Original Contribution

Survey of Patients Referred to a University Cancer Center for Benign Hematology: Quality Measures and Patient Understanding

By Farhad Khimani, MD, Brendan Curley, DO, MPH, and Mohammed Almubarak, MD

Mary Babb Randolph Cancer Center; and West Virginia University School of Medicine, Morgantown, WV

Abstract

Objective: To investigate patients' knowledge and understanding of benign hematology and the potential psychological impact that is associated with referral to outpatient clinics.

Methods: At Mary Babb Randolph Cancer Center, an anonymous and voluntary survey including 28 questions was designed on the basis of information obtained from a single focus group. A participatory pilot survey was performed with 10 patients followed by a full-scale survey from May until November 2013. Statistical software was used for analysis.

Results: Among 98 patients who received the questionnaire, 37.6% were men, 62.4% women, 70.9% ≥ 40 years of age, 94.6% white, and 51.6% had some college education or above. Of the patients surveyed, 62.4% were surprised to find that their appointment was at a cancer center, and 36.6% received no explanation before their referral. A total of 61.3% did not know what benign hematology was, and only 61.2% knew that cancer physicians are also frequently trained to see patients with benign hematology conditions. Among the patients, 46.2% and 39.8% had an increase in anxiety and stress, respectively; 30.1% were afraid that they might have cancer; and 32.3% thought that the reason for their referral to the cancer center was for an evaluation for cancer. Knowledge was significantly better in women patients and patients who had been seen by an outside hematologist before or had been to a cancer center before.

Conclusion: Referral to outpatient clinics in a cancer center for benign hematologic diseases seems to increase psychological stress and anxiety among patients, who may perceive that they are being referred for evaluation of a cancer diagnosis.

Introduction

Benign hematology or nonmalignant hematology deals with blood disorders that are essentially benign conditions. Often physicians trained in hematology are also trained in oncology and see patients in cancer centers for both benign hematology and oncologic issues.[1]

Patients with benign hematologic problems are generally referred by various providers for evaluation and management of disorders that typically include CBC abnormalities (anemia, thrombocytopenia, leukopenia), hypercoagulable states, and bleeding disorders, among others.[2] The evaluation of these disorders can potentially reveal a malignant source (a pancytopenia evaluation may result in a leukemia diagnosis), but often these disorders are not secondary to a malignancy. Hematology clinics are often located in cancer centers, which may be misleading to patients who do not have a diagnosis of cancer and are not being referred for a cancer evaluation. It has been our clinical observation that these patients often have a poor understanding of the reason for their referral to a physician in a cancer center at the time of their initial visit. This referral and consultation may contribute to anxiety and psychological distress in patients.[3] To our knowledge, this issue has never been studied in our population, and therefore, to our knowledge, our study is the first to explore this issue.

Methods

Survey Design

At Mary Babb Randolph Cancer Center of West Virginia University, a survey was designed on the basis of information obtained from a single focus group of four physicians, whose practice involves benign hematology, and a review of the literature. The survey was anonymous and voluntary and included 28 questions that abstracted patient data such as age, sex, race, level of education, understanding of reason for referral, knowledge of aspects of basic training of hematologists, and multiple questions concerning stress and the impact on emotional well-being of a referral to the cancer center. Multiple-choice questions were drafted with four to six answer choices and no option for unknown. Complicated scales and questions were avoided.

A few explanatory words were added to the questionnaire in parentheses for patient clarification, for example, "Oncology (Cancer)" and "Hematology (Blood)." This survey was approved by the Institutional Review Board at West Virginia University.

Pilot Survey and Administration

Initially, a participatory pilot survey was performed with 10 patients. On the basis of a review of the data that were gathered from the pilot survey, logistical, technical, and other issues were addressed. Minor issues were observed with respect to the mechanism of patient selection, collection of questionnaires before patient departure, and the wording of a few questions (on the basis of feedback from the clinic staff). The selection and collection process was streamlined and the questionnaire was updated. After this, the full-scale survey was executed. Surveys were collected exclusively from new patients presenting for benign hematology visits from May 2013 to November 2013. Patients were surveyed at outpatient appointments after a verbal

Table 1. Patient Demographic Characteristics

Characteristic	No.	%
Sex		
Male	35	37.6
Female	58	62.4
Age, years		
≤ 40	27	29
41-50	23	24.7
51-60	21	22.6
61-70	13	14
71-80	4	4.3
> 80	5	5.4
Race/ethnicity		
White	88	94.6
Black	3	3.2
Hispanic	0	0
Asian/Pacific Islander	1	1.1
Prefer not to answer	1	1.1
Education		
8th grade or less	3	3.2
Some high school	12	12.9
GED/high school diploma	29	31.2
Some college	25	26.9
Associate degree	9	9.7
Bachelor's degree	5	5.4
Master's degree	5	5.4
Doctorate degree	4	4.3
Income per annum, $		
0-8,925	28	30.1
8,925-36,250	41	44.1
36,250-87,850	17	18.3
> 87,850	5	5.4

Abbreviation: GED, general educational development.

consent was obtained, before their first contact with a hematologist. Patients received a cover letter and the questionnaire and were asked to return the completed survey in an empty envelope before leaving the cancer center. Returned questionnaires were kept in the clinic in a secure location and were given to the investigators once five or six completed surveys had accumulated to preserve the anonymity of respondents, given that questionnaires had no identifying information otherwise.

Statistical Analysis

The primary objective was to investigate patients' knowledge and understanding of benign hematology and the potential psychological impact associated with the referral. SPSS software (version 22.0; SPSS, Chicago, IL) was used for analysis. Basic frequencies and percentages were calculated for demographic and knowledge variables. χ^2 testing was performed to identify any potential associations between variables.

Results

A total of 98 patients were surveyed; five questionnaires were incomplete, with less than 50% of the questions answered, and were not included in the analysis. The characteristics of the respondents are depicted in Table 1. Basic understanding of the reasons for referral and patient understanding are noted in Table 2. Overall, of the patients surveyed, 46.2% (43 patients) surveyed noted increased anxiety levels associated with their referral for a hematologic evaluation to a cancer center; 30.1% (28 patients) noted a fear of having cancer during the referral process; and 32.3% (30 patients) thought that the reason for referral to the cancer center was for evaluation of a possible cancer. The patient population that we surveyed included 39.8% (37 patients) with a history of anxiety and 28% (26 patients) who stated that they were being treated for anxiety.

We did not find any significant associations of knowledge, attitudes, and anxiety to age, ethnicity, education, and income level. The results of those patients being referred for a new (< 3 months) hematologic disorder versus those with a longer-standing, known issue is shown in Table 3. The patients who were noted to have a new problem were significantly more likely to think that their referral was for a cancer diagnosis ($P = .015$) and indicated an increased stress level ($P = .001$).

Patients who had previously seen a hematologist and were being referred to our university center for a second opinion were more likely to understand the reason for referral and less likely to be surprised that their appointment was at a cancer center (Appendix Table A1, online only).

Discussion

The term cancer is associated with significant anxiety and psychological stress. When a patient is referred to a cancer center for a nonmalignant disorder, the referral may lead to distress if the referring physician does not properly explain why the referral is being made. Unsurprisingly, patients with a history of anxiety and those receiving anxiety medications were more likely to have an increase in their anxiety levels compared with those who did not have anxiety. We noted a significant association with sex and that women surveyed were noted to have a better understanding of the role of a hematologist/oncologist in their benign hematologic evaluation. We hypothesize that this

Table 2. Responses by Sex

	Women			Men			
Question	Y	T	%	Y	T	%	*P*
Did you know that your appointment today would be with a physician who practices oncology (cancer) and hematology (blood)?	50	58	86	24	35	68	.041
Do you know what benign hematology is?	26	58	44.8	7	35	20	.032

Abbreviations: T, total No. of responders; Y, No. of responders who said yes.

Table 3. Responses According to Whether Patients Were Referred for a New Blood Problem (< 3-month duration)

Question	New Blood Problem Group			Others			*P*
	Y	T	%	Y	T	%	
Did you think at any point during this process that the reason for your referral to the cancer center is evaluation for cancer in you?	14	39	35.8	13	48	27	.015
Do you know what benign hematology is?	16	39	41	16	48	33	.03
Did it increase your anxiety when you found out that you will be seen at the cancer center?	11	39	28.2	16	48	33	.001
Do you think you have a benign hematologic problem?	17	39	43.5	12	48	25	.033
Do cancer doctors often have training in benign blood disorders?	26	39	66.6	27	48	56	.016

Abbreviations: T, total No. of responders; Y, No. of responders who said yes.

could either be a result of a comparatively lower number of men in our study or because it has been noted that women express more interest in their care than men, and hence, have more knowledge.[4,5]

Our study also shows that if a patient is being referred for a new blood problem, they are more likely to be afraid but do not necessarily have poor knowledge or increased anxiety. On the contrary, patients who are referred for a chronic blood problem are less likely to think that they have a benign blood disorder (and are concerned about a more threatening diagnosis, such as cancer) compared with patients coming in for new hematologic visits. We also noted, on the basis of our data, that if a patient had been previously evaluated by a hematologist, was given an explanation of the reason for the referral, or had been in a cancer center before, the patient was less likely to have anxiety or poor understanding. Although we do not have data regarding the exact words used by referring providers to patients (which would be difficult to obtain), responses to a few of our questions indicate that the location of the referral (a cancer center) was omitted by many referring providers.

On the basis of our observations and the results of this study, it is hypothesized that there is a lack of communication between referring physicians' offices and patients.[6] Possible reasons are likely multifactorial, including lack of time as a result of busy schedules at referring physicians' offices and a lack of awareness among health care teams about possible anxiety and distress that may be experienced by the patients.[7] Referrals to hematology are often based on abnormal results, and frequently, laboratory results are received and reviewed after the patient's visit, which may result in a lack of communication and the omission of counseling on the part of the provider to the patient. The CBC is a commonly ordered test and is often part of the basic set of tests performed during health checkups; interpretation of the CBC may be problematic, especially if reactive abnormalities are to be differentiated from serious hematopoietic conditions. As a result, patients with CBC abnormalities may be referred for hematology consultations without any previous counseling.

Referral to a cancer center can have a negative impact on the psychological state of patients as a result of the connotation attached to the term cancer center, and our survey underscores the importance of communication between a referring provider and the patient. Strategies to achieve this could include dedicated 3- to 5-minute counseling sessions regarding the referral or phone calls to the patient to explain the reason for the referral if the decision is made after the patient leaves the office. This is an important issue that affects the psychological well-being of patients and is easily avoidable with brief counseling.[8] Hematologist/oncologists can also improve patient understanding when scheduling a patient for a referral, given that the reason for the referral is often noted during the appointment. A description of the nature of benign hematology visits can be described in a letter about the appointment or in an informational brochure, which are often sent to patients from cancer centers before a visit. Future studies are needed to further explore this topic among various ethnic groups and to test the potential usefulness of the strategies described here; such studies should include a comparative group that is not referred to a cancer center.

Study limitations include a relatively small sample size, mostly white patients, and the study was performed in a single center in the state of West Virginia; the sample may not reflect the attributes of other ethnicities. Physician practices and patients' knowledge and attitudes may differ from center to center and may vary among different states with populations that have different demographic characteristics. The questionnaire that was used has not been validated and would need to be validated for future studies.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

Author Contributions

Conception and design: All authors

Collection and assembly of data: Farhad Khimani, Brendan Curley

Data analysis and interpretation: All authors

Manuscript writing: All authors

Final approval of manuscript: All authors

Corresponding author: Farhad Khimani, MD, Moffitt Cancer Center, University of South Florida, Mail stop: BMT-FOB3, 12902 Magnolia Dr, Tampa, FL 33612; e-mail: farhad.khimani@moffitt.org.

DOI: 10.1200/JOP.2014.001543; published online ahead of print at jop.ascopubs.org on November 18, 2014.

References

1. Arnold DM, Cuker AC, Neunert C: Consultative hematology I: Hospital-based and selected outpatient topics. American Society of Hematology Self-Assessment Program, 2013. http://ash-sap.hematologylibrary.org/

2. Zaucha J, Adamowicz K, Zalewska M, et al: Analysis of patient referrals to the outpatient haematology clinic in Elbla̧g. Współczesna Onkol 15:385-392, 2011

3. Suchman AL: Book review: Through the patient's eyes—Understanding and promoting patient-centered care. N Engl J Med 330:873, 1994

4. Drageset S, Lindstrøm TC: Coping with a possible breast cancer diagnosis: Demographic factors and social support. J Adv Nurs 51:217-226, 2005

5. Meechan GT, Collins JP, Moss-Morris RE, et al: Who is not reassured following benign diagnosis of breast symptoms? Psychooncology 14:239-246, 2005

6. Bains S, Egede LE: Mediators of patient-physician communication discrepancies. Arch Intern Med 171:475-476, 2011; author reply 476

7. Laing SS, Bogart A, Chubak J, et al: Psychological distress after a positive fecal occult blood test result among members of an integrated healthcare delivery system. Cancer Epidemiol Biomarkers Prev 23:154-159, 2014

8. Rodríguez JN, Quesada JA, Sánchez JL, et al: Information and worry among patients with non-oncohematological pathologies upon arrival at the hematology clinic [in Spanish]. Sangre (Barc) 44:364-370, 1999

Appendix

Table A1. Responses According to Whether an Outside Hematologist Was Previously Seen

	Seen Outside Hematologist Group			Others			
Question	**Y**	**T**	**%**	**Y**	**T**	**%**	***P***
Were you surprised when you found out your appointment was in a cancer center?	4	14	28.5	53	77	69	.015
Do you know the reason for referral to our facility?	13	14	92.8	65	77	84	.028

Abbreviations: T, total No. of responders; Y, No. of responders who said yes.