participation was both voluntary and anonymous. Criteria for inclusion were at least eighteen years of age and a confirmed diagnosis of a gastrointestinal cancer, which includes any malignancy of the gastrointestinal tract from the oesophagus to the anus, as well as cancers of the liver, biliary tree and pancreas. Questionnaires were to be completed by patients without supervision from research staff. Accompanying family members or friends were able to assist if needed. Approval to conduct the study was obtained from the University Health Network Research Ethics Board.

Measurement instrument

A non-validated questionnaire was designed based on previous work that sought to identify patient supportive care needs.²⁷ The questions were modified and expanded based on a review of the literature on common symptoms and

side-effects faced by patients with gastrointestinal patients and feedback from gastrointestinal clinicians. The questionnaire was divided into three sections.

1. Demographic and health information – The questionnaire included 15 questions to collect demographic and diagnosis related information. Demographic information collected in this section included sex, race, age, income, education, languages spoken, marital status and employment status. Information was also collected about the patient's cancer diagnosis, stage in the cancer journey and treatments received.
2. Informational needs – The questionnaire included 34 multipart questions focused on the informational needs of gastrointestinal patients. Questions on informational needs were structured with two components. Study participants were (1) asked to indicate the level of importance of each specific need on a Likert scale, where 1 is not important and 5 is very important; and (2) asked to indicate their preferred method of receiving information related to the question. The 34 questions on informational needs were divided into six domains: eight questions for the medical domain, five for the practical domain, seven for physical, five for social, five for emotional and four for spiritual.

Questions in the medical domain focused on cancer itself and the treatment process with questions on topics such as 'Information about possible side-effects of treatment', 'Information about treatment options' and 'Information about the likelihood of a cure'. Similarly, the practical domain encompassed logistical issues such as 'Information about transportation to and from my cancer-related appointments', 'Information about caring for myself at home including housekeeping, social worker and home visits' and 'Information about payment for my treatment'. The physical domain encompassed issues relating to body function associated with but not directly related to the cancer process, such as 'Information about how to manage feelings of wanting to vomit (nausea)', 'Information about how to deal with pain in

parts of my body', and 'Information about how to adjust to living with a colostomy'. The social domain encompassed issues relating to personal relationships such as 'Information about how my relationships with friends might be affected', 'Information about how my family and friends may be affected by my illness', and 'Information about how my relationships with people in my workplace/school might be affected by my illness'. The emotional domain encompassed managing personal feelings such as 'Information about how to deal with feelings of hopelessness', 'Information about how to deal with feelings of anger and frustration', and 'Information about how to deal with feelings of sadness and despair'. The spiritual domain encompassed metaphysical questions such as 'Information about the thoughts I have had about the meaning of death', 'Information about the thoughts I have had about the meaning of life', and 'Information related to ideas about suffering'.

Three main response categories for methods of receiving information were given: (i) hard copies, (ii) virtual sources or (iii) in-person source. Potential selections for hard copies of data were as follows: pamphlet, book, DVD or audiotape. For virtual sources, the choices were as follows: an audio podcast, a video podcast, an online forum/bulletin board, an online live chat or text on a website. Lastly, for in-person information, the available options were as follows: an instructional group class, a one-on-one instructional class or a support group.

3. Comments – Open-ended questions were included at the end of the questionnaire to provide the opportunity for study participants to describe any needs that were not addressed in the questionnaire. This section included three questions: what is your biggest informational need right now, have you received this information and in what form would you like to receive this information. The respondents were also asked to write any other additional comments. The results of this section will be presented in a future publication.

Statistical analysis

For each patient, the frequency in which the patient responded (important) 4 or 5 on the Likert scale was recorded for the distinct informational need domains; this frequency, expressed as a percentage of completed questions in that domain, was labelled the categorical importance score. Questions for which no rating was indicated were excluded. Relative ratings of importance between the domains were measured using the Friedman test and the Wilcoxon signed-rank test as appropriate. To assess the impact of demographic or clinical factors on informational needs, univariate analysis with Wilcoxon rank sum tests and Kruskal–Wallis tests were initially performed, followed by linear regression on the categorical importance scores. To analyse the effect of importance score on modality selection, chi-squared tests were conducted based on the number of times a modality was selected or not selected. All statistical analyses employed an α of 0.10, with Bonferroni corrections applied to sets of tests as appropriate.

Results

Eighty-eight questionnaires were completed in a two-month period. Five questionnaires were excluded because the study participants had a cancer diagnosis that was not gastrointestinal in origin. One questionnaire was excluded because a friend of a patient completed it, without the patient being present.

Demographics

Demographic data, summarized in Table 1, shows that the majority of respondents were male (53.8%), over the age of 50 (77.8%), and born outside of Canada (51.9%). Nearly all indicated that they were comfortable receiving health information in English (97.5%). The majority of respondents were college educated (79.3%) and married (73%).

Table 1 Demographic information

Variable	Number	Percentage
Gender (<i>n</i> = 80)		
Male	43	53.8
Female	37	46.3
Age (<i>n</i> = 81)		
21–30	2	2.5
31–40	6	7.4
41–50	10	12.3
51–60	30	37.0
61–70	27	33.3
71–80	6	7.4
Country of birth (<i>n</i> = 81)		
Canada	39	48.1
Other	42	51.9
Language as a child (<i>n</i> = 80)		
English	43	53.8
Other	37	46.3
Language spoken at home (<i>n</i> = 81)		
English	63	77.8
Other	18	22.2
Preferred language (<i>n</i> = 79)		
English	68	86.1
Other	11	13.9
Comfortable receiving information in English (<i>n</i> = 81)		
Yes	79	97.5
No	2	2.5
Level of education (<i>n</i> = 82)		
Grade School	4	4.9
Some High School	4	4.9
High School	9	11.0
Some University/College	15	18.3
University/College	35	42.7
Graduate School	15	18.3
Marital status (<i>n</i> = 82)		
Single, never married	6	7.3
Married	60	73.2
Separated	4	4.9
Divorced	7	8.5
Widowed	4	4.9
Other	1	1.2
Number of people in the household, including respondent (<i>n</i> = 81)		
One	10	12.3
Two	34	42.0
Three	18	22.2
Four	9	11.1
Five	5	6.2
Six	3	3.7
Seven or more	2	2.5
Annual household income (<i>n</i> = 80)		
<\$25 000	8	10.0
\$25 000–\$49 999	14	17.5
\$50 000–\$74 999	11	13.8

Table 1 Continued

Variable	Number	Percentage
\$75 000–\$99 999	11	13.8
>\$99 999	19	23.8
Prefer not to answer	17	21.3
Point in cancer journey (<i>n</i> = 77)		
Newly diagnosed	10	13.0
Currently getting treatment	44	57.1
Recently finished treatment	8	10.4
Long term follow-up	15	19.5
Type of cancer (<i>n</i> = 82)		
Colorectal	32	39.0
Stomach	3	3.7
Small intestine	4	4.9
Pancreatic	10	12.2
Oesophageal	6	7.3
Anal	1	1.2
Liver	7	8.5
Biliary	10	12.2
Appendix	3	3.7
Carcinoid	2	2.4
Multiple	3	3.7
Unspecified	1	1.2
Cancer stage (<i>n</i> = 81)		
Stage I	1	1.2
Stage II	8	9.9
Stage III	17	21.0
Stage IV	24	29.6
Don't know	28	34.6
Not applicable	3	3.7
Type of treatment (<i>n</i> = 81)		
Surgery	47	58.0
Radiation therapy	30	37.0
Chemotherapy	74	91.4
Hormonal therapy	1	1.2
No treatment planned	1	1.2

Clinical characteristics

Cancer types reported by patients were diverse, with the most common being colorectal cancer (39%), followed by pancreatic cancer (12%) and cancer of the gallbladder or of the bile duct (12%). Of respondents who were aware of the stage of their cancer, most had stage III (34%) or stage IV (48%) cancers. Chemotherapy (91%) and surgery (58%) were the most common treatments planned, in progress, or completed for respondents. The majority of respondents were undergoing therapy at the time that the questionnaire was administered (57.1%).

Most important domain and relationships with demographic information

In comparing the rated importance of all domains using the Friedman test, it was determined that there was a statistically significant difference between the six domains ($P < 0.001$). Subsequent analysis between individual domains was performed with Wilcoxon signed-rank tests. As 15 separate comparisons were necessary, a Bonferroni correction was applied, resulting in an effective α of 0.0067. This revealed that the medical domain was significantly more highly rated as important than all other domains ($P < 0.001$) as shown in Table 2. Furthermore, the physical domain received higher importance scores than those in the practical, social, emotional and spiritual domains ($P < 0.0067$), but no statistical significance in importance scores were found between the

physical domain and either the practical or emotional domains. Comparisons between importance scores of any two of the remaining domains (practical, social, emotional and spiritual) did not demonstrate statistical significance. In addition, eight of the ten questions that were rated as most important were from the medical information domain, as shown in Table 3.

Univariate analysis, intended to inform parameter selection for subsequent multivariable analysis provided no evidence of a relationship between any clinical factors and importance scores in any domain ($P > 0.10$ in all domains). A correlation ($P < 0.10$) did, however, exist between age, language spoken at home, annual household income, and marital status and at least one domain's importance score using Wilcoxon rank sum tests. The remaining demographic factors of sex and level of education did not demonstrate

Table 2 Summary of importance scores by category

	Medical	Practical	Physical	Social	Emotional	Spiritual
<i>N</i>	82	82	82	82	81	79
Mean	81.5	43.9	54.0	43.0	45.1	38.1
Median	87.5	40.0	63.3	40.0	20.0	25.0
IQR	75.0–100.0	20.0–65.0	14.9–85.7	0.0–80.0	0.0–100.0	0.0–75.0
Range	0.0–100.0	0.0–100.0	0.0–100.0	0.0–100.0	0.0–100.0	0.0–100.0

Within each category, the percentage of answered items to which a respondent selected 4 or higher for importance on the Likert scale was calculated for each respondent. Each respondent has an amount score ranging from 0 to 100.

Table 3 Ten individual questions that received the greatest proportion of ratings of 4 or 5 for importance

Rank	Question	Domain	% of patients that gave ratings of 4 or 5
1	Information about the different types of treatment and their advantages and disadvantages	Medical	93.8
2	Information about possible side-effects of treatment	Medical	91.3
3	Information about the likelihood of cure for my cancer	Medical	90.1
4	General information about my cancer	Medical	86.3
5	Information about how this disease will physically affect my body (symptoms)	Medical	83.8
6	Information about whether my children or other members of the family are at risk of having this cancer	Medical	81.5
7	Information about how to deal with pain in parts of my body	Physical	74.1
8	Information about caring for myself at home including housekeeping, social worker and home visits	Practical	66.7
9	Information about the different types of health-care workers involved in my care and in what ways they can help me	Medical	64.2
10	Information about the dying process and end-of-life decision making	Medical	62.5

any significant relationship with importance scores.

Multivariable linear regression was performed for each of the domain importance scores against only the demographic factors. Gender and level of education were included, despite the lack of significance found by the univariate analysis, as previous studies have indicated a potential impact of these factors on informational needs.^{23,26,28} For the medical information domain, importance scores increased when the patient spoke a language other than English at home ($P = 0.083$; $\beta = 0.235$) and when they were married or in a common law relationship ($P = 0.008$; $\beta = 0.371$). For practical information, the importance score was higher for patients who were female ($P = 0.057$; $\beta = 0.255$), 60 years old or younger ($P = 0.081$; $\beta = -0.220$), spoke a language other than English at home ($P = 0.018$; $\beta = 0.320$) or had a household income of less than \$25 000 a year ($P = 0.064$; $\beta = -0.249$). Social information was considered more important for those 60 years of age or younger ($P = 0.003$; $\beta = -0.392$), and emotional information was more important for those with an annual household income of less than \$25 000 ($P = 0.012$; $\beta = -0.354$). Physical and spiritual importance scores were not significantly affected by any demographic factors through linear regression analysis.

Preferred method for receiving information

In terms of the modality in which patients indicated their preference for receiving information,

pamphlets were most often chosen, followed by text on a website and one-on-one instructional classes as demonstrated in Table 4. However, preferences for modality changed depending on whether the patient rated the question as important (4 or 5), or unimportant (3 or lower) on the Likert scale. Moreover, patients rating a question as important indicated a desire for information from a greater number of sources than those rating a question unimportant ($P < 0.001$).

The effect of the importance of a question on the frequency of modality selection was evaluated using chi-squared tests. The total number of modalities selected was analysed, as was the frequency that each of the individual 12 modalities were selected. As such, a Bonferroni correction was applied to the chi-squared tests, setting the effective α at 0.0077. It was found that patients rating a question as important indicated a desire for information from a greater number of sources than those rating a question unimportant ($P < 0.001$). Overall, when a respondent rated a question as important, the number of preferred modalities they selected increased significantly relative to when they rated a question as unimportant [RR 1.86, 95% CI (1.77, 1.95)]. Each of the 12 individual modalities were significantly more likely to be requested when the respondent indicated that the question was important ($P < 0.0077$), with the exception of audiotapes and instructional group classes,

The domain of information need also appeared to affect how often modalities were requested. Table 5 details the rate for which modalities were requested for questions in each

Table 4 Top 5 preferred modalities for receiving information overall, and when question was rated as either unimportant (3 or lower on Likert scale) or important (4 or 5 on Likert scale) by respondent

	No. 1 choice	No. 2 choice	No. 3 choice	No. 4 choice	No. 5 choice
Overall	Pamphlet (49.4%)	Text on a website (37.4%)	One-on-one instructional Class (36.2%)	DVD (24.5%)	Book (17.5%)
Question rated as unimportant	Pamphlet (41.0%)	Text on a website (29.9%)	One-on-one instructional Class (16.2%)	Instructional group class (14.9%)	DVD (13.7%)
Question rated as important	Pamphlet (56.7%)	One-on-one instructional Class (53.2%)	Text on a website (43.8%)	DVD (33.6%)	Book (22.4%)

informational needs domain. As the importance of each question appears to be a major factor in the frequency with which modalities are selected and certain domains were regarded as more important than others, only questions a respondent rated as 4 or 5 on the associated Likert scale were considered in Table 5, to better isolate the relationship between desired modality and informational needs domains. While the frequency of selection for certain modalities did not appreciably change from one informational needs domain to another, others showed some variation. For example, support groups were one of the least frequently selected modalities for medical or practical information, yet they were one of the more frequently selected in the emotional and spiritual domains, as can be seen in Table 5.

Discussion

Respondents consistently rated information in the medical domain as more important than information in any of the remaining domains. This is consistent with the results from previous studies on the needs of gynecological and head and neck cancer patients^{23,29} and overlaps with findings from a recent literature review on the informational needs of colorectal cancer patients.²⁴ Additionally, the physical domain received the second highest ratings. This was also suggested by similar investigations in the

gynecological cancer patient population and on findings from a comprehensive literature review on information needs of cancer patients in general.^{22,23} However, these results differ from work conducted by Fitch and Steele on the supportive care needs of ovarian, lung and gynecological patients as a whole.^{27,30,31} In each of these studies, Fitch and Steele found that in addition to needs in the physical domain, including pain management and fatigue, that needs in the psychosocial domain were rated as the most important needs of these patients.^{27,30} This difference in importance may be attributed to where patients are in their cancer journey. The majority of patients in our study were undergoing treatment at the time of questionnaire completion, while the majority of patients in the Fitch and Steele studies were no longer on treatment.^{27,30,31}

This study found that age was a factor for practical and social information, with younger patients placing higher importance on these domains. In previous studies, younger cancer patients expressed higher social information needs than older patients.^{23,32} A household income near or below the Ontario poverty line (<\$25 000/year)³³ was associated with higher practical and emotional informational needs. This result is consistent with previous investigations where patients with lower income report experiencing challenges in accomplishing

Table 5 Percentage of respondents indicating modality as preferred source of information by informational needs category, restricted to questions within that category rated as important (4 or 5 on the associated Likert scale) by the respondent

	Medical	Practical	Physical	Social	Emotional	Spiritual
Pamphlet	60.8	61.4	59.5	56.3	45.9	41.7
Book	24.0	19.3	22.5	24.0	21.1	19.1
DVD	33.5	29.5	35.2	38.3	31.9	32.2
Audio tape	1.7	1.2	0.4	0.6	2.7	2.6
Audio podcast	4.4	1.8	2.8	3.6	6.5	7.8
Video podcast	19.0	13.3	16.2	15.0	16.8	19.1
Online forum	19.2	21.1	20.4	15.6	18.9	20.0
Online live chat	7.6	4.8	8.8	7.8	16.8	14.8
Text on a website	45.7	44.0	45.8	44.9	39.5	35.7
Instructional group class	18.7	17.5	17.6	18.0	19.5	19.1
One-on-one instructional class	61.0	53.6	60.2	40.7	42.2	35.7
Support group	14.5	16.3	17.6	26.3	33.5	33.9

practical tasks³⁴ and greater emotional distress.³⁵ Women were also more likely to place higher importance on practical needs. This is not unexpected, as a recent publication indicated that women are more likely than men to report greater informational needs of a practical or psychosocial nature.³⁶

That languages spoken at home other than English was correlated with more importance assigned to the medical and practical domains of need was not anticipated given that all but two respondents indicated comfort with receiving information in English. It is possible that while most respondents indicated that they were comfortable receiving health information in English, some may not possess the oral English language skills that are necessary to closely follow a conversation steeped in medical language. As such, those who indicated 'language spoken at home other than English' may require more medical and practical information than those who indicated 'English spoken at home' to augment conversations with health-care providers. The relationship between marital status and informational needs was also somewhat unexpected. Previous studies found a correlation between being married and not wanting information about self-care³⁷ and a preference for not participating in medical decision making.³⁸

In terms of desired modality, patients were most strongly in favour of receiving information by pamphlet, text on a website or through one-on-one instructional classes. Pamphlets in particular had a consistently high frequency of selection. This finding is also consistent with previous studies.^{23,39} Furthermore, while all three modalities were rated as preferred methods for receiving information about an important question, only pamphlets and text on a website were selected when a question was rated unimportant by the patient. This suggests that for issues where the importance to the patient is not yet established, or varies considerably throughout a patient population, pamphlets and text on a website may be the best approaches for conveying this information. An explanation for this could be that pamphlets

and text on a website might be less intimidating, less time consuming and more easily accessible compared to one-on-one instructional classes. In contrast, one-on-one instructional class was a popular modality when a respondent considered an issue to be important. This is a more time-intensive modality than pamphlets or text on a website, but may be more comprehensive and personalized to a patient's individual needs.

In total, these results suggest that certain modalities appear to be more appropriate for the communication of information in some domains, but not in others. Support groups appear unsuited for the communication of medical or practical information, but relatively well suited for emotional or spiritual concerns. However, most modalities were consistent in the frequency with which they were requested by respondents, or at least retained relative standing against other modalities.

Acknowledgement of limitations

Sampling by convenience limits the generalizability of these findings. That all respondents were comfortable receiving health information in English may not be representative of the patient population at the Princess Margaret Cancer Centre. In addition, the questionnaire was only available in English and thus excluded participation from those unable to read English. The sample was also highly educated which may suggest that those with less education were not comfortable to participate. Information bias may have been introduced by using a non-validated measure of information need.

Conclusion

This study demonstrates that patients with gastrointestinal cancers that are engaged in active treatment are most concerned with information about their medical illness and management plan as well as how the illness will affect them physically. In general, they prefer to receive this information by pamphlet or text on a website. Where an informational need is

particularly important, a one-on-one instructional class is preferred. These findings will guide the format in which educational resources and clinical services are provided for future gastrointestinal cancer patients at the Princess Margaret Cancer Centre and should be a focus for patient education in other cancer centres. Future research directions could include duplicating these methods in a larger sample and expanding the questionnaire to include an exploration of whether informational needs are met. Exploring whether information needs are met, how they are met and whether patients are satisfied with the information received is an important next step to improving the gastrointestinal cancer patient experience.

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Conflict of interest

No conflict.

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