

# Patients seeking second medical hematology/oncology opinions in the United States: a report of their demographics and disease processes

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The seeking and rendering of second opinions are common occurrences in the routine delivery of medical care in the United States. Virtually all subspecialties of medicine offer second opinions to patients seeking them. For patients and the medical community alike, however, the benefit associated with obtaining a second opinion remains unclear.

**U**nique to the United States, a second opinion is typically any opinion provided by a medical subspecialist in addition to the medical opinion the patient already received within the same subspecialty. The purpose of second opinions differs from that found in many other nations, such as in England, where second opinions are sought from medical subspecialists subsequent to the opinion/diagnosis of a primary care physician.<sup>1</sup> What specifically are patients here in the United States seeking in a second medical opinion?

Understanding patient benefit is especially relevant in the field of medical hematology/oncology, where cancer patients routinely seek and obtain second opinions. Although objective data on the pursuit of second opinions are limited, a 1992 study determined that approximately 55% of patients with cancer had received a second opinion.<sup>2</sup> Indeed, our experience at the Mayo Clinic Arizona (MCA), and that of others, suggests that this phenomenon is persistent. In support of the notion that cancer patients frequently seek second opinions, current policy at M. D. Anderson Cancer Center in Houston states that no breast cancer patient should be offered appointments unless they intend to remain at the Center for treatment.<sup>3</sup> This policy highlights the problematic nature of the volume of patients seeking second opinions as well as the service demands placed on a center by such requests.

Although authorities on cancer care routinely recommend that patients obtain a second opinion, there is little evidence that supports a clinical ben-

efit for this practice.<sup>4</sup> No randomized controlled studies or case-control studies have been performed to demonstrate that patients obtaining second hematology/oncology opinions have better clinical outcomes. There are reports within pathology, radiology and surgical literature that detail changes in diagnoses and therapies due to a second review of cases.<sup>5-15</sup> However, reports of this type are essentially anecdotal and do not provide clear evidence that second opinions improve patient outcome.

Similarly, no updated information exists regarding the costs generated by second opinion seeking.

## KEY POINTS

Seeking and rendering second opinions are costly medical phenomena with unclear patient benefit.

Patients seeking second medical opinions tend to be younger, women, and married.

Metastatic disease is associated with a greater perceived need for a second opinion than non-metastatic disease.

There are two main motivating factors for second opinions: the need for more information to comprehend and ease the anxiety of diagnosis; dissatisfaction with or skepticism toward previous providers.

Received October 3, 2006; accepted January 10, 2007.

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**TABLE 1**

Demographics of patients seeking second medical hematology/oncology opinions at the Mayo Clinic Arizona

Characteristic	Number (%) of patients (n = 641)
Gender	
Male	308 (47)
Female	347 (53)
Marital status	
Married	431 (66)
Unknown/not recorded	91 (14)
Single	67 (10)
Widowed	38 (6)
Divorced	28 (4)
Geographical location (residence)	
Arizona	378 (58)
Bordering state	144 (22)
Other US state	111 (17)
Canada	19 (3)
Other country	3 (<1)

**TABLE 2**

Oncologic diagnoses for which second opinions were sought at the Mayo Clinic Arizona

Cancer type	Number (%) of patients (n = 374)
Breast	68 (18)
Lung	63 (17)
Colorectal	43 (11)
Pancreatic	29 (8)
Prostate	20 (5)
"Adenocarcinoma"	13 (3)
Gastric	12 (3)
Esophageal	11 (3)
Other cancer	115 (31)
Non-cancer diagnoses	3 (1)
Metastatic disease	113 (30)

Wagner and Wagner report that an estimated \$3.2 billion was spent on second opinion seeking in 1994.<sup>16</sup> The cost of second opinions has surely increased since this report, given

the dramatic overall rise in health-care costs during the past decade. Increased costs associated with second opinions include added physician charges, as well as additional, and sometimes duplicative, diagnostic procedures, therapeutic procedures, laboratory studies, radiologic studies, and pathology reviews. The incidence of such redundant medical practices necessitates the question, "How beneficial is this practice in terms of a cost-benefit ratio?"

Given the lack of evidence for a clinical benefit and the costliness associated with second opinion seeking, we sought to characterize the type of patient seeking second opinions to aid in better addressing their needs in the future. Toward this goal, we collected the demographics, disease characteristics, as well as motivating factors over a 6-month period for patients coming to the MCA for second opinions within the field of medical hematology/oncology. Demographic information (name, address, date of birth, gender, and marital status) and disease-related information (patients' understanding of the diagnosis and severity of disease) were collected from those who contacted the clinic for an appointment. The Mayo Foundation Institutional Review Board approved the conduct of this study.

**Patient characteristics**

The demographics of the patients who sought second opinions in our department (Table 1) reveal that women comprised the majority of second opinion seekers (53%, 347 of 655). Two previous studies have shown that women are more likely than men to seek second opinions and inform themselves about their diagnoses.<sup>17,18</sup> Factors leading women to be more likely to seek second opinions than men have not been specifically identified, but it has been suggested that women prefer a more active role in their care and may feel

that their diagnosis and treatment options have not been adequately explained by their first physician.<sup>19</sup> Future research should focus on determining why more women than men seek second opinions.

The vast majority of patients who sought second opinions at MCA in hematology/oncology were married (66%, 431 of 655). One previous study found that 68% of patients who actively sought information and were involved in their healthcare decision-making were married.<sup>17</sup> In contrast, only 20% of the patients seeking second opinions in our department were single, widowed or divorced. Given that 59% of the US population was married in 2002,<sup>20</sup> and we gave second opinions to a higher proportion of those married than in the general population, marital status may indeed play a role in this process.

The average age of patients who sought a second opinion was 62.3 years, which we found to be older than that previously reported in other studies. Clauson et al reported a mean age of 51.4 years for 231 breast cancer patients presenting for second surgical opinions at Northwestern Memorial Hospital.<sup>15</sup> Specifically looking at cancer survivors, Hewitt and colleagues found that patients younger than 65 were more likely to have obtained a second opinion.<sup>2</sup> It has also been reported that older patients (mean age 63 years) were more likely to be low-level information seekers and delegate decision making and information gathering to their physicians.<sup>17</sup> Our findings suggest that this is not true, although there are likely multiple factors that additionally impact the likelihood of seeking a second opinion.

The vast majority of our patients were from Arizona and bordering states. Approximately one-fifth of patients were from the states bordering Arizona (California, Colorado, Nevada, New Mexico, and Utah). Within Arizona, the majority of patients were from the

greater Phoenix area. Nineteen patients were from Canada, with 14 of those being from British Columbia. One patient was from Mexico, one was from Puerto Rico, and one was from Sweden. This supports the notion that patients seeking second hematology/oncology opinions at tertiary care centers prefer to do so close to their homes.

### Disease characteristics

In our department, the majority of patients (60% of 374 reported oncologic diagnoses) stated a diagnosis of breast (68 patients), lung (63), colorectal (43), pancreatic (29), or prostate (20) cancer (Table 2). Three percent of patients with a cancer diagnosis could not characterize their cancer beyond “adenocarcinoma” at the time of the telephone interview, and it was not possible to determine their primary site of disease. Additionally, approximately one-third of patients had metastatic disease at the time they sought evaluation at MCA. Three patients for whom an appointment request was received by the division of hematology/oncology were seeking evaluation for non-cancer-related conditions (one for obstructive sleep apnea, one for myasthenia gravis, and one for Osler-Weber-Rendu syndrome).

The majority of patients seeking evaluation for hematologic abnormalities (58%, 160 of 278) were seeking evaluation for non-malignant conditions (Table 3). Within this group, 57 patients (36%) could not characterize their condition beyond broad terms, such as “anemia” (19%), “coagulation disorder” (9%), “thrombocytopenia” (3%), “leukocytosis” (2%), “macroglobulinemia” (2%), “blood abnormal” (1%), and “myeloproliferative disorder” (1%). Of those with malignancies (42%, 118 of 278), Hodgkin and non-Hodgkin lymphomas were the most common (45%), followed by multiple myeloma (21%) and chronic lymphocytic leukemia (15%). Chronic

**TABLE 3**

Hematologic abnormalities for which second opinions were sought at the Mayo Clinic Arizona

Hematologic abnormality	Number of patients	Total hematologic abnormalities (%)	Lymphoid malignancies (%)
Lymphoma	53	19	45
Anemia, not otherwise specified	30	11	–
Multiple myeloma	25	9	21
Amyloidosis	20	7	–
Myelodysplasia	20	7	–
Chronic lymphocytic leukemia	18	6	15
Coagulation disorder	14	5	–
Myelofibrosis	12	4	–
Polycythemia vera	12	4	–
Essential thrombocythemia	10	4	–
Other hematologic abnormality	64	23	–

myeloid leukemia (6%), “leukemia” not further characterized by patient (4%), acute myeloid leukemia (3%), mastocytosis (3%), plasmacytoma (3%), and acute lymphoblastic leukemia (0.8%) were also reported.

These data indicate that patients who presented to the hematology/oncology division at MCA for second opinions had common hematologic and oncologic conditions. We noted a slight overrepresentation of pancreatic cancer cases and underrepresentation of urinary bladder cancer cases compared with US incidence rates.<sup>21</sup> Nevertheless, diagnosis of a rare disease does not appear to have been a component of the patients’ motivation for seeking second opinions at our institution.

A higher proportion of patients seeking second opinions in oncology had metastatic disease than in patients for whom an initial diagnosis or opinion was rendered. At MCA, over the 4-year period 2000–2003, an average of 18.4% of patients received an initial diagnosis of metastatic disease (personal communication with K. Coppola, tumor registrar at MCA). The fact that roughly one-third of patients seeking second opinions had metastatic disease, an increase of approxi-

mately 15%, suggests that patients with this diagnosis were more likely to seek second opinions.

### Motivating factors

Our findings suggest that a significant proportion of patients may have been motivated to seek second opinions due to a basic lack of understanding of their diagnosis. More than one-third of patients with hematologic abnormalities were unable to specify their condition, and 3% of cancer patients could only characterize their diagnoses as “adenocarcinoma.” In addition, three patients were seeking evaluation in hematology/oncology for conditions that would best be evaluated within other subspecialties. The older average patient age in our findings may also have been reflective of an inherent difficulty in communicating with their physicians, leading them to seek second opinions. Although no definite conclusions can be drawn about the motivation for those who sought a second medical hematology/oncology opinion in our department, our findings do indicate certain individuals may indeed have a greater need for them.

A study of the motivating factors for surgical oncology patients de-

terminated that motives for seeking a second opinion could be classified in two broad categories: internal motivation and external motivation.<sup>18</sup> Internally motivated patients were characterized by a greater need for reassurance and certainty, whereas those externally motivated typically had a negative evaluation of the first specialist and doubts about his/her advice. These findings suggested that the majority of patients (62%) were internally motivated.

Similar reports from other medical subspecialties indicated that most patients harbor skepticism toward doctors and medicine and were more likely to seek personal control over decision-making.<sup>22</sup> Along these lines, a survey of 2,079 patients presenting for second opinions at an orthopedic surgical clinic in the Netherlands found that most patients did so either out of a need for more information concerning their disease and treatment options or from dissatisfaction with the first consultant or results of treatment.<sup>23</sup>

Taken together, patients seeking second opinions are apparently motivated by two main factors: 1) the need for more information to comprehend and ease the anxiety of diagnosis or 2) dissatisfaction with or skepticism toward previous providers. Future research should address motivation for second opinions in medical hematology/oncology.

It should be kept in mind that fluctuations in patient demographics, diagnosis, and motivations vary within the United States and may not reflect those seen in our department at MCA or at other cancer or university-based centers. Race, level of education, and income bracket of patients were not recorded and impact patient decisions concerning second opinions as well. In the future, we hope to examine patient satisfaction and motivation to gain a better understanding of the factors behind this behavior.

## Conclusion

Since many national organizations routinely recommend second opinions (eg, American Cancer Society), and other centers are now placing limits on the number of second opinion-seekers they will see, the demand for second opinions must be supported by evidence associating it with patient benefit. Our findings represent a first step in understanding the needs patients seek to address with second opinions.

Continued research in the future into the growing trend of seeking second opinions is needed within the field of medical hematology/oncology as well as other subspecialties. Although this type of evaluation may serve a variety of purposes, including improving patient knowledge, changing disease management, and lessening anxiety, the cost of second opinions is high and puts an economic burden on the healthcare system. Ideally, the end goal of these studies would be to adjust patient care practices, lessen the need for second opinions, and, ultimately, decrease the cost of healthcare in the United States.

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**Conflicts of interest:** None disclosed.