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ORIGINAL REPORT

Disclosing a Diagnosis of Cancer: Where and How Does It Occur?

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ABSTRACT

Purpose
While disclosing a cancer diagnosis to a patient is common practice, how it is disclosed and the impact it has on the patient are poorly understood. We examined how cancer diagnoses were first given to patients and the impact of different aspects of disclosure on patient satisfaction.

Patients and Methods
We provided a self-administered questionnaire to a total of 460 oncology patients of the National Cancer Institute (NCI) being treated at the National Institutes of Health (NIH) Clinical Center in Bethesda, MD.

Results
Of the 437 patients who completed the survey, 54% were told their diagnosis in-person in the physician's office, 18% by phone, and 28% in the hospital. Forty-four percent of patients reported discussions of 10 minutes or fewer, 53% reported discussions lasting longer than 10 minutes, and 5% could not remember. Treatment options were not discussed for 31% of those who could clearly remember. Higher mean satisfaction scores were associated with diagnoses revealed in person rather than over the phone (68.2 ± 1.6 *v* 47.2 ± 3.7), diagnoses revealed in a personal setting rather than an impersonal setting (68.9 ± 1.6 *v* 55.7 ± 2.8), discussions lasting longer than 10 minutes rather than fewer than 10 minutes (73.5 ± 1.9 *v* 54.1 ± 2.4), and inclusion of treatment options rather than exclusion (72.0 ± 1.9 *v* 50.7 ± 3.2; $P < .001$ for each aspect).

Conclusion
Physicians should disclose a cancer diagnosis in a personal setting, discussing the diagnosis and treatment options for a substantial period of time whenever possible.

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INTRODUCTION

Fifty years ago, it was common practice to avoid revealing and discussing a diagnosis of cancer;[1,2] however, since the late 1970s, that practice has changed.[3] Physicians now routinely discuss cancer diagnoses, treatment options, and prognoses with patients. The current challenge is not whether to reveal a diagnosis of cancer, but how best to disclose the diagnosis.

There are some recommendations on how best to deliver bad news, but few have considered the unique issues associated with oncology patients.[4-7] Furthermore, where, when, and how the delivery of a cancer diagnosis actually occurs have not been widely studied.[8-10] Some studies suggest that 16% to 40% of patients with cancer have received their diagnosis over the phone and/or through the mail.[4,11-13] However, these studies have significant limitations in that they are either single institution studies or underpowered.[4,5,11-15] Two studies examined how a cancer diagnosis was disclosed in relation to the patient's preferences,[16,17] but the authors did not adequately evaluate patients' satisfaction with the disclosure approach and the psychological impact of the different approaches to disclosure.

To better understand how the diagnoses of cancer are disclosed and the consequences of different disclosure approaches, we conducted a study that examined how the diagnoses were given to patients. We hypothesized that patients given a diagnosis of cancer in a personal manner (ie, in person in a private setting) would have higher satisfaction with the way in which they were told they had cancer. The main end points of this study include determining the manner in which patients are given their cancer diagnoses, and how different aspects of disclosure affect their level of satisfaction with the disclosure.

PATIENTS AND METHODS

Patients

The study participants were patients of the National Cancer Institute (NCI) being treated at the National Institutes of Health (NIH) Clinical Center in Bethesda, MD. The study was conducted in compliance with good clinical practice and the Declaration of Helsinki. The NCI institutional review board approved the consent form. All participants had to be at least 18 years of age, have been previously diagnosed with cancer, be able to read and write in English, and provide signed consent. Between May 2008 and August 2008, we invited 460 patients to participate, 437 of whom completed the self-administered survey (95% response rate), although some were incomplete. The NCI is a referral center, and patients enrolled on this study were referred to the NCI from 45 states and nine US territories and foreign countries. Patients, therefore, had a diagnosis of cancer from an outside institution, and the self-administered survey examined their experience from that outside institution explicitly.

Survey Development and Administration

The survey instrument was developed through a six-step process: (1) literature search and review of prior surveys on disclosure of cancer diagnoses, (2) development of a draft survey instrument, (3) review by survey methodologist for wording and question sequencing, (4) revision of the survey, (5) behavioral testing with cancer patients to assess comprehension of the questions, and (6) final revision of the survey instrument.

The survey instrument contained 34 questions. Overall, seven questions assessed the circumstances of the actual disclosure of cancer to the patient. The survey also contained nine questions from the Communication Assessment Tool (CAT), a validated instrument that examines physicians' interpersonal and communication skills.[18] The CAT instrument has been tested and proven to be reliable across clinical specialties. In addition, questions from the Wake Forest Trust Scale (short-form) were included. This is a five-item validated tool with strong reliability among English-speaking adults that evaluates a patient's trust in doctors.[19,20]

Although some surveys were returned with some questions unanswered, no surveys were excluded because of incompleteness. Blank responses were not included in analyses. If a particular response is presented as a percentage, it is the percent of responses to that specific question, not of the total number of survey instruments returned.

Statistical Methods and Human Subjects

Satisfaction was evaluated using a scale from 0 to 100, and comparisons between groups were evaluated using a Wilcoxon rank sum test. The communication scale had a range from 9 to 45 with scores higher 28 constituting better communication. The Trust scale had a range from 5 to 25, with scores between 5 and 15 constituting lower trust, and sums between 16 and 25 constituting higher trust. These categorized results were compared between groups with a χ^2 test or Fisher's exact test as appropriate. All P values are two tailed, without adjustment for multiple comparisons.

The NCI institutional review board approved the study and all participants provided signed informed consent.

RESULTS

Demographics

The survey was completed by 437 patients with a median age of 53 years (range, 19 to 88 years; Table 1). Overall, 38% (n = 164) were female and 85% described themselves as white, 8% as African American, 3% as Hispanic, and 2% as Asian/Pacific Islander. Of the patients, 37% had lymphoma or leukemia, 22% had brain cancer, 14% had prostate cancer, and 27% had other cancers (Table 1). Other sociodemographic characteristics, including religion, education, income, and place of residence, are presented in Table 1.

Table 1. Sociodemographic Characteristics of the Patients With Cancer (N = 437)

Characteristic	No.	%
Age (n = 429*)		
Median	53	
Range	19-88	
Sex (n = 432)		
Female	164	38
Male	268	62
Race/ethnicity (n = 429*)		
White	362	84
African-American	32	8
Hispanic	14	3
Asian/Pacific Islander	10	2
Other	11	3
Religion (n = 424*)		
Protestant	181	43
Catholic	125	29
Jewish	24	6
Other	94	22
Education (n = 424*)		
6-11 years of schooling	12	3
High school diploma	101	24
Associate's degree	66	15
Bachelor's Degree	119	28
Postgraduate	126	30
Income (n = 413*), $		
< 25,000	43	10
25,000-49,999	72	17
50,000-74,999	56	14
75,000-99,999	64	16
≥ 100,000	160	39
Do not know	18	4
Place of residence (n = 430*)		
South	303	70
Northeast	62	14
Midwest	30	7
West	27	7
Outside United States	8	2
Type of cancer (n = 437*)		
Leukemia/lymphoma	160	37
Brain	96	22
Lung	13	3
Ovary	19	4
Prostate	60	14
Other	89	20

*Responses to a given question; a total of 437 surveys were completed, although some were incomplete.

Disclosure of Cancer Diagnosis

Of the 437 patients who responded to the survey, 54% (n = 233) were told their cancer diagnosis in-person in the physician's office, while 18% (n = 79) were given the diagnosis over the phone. The remaining 28% (n = 122) were told in the hospital, with nearly half of these (43%) told in their personal hospital room, approximately one fourth (23%) in the emergency room, 13% in the recovery room, 7% in the radiology department, and the remaining 13% in a variety of other hospital locations (Table 2). One person learned of his/her diagnosis by reading a radiology report.

Who Informed Patients of Their Diagnosis?

Most patients (96%) received their cancer diagnoses from physicians. Surgeons disclosed the diagnosis to 25% of patients, primary

Table 2. Disclosure of Cancer Diagnosis to Patients

Parameter	No. of Responses	%
Method of disclosure (n = 434*)		
By phone	79	18
In physician's office	233	54
In hospital	122	28
Specified area in hospital†		
Emergency room	28	23
Radiology department	9	7
Recovery room	16	13
Private room	53	43
Other	16	13
Who disclosed (n = 428*)		
Primary care physician	97	23
Oncologist	95	22
Surgeon	108	25
Other physician	109	26
Nonphysician	19	4
Was another person present? (n = 431*)		
No	166	39
Yes	265	61
Who was with the patient‡		
Parent	45	17
Spouse	192	72
Sibling	27	10
Child	27	10
Significant other	21	8
Other	18	7
Length of disclosure discussion (n = 430*), minutes		
< 1	34	8
1-10	155	36
11-30	152	35
31-60	54	13
> 60	12	3
Do not remember	23	5

*Responses to a given question; a total of 437 surveys were completed, though some were incomplete.
†Percent for this category refers to percentage of those told in hospital.
‡Percent for this category refers to percentage of those with another present.

care physicians to 23%, medical oncologists to 22%, and other physicians to 26%. The remaining 4% of patients were told by nonphysicians, which includes radiology technicians, nurses, physician assistants, and relatives (Table 2).

Who Was Present With the Patient?

Thirty-nine percent of individuals indicated that they did not have anyone with them when they were first informed of their diagnosis of cancer. Of those with another present, 72% were with their spouse, 17% with a parent, 10% with a sibling, 10% with a child, 8% were with their significant other, and 7% were with a friend (Table 2). It is important to note that these groups are not mutually exclusive as some patients had more than one person present.

Length of the Initial Discussion and Information Discussed

When asked about the length of the initial discussion of diagnosis, 8% of patients reported it being shorter than 1 minute long, 36% said 1 to 10 minutes, 35% said 11 to 30 minutes, and 3% said longer than 60 minutes. Five percent of people did not remember how long the discussion lasted (Table 2).

Among those who could remember, 13% of patients reported that they had no explanation of their diagnosis, and 31% indicated that they received no discussion of treatment options. Seventy-seven percent of patients indicated the discussion did not include experimental therapy options, and 30% were not presented with referrals to other specialists. Five percent of patients could not remember an explanation of the diagnosis and 4% could not remember a discussion of treatment options.

Change of Physicians

Overall, 57% of patients reported changing physicians after their cancer diagnosis. When given the option to choose more than one answer, of the patients who changed physicians, 8% changed to be closer to home, 33% to receive treatment at another facility, 48% were referred elsewhere, 20% changed in order to receive experimental treatment, and 21% changed in order to receive a second opinion. Of note, 15% of those who changed reported that they did so because they lost trust in their physicians, 10% because of poor communication, and 12% because of general dissatisfaction (Table 3). It is important to note that because participants were allowed to select more than one reason for changing physicians, these groups are not mutually exclusive.

Satisfaction, Trust, and Communication Assessment

Patients were asked to rate "how satisfied [they] were with the way [they] were first informed about [their] cancer." The median overall satisfaction score was 73.5 (of 100; interquartile range, 45 to 93). Also, nearly 80% of patients expressed greater than a neutral level of trust in their physician, and 16% had absolute trust. Similarly, 84% reported higher than neutral satisfaction with communication with their physician while 5.6% reported very poor communication.

Patients commented on their experiences: "my doctor at the time called me on Valentine's day to say I had a lesion in my chest…he left this message on my home answering machine"; "[I was] very disgusted and confused to get a call at home when my grandson was sitting on my lap"; "[The doctor] telephoned and left a voice message saying you have lymphoma…call me if you have any questions"; "The

Table 3. Changing of Physicians

Parameter	No.	%
Changed physicians after diagnosis? (n = 427*)		
No	183	43
Yes	244	57
Selected reasons for changing physicians†		
Referred to another physician	118	48
Wanted treatment at another facility	81	33
Lack of trust/bad relationship with physician	36	15
To obtain treatment closer to home	19	8
Poor communication	24	10
Obtain experimental treatment	48	20
To get second opinion	50	21
General dissatisfaction	28	12

*Responses to the question; a total of 437 surveys were completed, though some were incomplete.
†Not mutually exclusive groups because patients could select multiple answers.

Table 4. Aspects of Disclosure and Satisfaction Scores

	Satisfaction Score		
Parameter	Mean	SEM	*P*
Method of disclosure			
In person	68.2	1.6	< .001
Over the phone	47.2	3.7	
Location of disclosure			
Personal setting	68.9	1.8	< .001
Impersonal setting	55.7	2.8	
Length of discussion, minutes			
≤ 10	54.1	2.4	< .001
> 10	73.5	1.9	
Discussion of treatment options?			
Yes	72.0	1.9	< .001
No	50.7	3.2	

Table 5. Aspects of Disclosure and Type of Physician

Parameter	Medical Oncologist/Primary Care Physician (%)	Other Physician (%)	*P*
Method of disclosure			
In person	83	81	.61
Over the phone	17	19	
Location of disclosure			
Personal setting	75	59	< .001
Impersonal setting	25	41	
Length of discussion, minutes			
≤ 30	83	85	.69
> 30	17	15	
Discussion of treatment options?			
Yes	84	64	< .001
No	16	36	

doctor phoned me at 9 PM on a Sunday night…it was a horrible experience"; "the neurologist called saying he had made arrangements [for me] to see a neurosurgeon. I asked why? He said, you've got a brain tumor and hung up."

Predictors of Satisfaction

Several tendencies of interest were found in our study. Having another person present was not associated with satisfaction ($P > .51$), though method and location of disclosure, length of discussion, and discussion of treatment options were associated with levels of satisfaction based on bivariate analyses (Table 4). Patients who heard their diagnoses in person had significantly higher mean satisfaction scores than those who received their diagnoses over the phone (Table 4). Those who received their diagnoses in personal settings, such as the physician's office or hospital bedroom, had significantly higher mean satisfaction scores than those who received their diagnoses in impersonal settings, such as a radiology suite or recovery room (Table 4). Longer discussions (longer than 10 minutes) and discussions that included treatment options were also associated with higher satisfaction scores (Table 4). Similarly, high trust in their physicians (as measured by the Wake Forest Trust Scale) was associated with longer discussions and inclusion of treatment options ($P < .001$), although trust was not associated with having a diagnosis revealed over the phone or in an impersonal setting. Sociodemographic factors, including age, sex, race, education, religion and income, as well as which physician discussed the diagnosis were not significantly associated with the level of satisfaction in the physician-patient relationship.

We also noted relationships within the predictors of satisfaction themselves. For example, discussions in personal settings tended to be longer. Eighty percent (80%) of patients receiving a cancer diagnosis by phone had a discussion lasting 10 minutes or fewer, compared with 39% of those who had the disclosure provided in person ($P < .001$). Of those who received their diagnoses in person, only 35% who received their diagnoses in personal settings reported discussions of 10 minutes or fewer, compared to 68% of discussions in impersonal settings ($P < .001$). Impersonal discussions tended to exclude treatment options, as 52% of disclosures on the phone included treatment options, which is significantly less than the 72% of in-person disclosures that included these options ($P = .0038$).

We also noted trends in how different kinds of physicians revealed a cancer diagnosis. Regardless of who disclosed the cancer diagnosis, whether medical oncologist or primary care physician as compared with surgeon or other, the rate of using the phone was similar, as was length of discussion (Table 5). However, medical oncologists and primary physicians more frequently presented the diagnosis in personal settings ($P = .0006$) and discussed treatment options ($P = .0005$; Table 5).

Finally, we evaluated predictors of changing physicians. Sociodemographic characteristics, such as age, sex, race, education or income, did not predict who changed physicians. There was a slight tendency for patients receiving a diagnosis over the phone or in an impersonal setting to change physicians, as 28% of patients who changed physicians due to dissatisfaction received their diagnosis by phone, compared to 17% of those who did not change physicians at all or did so for reasons which were not related to a negative characteristic of the physician ($P = .056$). Also, 45% of those who changed physicians because of dissatisfaction received information on treatment options, compared to 71% of all others ($P = .0007$).

DISCUSSION

Our study provides important information regarding not only where and how a cancer diagnosis is disclosed throughout the country but also how these factors affect the patient. About two thirds of patients were told about their cancer diagnosis in-person in a physician's office (54%) or in their personal hospital room (12%). However, a sizable minority of patients were told by telephone (18%), in an emergency room (7%), or other impersonal manner or settings. In some cases, a situation may warrant the disclosure of a new diagnosis of cancer on the phone or in the emergency room rather than in a more personal, private manner. For example, results of a final test may confirm the cancer diagnosis, and calling the patient rather than waiting several days for an office appointment may be in order. In other cases, strong suspicions of acute leukemia may be diagnosed on a routine blood test in the emergency room. However, having more than 20% of patients told their diagnosis in an impersonal manner suggests too many physicians are either unaware of or not practicing good communication skills in such bad news circumstances.[4,8,9] Furthermore, poor communication skills seemed more common among physicians who were not medical oncologists or primary care physicians, despite discussing bad news guidelines widely published in the literature.[21] Providing more communication training around bad news may be important in surgical, radiologic, and other training programs.

These data provide some important insight into communicating a new cancer diagnosis. The diagnosis should be given face-to-face in a personal setting rather than on the phone or in an impersonal setting. Physicians should plan to talk for longer than 10 minutes. Finally, the discussion should include more than just revealing the diagnosis. We recognize that not discussing treatment options may be appropriate in certain situations, such as if a specialist's opinion or more information is needed, and this may be why primary care physicians or medical oncologists discussed treatment options more frequently than other physicians. Similarly, it may not be appropriate to discuss experimental treatments at the time of diagnosis or provide referrals, especially if the patient is already seeing a specialist. However, our analysis of satisfaction and other factors suggests that patients want to know what to do following the diagnosis. Consequently, discussions should include treatment options whenever possible.

In our analysis of patients' changing physicians after the initial diagnosis, we saw that more than 50% of our participants changed physicians. The most common reasons for changing physicians were referrals, to obtain treatment at another facility, to obtain experimental treatment, and to get a second opinion (Table 3). These results are not surprising, as it may often be appropriate for patients with cancer to seek out a specialist after the diagnosis. However, we find it concerning that 15% of those who changed physicians cited lack of trust or a bad relationship with the physician as one reason for changing physicians (Table 3). We would like to increase the level of patient satisfaction with how their cancer diagnosis is revealed, and we believe this study contributes to this end.

This study has several limitations. Patients reported how they were told based on their recollection, and memory can be faulty, possibly to due age or the emotional trauma that often accompanies a cancer diagnosis. Details such as length of discussion may not be accurately recalled, and the accuracy of the participants' memories is outside the scope of this study. Also, this study was conducted at a referral hospital, and thus the survey represents physicians from the patient's home institution, potentially leading to other limitations. For example, a dissatisfied patient may be more likely to undergo experimental treatment at the NCI; thus, our patient population may have a higher rate of dissatisfaction than a population surveyed outside the NCI or a similar referral center. Most patients were seen by several clinicians before arriving at the NCI. Because we asked patients to reflect on their initial diagnosis, some faced a multitude of memories surrounding a long diagnosis process, which often includes referrals to other specialists. This may cloud some of our results found since some physicians may be unable to tell a patient specific details because it is outside the scope of his or her practice. Future studies may benefit from differentiating when a cancer diagnosis is given by an oncologist versus other physicians. Making this differentiation could paint a clearer picture of disclosure and a patient's satisfaction thereof. In addition, it could help determine where bad news communication training is needed most in the medical field.

The study also has several limitations in its sample population. First, there was a greater number of patients with leukemia/lymphoma or brain tumors in this sample than may be expected. This disproportion could be attributed to the lymphoma/leukemia and brain tumor studies that were enrolling patients at the time of our study. Second, although this study included patients from across the country, this sample population has limited nationwide generalizability because of the skewed representation of patients from the South. Additional studies would benefit by including a more geographically homogenous patient population to better evaluate the disclosure of cancer across the nation.

Despite these limitations, we feel this study could be used by physicians to better disclose a cancer diagnosis or other bad news to their patients. This study indicates a minority of patients (approximately 20%) are told they have cancer over the phone or in an impersonal setting. Such discussions, especially when they are short and lack information about treatment options, are associated with dissatisfaction and the patient changing physicians due to that dissatisfaction. Based on the results of this study, we suggest that physicians revealing a cancer diagnosis or bad news disclose the information in a personal setting, discussing the diagnosis and possible treatment options for an extended period of time whenever possible.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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