

Cancer Patients Seeking a Second Surgical Opinion: Results of a Study on Motives, Needs, and Expectations

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Purpose: To explore the sociodemographic and clinical characteristics of cancer patients seeking a second-opinion consultation and to analyze their second opinion-related motives, needs, and expectations.

Patients and Methods: In 212 consecutive patients seeking a second opinion at the Surgical Oncology Outpatient Clinic, satisfaction with the first specialist, motivation for the second opinion, need for information, preference for decision participation, and hope for and expectation of a different second opinion were assessed with a questionnaire.

Results: The mean age was 53 years. Most patients were women (82%), of whom 76% were diagnosed with breast cancer. Half of the patients (51%) had a low educational level. The majority of patients (62%) only had internal motives for second-opinion seeking associated with the

need for reassurance and more certainty, whereas a substantial minority of patients (38%) also had external motives related to negative experiences or unfulfilled needs. The externally motivated patients had a higher anxiety disposition, were less satisfied with their first specialist, preferred a more active role in medical decision making, and more often hoped for and expected a different second opinion.

Conclusion: Motives for second-opinion consultations differ greatly. Understanding the difference between internal and external motivation is necessary to develop strategies to prevent unnecessary second-opinion seeking. Additional studies are warranted to evaluate the objective and subjective outcomes of second-opinion consultations.

J Clin Oncol 21:1492-1497. © 2003 by American Society of Clinical Oncology.

SEEKING A SECOND opinion is a well-recognized phenomenon in medical practice. The basis of the second-opinion consultation is a thorough re-evaluation of the patient's case, including revision of diagnostic material. In this consultation, the interaction between the patient and the second-opinion specialist is essential, but the relationship with the first (treating) specialist, to whom the patient in principle is referred back, plays a role as well.

Patients usually have high expectations for this consultation. Their preparation for the second opinion often results in many questions about different aspects of the disease and its treatment possibilities. In addition, patients often fear that their initiative to consult another expert might negatively influence the relationship with their first specialist.

The second-opinion specialist will evaluate the patient's case and give advice based on evidence or guidelines, with an attitude of respect for both the patient's self-chosen role to seek more information or participate in medical decision making and his or her relationship with the first specialist. For the specialist, seeing second-opinion patients is a complicated and delicate medical activity, which is time consuming.

Patient-initiated second opinions occur in all fields of medicine. Although data on the incidence are lacking, it probably

differs by specialty and disease. In oncology, seeking a second opinion is likely to occur relatively frequently because of the life-threatening character of the disease and its usually mutilating or toxic treatment modalities. In 1992, 56% of more than 1,500 cancer survivors in the United States reported to have obtained at least one second opinion.¹ Although these numbers will be lower in most other countries, they clearly indicate that second opinions put a strain on health care systems. However, to our knowledge, only a few publications are dedicated to the phenomenon of the second opinion in the oncologic literature, and these only reflect personal views.²⁻⁴ Clearly, a discrepancy exists between the incidence of this type of consultation and the time and energy invested and attention it has received in scientific medical and psychological literature thus far.

It has been suggested that a proportion of second opinions, or at least some of the nonrealistic expectations of their outcome, can and should be prevented.^{2,3} To influence the second opinion-seeking behavior of cancer patients, underlying mechanisms need to be clarified by empirical data. To contribute to the understanding of these mechanisms, the following questions need to be answered: Why do patients seek a second opinion, what do they want out of this consultation, and what are their expectations related to its outcome?

We hypothesize that two tendencies contribute to second-opinion seeking in modern society. First, there is the growing autonomy of patients and their increasing need for medical information and shared decision making.⁵ In the Netherlands and other Western countries, these needs are acknowledged as patients' rights and are embodied in new laws on Medical Treatment Enactment. Second, patients have a more critical attitude toward care provided, leading to a more consumer-like attitude. This is evidenced by the growing interest in and implications of patient satisfaction and also by the increase in malpractice suits.⁶⁻⁸

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Submitted December 12, 2001; accepted January 10, 2003.

Supported by a grant from the Dutch Cancer Society.

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0732-183X/03/2108-1492/\$20.00

The aim of this study is to describe the basic sociodemographic and clinical characteristics of this specific subgroup of patients and to explore their motives for second-opinion seeking as related to the following patient variables: (1) anxiety disposition, (2) (dis)satisfaction with the first specialist, (3) preference for decision participation, (4) need for more information, and (5) hope for and expectation of the second opinion being different from the first opinion.

PATIENTS AND METHODS

Sample

For logistic and research reasons, a dedicated Second Opinion Outpatient Clinic was established within the department of Surgical Oncology of the University Medical Center Rotterdam/Daniel den Hoed Cancer Center. Second-opinion patients were defined as those who took the initiative for the second consultation themselves, after being seen by an oncologic specialist in a general or university hospital. No publicity was given to this facility during the study period. Therefore, it can be assumed that patients attending the clinic are representative of second-opinion seekers attending a surgical oncology clinic within a cancer center. Patients were accepted on the basis of having informed their first (treating) specialist about the consultation and having a pathologically confirmed or clinically suspected diagnosis of malignancy. All patients were initially seen by a general oncologist. Depending of the type of question or clinical problem, the second-opinion patient also was seen by an oncologic expert in the field during that first (and usually only) consultation, or the case was discussed in a multidisciplinary team.

All patients who made an appointment received a written request to ask for their participation in the study. Patients who agreed to participate were asked to complete a 12-page questionnaire just before the consultation. Patients who were excluded from the study included those who were non-Dutch speaking, those with a World Health Organization performance status of less than 4, and those who were receiving treatment or follow-up in the University Hospital Rotterdam or Daniel den Hoed Cancer Center. Of the 230 consecutive patients seen between November 1997 and January 2000, 212 patients (92%) completed the questionnaire, four patients were ineligible, three refused to participate, and 11 did not receive or return the questionnaire because of logistic problems.

Variables and Instruments

Pilot study to develop instruments to analyze satisfaction and motivation. To analyze patient satisfaction with the first specialist, a short instrument had to be developed because it is likely that cancer patients have different needs and expectations related to their physician compared with patients in general practice or with other types of (chronic) diseases for whom validated instruments exist. On the basis of the literature,⁹ we defined the following three domains of patient satisfaction with their physician: professional competence, communication skills (ability of the doctor to gather information from and to transfer information to the patient), and interpersonal skills (empathy). The main research objects of this explorative study were the motives and needs related to second-opinion seeking in oncology. Because these were never studied previously, a new instrument had to be constructed for this study issue as well. To develop the two new instruments, a pilot study was conducted. Fifty consecutive patients were interviewed preceding the actual second-opinion consultation. The semistructured interviews were conducted by a physician and a psychologist, both working with cancer patients and involved in psycho-oncologic research. Patients were asked to disclose their satisfaction with the first specialist and their reason(s) for initiating the second-opinion consultation. In the first phase, the interviews of 20 consecutive patients attending the clinic were audiotaped and independently analyzed for item generation by both researchers. For the satisfaction instrument, agreement was reached on six items representing the three different domains mentioned above, and for the motivation instrument, agreement was reached on nine items representing different reasons for second-opinion seeking. All items were worded as positive and negative statements. In the second phase of the pilot study, the nine motivation

statements and the six satisfaction statements were tested by means of a self-administered questionnaire in a cohort of 30 consecutive patients. Open questions in this questionnaire to fill in other motives or satisfaction issues resulted in one additional statement for both scales, resulting in a seven-item satisfaction scale and a 10-item motivation scale. In the definitive questionnaire, patients were asked to score their (dis)agreement on a four-point Likert scale ranging from 1 (very negative) to 4 (very positive).

Sociodemographics, clinical parameters, and anxiety disposition. Sociodemographics, clinical parameters, and anxiety disposition were assessed in the questionnaire or were prospectively registered within a clinical database. The parameters that were registered were sex, age, education, primary cancer site, stage of the disease (metastatic v nonmetastatic), and whether malignancy was histopathologically confirmed. Patients' trait anxiety was assessed using a 17-item version of the Spielberger Trait Inventory.¹⁰⁻¹² The scale had a reliability of $\alpha = 0.92$.

Satisfaction with the first specialist. Factor analysis of the seven-item satisfaction instrument revealed one clear factor (satisfaction with first specialist) with an Eigen value of 4.28, explaining 61.1% of the variance of dissatisfaction. The scale had a reliability of $\alpha = 0.89$. Patients were considered to be dissatisfied when they had a mean score lower than 2.5 corresponding with some level of dissatisfaction. For the logistic regression, satisfaction was used as a continuous variable. In one additional question, the patient was asked whether he or she was aware of the first specialist having discussed the case with another oncologic expert.

Motives for second-opinion seeking. Factor analysis revealed two subscales, and clustering of the items seemed to support our hypothesis that indeed motives can be divided into two different types. The first subgroup of motives comprises those related to the need for reassurance and more certainty, which were interpreted as internal motives ($\alpha = 0.66$). The motives clustered in the second subgroup were related to a negative appraisal by the patient of different aspects of care given by the first specialist, including doubts on the advice given, which were interpreted as external motives ($\alpha = 0.84$). After factor analysis, two items were eliminated.

Information on disease and treatment. Need for more information on disease and treatment was assessed with a four-point scale, validated instrument developed in previous studies,^{11,13} ranging from 1 (not at all) to 4 (a lot). Factor analysis showed three underlying factors, which were interpreted as the need for information about the disease (five items, $\alpha = 0.82$), disease treatment (three items, $\alpha = 0.71$), and the prognosis and expected course of the disease (three items, $\alpha = 0.72$).

Participation in treatment decision making. Preference for participation in treatment decision making was measured on a five-point rating scale;¹⁴ the scale ranged from 1, representing the specialist assuming full responsibility, to 5, representing the patient assuming full responsibility, with point 3 representing the specialist and patient sharing responsibility. Points 4 and 5 will be referred to as a preferred dominant role of the patient in decision making.

Hope and expectation related to the second-opinion outcome. Patients were asked whether they hoped that the second opinion would differ from the first opinion (categories included yes, no, partly yes, and partly no) and to rate, on a four-point scale, their expectation of the chance (range, small to big) that this difference would occur.

Statistical Analysis

Patient variables, including sociodemographic and clinical parameters, satisfaction with the first specialist, second-opinion motives, information needs, preferred decision participation, and hope and expectations, were related to patient motives for second-opinion seeking. Pearson's correlation coefficients and *t* tests were used as appropriate. Logistic regression was conducted to determine the relative contributions of the different patient variables. All characteristics and measures that were included in the analysis were answered by at least 90% of the respondents.

RESULTS

Patient Characteristics

Table 1 lists the sociodemographic and clinical patient characteristics. Most patients were women (82%), the median (\pm

Table 1. Sociodemographic and Clinical Patient Characteristics (N = 212)

Characteristic	No. of Patients	%
Sex		
Male	39	18
Female	173	82
Age, years		
Mean \pm SD	53 \pm 12.2	
Range	25-87	
Highest level of education		
Less than high school	107	51
High school	48	23
More than high school	56	26
Missing	1	0
Primary cancer site		
Breast	131	62
Digestive tract	44	21
Other	37	17
Stage		
Nonmetastatic disease	142	67
Metastatic disease	53	25
Stage unknown*	17	8

*Twelve patients (6%) had a diagnosis of malignancy not confirmed by pathology.

SD) age was 53 years (\pm 12.2 years), and half of the patients (51%) had less than a high school education. The majority of all patients (62%), which is 76% of all women, were diagnosed with breast cancer; a minority (25%) had metastatic disease. In a small number of patients (6%), the malignancy was not (yet) pathologically confirmed. The mean trait anxiety score (\pm SD) was 2.10 (\pm 0.61; range, 1 to 4).

Patient Satisfaction With the First Specialist

With a range from 1 to 4, the mean (\pm SD) score on satisfaction with the first specialist was 2.8 (\pm 0.75), and 31% of the patients were dissatisfied (score $<$ 2.5). Half of the patients (51%) knew that their first specialist had discussed their case with an oncologic expert. Patients who were less satisfied with their first specialist had a higher trait anxiety ($r = -0.19$, $P < .05$) and a higher external motivation ($r = -0.68$, $P < .001$). In addition, they hoped more frequently for a different second opinion ($r = -0.19$, $P < .05$), and more often, they did not know whether the first specialist had consulted an expert ($r = -0.20$, $P < .05$).

Motivation for Second-Opinion Request

With a range from 1 to 4, the mean score (\pm SD) on internal motivation was 3.66 (\pm 0.44), and on external motivation, it was 2.48 (\pm 0.82). A high score ($>$ 2.5) on internal motivation only was observed in the majority of patients (62%), whereas a substantial minority (38%) had a high score ($>$ 2.5) on both internal and external motivation. Table 2 shows that no significant difference was observed for most patient variables between patients who were highly internally motivated and patients who were both highly internally and externally motivated. The only difference was that externally motivated patients more often hoped for different advice. Table 3 lists the results of logistic regression, contrasting different scores for internal and external

Table 2. Patient Variables by Type of Motivation for Second-Opinion Seeking

Variable	Internal Motivation* (n = 121) (%)	Internal and External Motivation* (n = 79) (%)	P†
Sex			
Male	21.9	11.5	
Female	78.1	88.5	NS
Age			
0-39 years	12.5	15.2	
40-59 years	59.4	57.0	
60+ years	28.1	27.8	NS
Education			
Less than high school	50.0	51.3	
High school	23.4	23.1	
More than high school	26.6	25.6	NS
Malignancy			
Not confirmed	6.3	5.1	
Confirmed	93.8	94.9	NS
Stage			
Nonmetastatic disease	76.5	69.3	
Metastatic disease	23.5	30.7	NS
Tumor localization			
Breast	60.9	64.6	
Other localizations	39.1	35.4	NS
Hope for different second opinion			
Yes	60.5	80.8	.01
No	26.1	13.7	
Partly yes, partly no	13.4	5.5	

Abbreviation: NS, not significant.

*Internal motivation = score $>$ 2.5; external motivation = score $>$ 2.5.

† χ^2 test used to identify group differences.

motivation on patient variables. Patients with nonmetastatic disease, a high level of anxiety disposition, and preference for an active role in decision making were relatively more often externally motivated to seek a second opinion.

Need for More Information

With a range from 1 to 4, the mean score (\pm SD) on information need was 3.4 (\pm 0.65) for the disease scale, 3.7 (\pm 0.52) the treatment scale, and 3.5 (\pm 0.66) for the prognosis and expected course scale. A high need for information on these three subject scales (score $>$ 2.5) was observed in 89%, 97% and 93% of patients, respectively.

Patient Preference for Participation in Treatment Decision Making

No patient participation was preferred by 2% of the patients, a little participation was preferred by 13%, and shared decision making was preferred by 53%, whereas 22% of patients wanted to have major decision responsibility, and 10% wanted to have full decision responsibility.

Hope and Expectation

Hope for a difference between the second and first opinion was expressed by 68% of the patients, whereas 22% hoped for identical advice, and 10% answered partly yes, partly no. Their chance for a different second opinion was expected to be high by 6% of the patients, moderately high by 29%, moderately low by 47%, and low by 18% of the patients. The mean score (\pm SD) was 2.2 (\pm 0.82).

Table 3. Logistic Regression Analysis Contrasting Internal Motivation Versus Internal and External Motivation

Variable	Regression Coefficient (B)	P
Constant	2.79	
Female sex	0.49	NS
Age		
0-39 years		NS
40-59 years	-0.46	NS
60+ years	-1.08	NS
Education		
Less than high school		NS
High school	0.15	NS
More than high school	-0.36	NS
Malignancy	-1.03	NS
Tumor localization	-0.88	NS
Stage	-2.29	.002
Satisfaction	-3.43	< .001
Anxiety	0.98	.04
Information disease	-0.74	NS
Information treatment	0.54	NS
Information prognosis	1.02	NS
Decision participation	0.81	.02
Hope for different second opinion		
Yes	-1.69	NS
No	0.28	NS
Partly yes, partly no	0.21	NS
Chance of different second opinion		

Abbreviation: NS, not significant.

DISCUSSION

To our knowledge, this is the first study with data on specific characteristics of cancer patients seeking a second opinion. Because 92% of patients who were seen at the Second Opinion Outpatient Clinic of the Department of Surgical Oncology could be included, our data give a reliable picture of this specific population. This study reveals several basic characteristics of this oncologic second-opinion population.

Mechanisms hypothetically related to second-opinion seeking, such as the need for more information, active decision participation, and a critical attitude toward care provided, are usually associated with young age and a high educational level.^{15,16} This seems to be only partly confirmed by our data; the mean age of our study population is 53 years, which is relatively young for patients with solid tumors. The educational level, however, was low (less than high school) in half of the patients. Furthermore, we found that the vast majority of patients in the study population were women. A study on cancer patients' information needs also showed that men are less likely to access additional information services.¹⁷

Although we do not report in this article our analyses of desired decisional participation, we found that women wanted a significantly more active role compared with men, which confirms the results of other studies.¹⁸ Second-opinion seeking can be interpreted as an expression of active involvement, which possibly contributes to the high percentage of women. Another reason for overrepresentation of women might be that breast cancer was the primary cancer site in the majority of patients. This confirms the findings of the 1992 National Health Interview

study,¹ in which breast cancer patients significantly more often were reported to have had a second opinion compared with patients with other cancer types. The explanation for this might be that breast cancer has many different treatment options with comparable cure or response rates. Therefore, treatment selection will be influenced by personal preferences of patient and specialist. Furthermore, breast cancer issues are frequently addressed in the media, and thus, most patients are aware of the fact that different options are available. These breast cancer-related factors may contribute to the high number of patients with this particular type of cancer among second-opinion seekers.

Dissatisfaction with the first specialist was observed in one third of the patients. Because dissatisfaction is one of the motives for second-opinion seeking, the percentage of dissatisfied patients in our population can be expected to be higher than previously reported in oncologic and nononcologic settings.^{9,19}

Most patients had a high need for more information. This does not necessarily mean that the first specialist did not provide the patients with enough information. It is well known that only 30% to 50% of all information given can be recalled.²⁰ Internally motivated second-opinion patients probably are so-called monitors, whose coping mechanism is to regain control by seeking information and who are generally less satisfied with the standard amount of information provided.²¹ A considerable minority of patients had internal and external motives for second-opinion seeking. Compared with patients who were only internally motivated, these externally motivated patients had a higher level of anxiety disposition and dissatisfaction with their first specialist, which could indicate that these patients were more prone to label their experiences as negative. The finding that all externally motivated patients also had a high internal motivation could indicate their induced or habitual need for reassurance. The question of whether they would have sought a second opinion without these negative experiences cannot be answered.

Externally motivated patients wanted a more active role in decision making. This could indicate that because of negative experiences, they had less trust in the correctness of the first opinion and, therefore, wanted to be more actively involved. In second-opinion patients, the need for active decision participation can be expected to be higher compared with patients who do not seek a second opinion simply because the very act of initiating this expert consultation indicates taking an active role in this process. Some support for this hypothesis can be found in comparing our results with the data of Ong et al,²² who used the same instrument to analyze the desired role in decision participation of 123 (also Dutch) oncologic outpatients who were not selected for second-opinion seeking. Ong reports that a dominant role (more than shared decision responsibility) is desired by 16% of patients, which is half as much as the 32% in our population.

Most patients hoped for different advice. However, only one third of all patients expected that there was a fair chance that this would be the case, and a very small minority thought that this chance was very high. Whether these expectations were confirmed by the real outcome will be analyzed in our next study.

In general hospitals in the Netherlands, most new cancer cases and major changes in the course of the disease are discussed with a team of regular visiting oncologic experts within the frame-

work of nine comprehensive cancer centers. Because only half of the patients knew this had actually happened, many first specialists apparently did not inform their patients about their consultation with this expert team. That patients valued this consultation highly can be concluded from the fact that patients who knew that this expert consultation had taken place had a higher satisfaction with their first specialist.

Some limitations of this study need to be mentioned. To establish whether, and in what respect, second-opinion patients are different from cancer patients who do not seek another opinion, a comparative study with a control group is needed. In addition, new instruments had to be developed on satisfaction and second-opinion motivation that were not validated, but they did prove to be highly internally consistent. Only recently, Loblaw et al²³ developed a psychometrically sound patient-satisfaction-with-specialist questionnaire to be used in an outpatient oncology setting. The four domains that he identified were information exchange, interpersonal skills, empathy, and quality of time, which are all covered by at least one question in our seven-item instrument. In our analyses, patients' needs for more information and decision participation were considered independent variables. However, it could be argued that these needs were influenced by the consultation with the first specialist.

Clearly, cultural differences between patients in different countries and subsequent expectations as well as variations in health care systems make the outcomes of this study relevant to one specific situation in the Netherlands. Even within one country, no population of second-opinion patients can be classified as typical because the various university hospitals or cancer clinics will attract different patient groups because of their specific expertise and geographic position. Comparable studies in other centers and other countries could teach us which findings are population specific and which are of universal significance.

Second opinions are an established part of health care, but the increasing strain they put on health care facilities, the emotions involved, and the energy spent on the side of patients and families make reflections based on empirical data necessary. The distinction between internal and external motivation is of practical importance because, in publications on second opinions, it is assumed that most second opinions stem from patient dissatisfaction and in many cases are the result of poor communica-

tion.^{2,3} Also, in the Netherlands, many physicians used to consider a second opinion as a lack of trust in the first specialist or at least related to dissatisfaction on the side of the patient. Because of this assumption, many patients find it hard to ask for a second opinion. Our results show that, for the majority of the patients in this study, negative experiences and dissatisfaction are not leading motivations for second-opinion seeking, and we think this is important information, for both physicians and patients. On the basis of our findings of two different sets of motivations, recommendations geared toward a reduction of unnecessary or preventable second-opinion consultations could be two-fold. For internally motivated patients who have a frequently occurring type of cancer and who mainly want more information on evidenced-based or protocol treatment, it should be assessed whether their needs can be adequately met by other, less costly, information providers. Another subgroup of internally motivated patients could be possibly adequately helped with a telephone or email consultation by the expert oncologist who should, therefore, be provided with the necessary medical information.

For prevention of externally motivated second opinions, effective communication skills of specialists are of major importance. They include dealing with the increasing information and participation needs of modern patients by being an educator and collaborator as well.²⁴ Repetitive training of these skills should be adequately incorporated in medical education but should also be obligatory in later stages of professional development.²⁵ Furthermore, counseling by other professionals like oncology nurses should be incorporated into standard care, and new tools and techniques assisting specialists and patients in the process of providing information and collaborative decision making²⁶⁻²⁸ should be further developed and applied.

Having established several characteristics of second-opinion patients and their main motives, more questions need to be answered: How often is the second opinion different from the first one and in what respect? How do patients evaluate (the effect of) this consultation? Our future studies will address these issues, which could provide important information for first specialists, second-opinion specialists, general specialists, hospital managers, and insurance companies who all have to deal with the increasing consumerism of well-informed and autonomous patients of which second-opinion seeking is a significant manifestation.

ACKNOWLEDGMENT

The acknowledgment is available online at www.jco.org.

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