



Patient preferences regarding the communication of biopsy results in the general otolaryngology clinic

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ABSTRACT

Objectives: To determine the preferred methods of communicating biopsy results for patients in our comprehensive otolaryngology clinic, and to examine factors associated with preferring remote vs. in-person communication of results.

Study design: Cross-sectional study.

Setting: Academic comprehensive otolaryngology clinic.

Subjects and methods: A survey instrument was administered to 107 consecutive adult otolaryngology patients undergoing head and neck fine needle aspiration biopsy from March 1, 2017 to April 30, 2018 assessing their health literacy using the Brief Health Literacy Score and their preferred method of notification of biopsy results (in-person vs. remote).

Results: 69% of patients preferred remote notification of their biopsy results (either by telephone or via an online portal). 54% of patients prioritized clear explanation of the results as the most important factor when communicating a malignant result. Adequate health literacy was associated with lower odds of preferring in-person notification (adjusted odds ratio 0.11, 95% CI 0.03 to 0.39). Patients who prioritized clear explanation of the results were more likely to prefer in-person notification (adjusted OR 4.13, 95% CI 1.31 to 14.88).

Conclusions: A significant proportion of patients in our comprehensive otolaryngology clinic undergoing fine needle aspiration biopsy preferred remote communication of their biopsy results. Patients most valued clear explanations from the provider and prompt receipt of the result when communicating malignant results. This highlights the need for individualized results communication plans, for patients undergoing biopsy.

1. Introduction

Otolaryngologists often perform or order biopsies, which may result in the diagnosis of malignancy. This leads to the dilemma of how best to communicate biopsy results to patients, especially if a malignant result is likely. While a number of tools and guidelines exist on the delivery of bad news [1,2], the best mode of communication is unclear. Traditional practice emphasizes in-person communication of bad news. However, for patients, waiting for in-person communication of biopsy results often leads to significant emotional distress [3–5]. Furthermore, for benign results, in-person communication may require scheduling unnecessary follow-up appointments.

Remote methods of communication such as telephone, email, and online patient portals are becoming more prevalent in healthcare.

Several studies suggest that many patients prefer to receive their test results remotely [6,7]. However, concern about miscommunication, and inability to provide adequate emotional support may act as barriers to communicating biopsy results remotely.

The Adult Comprehensive Otolaryngology Clinic at our institution frequently performs biopsies of lesions in the head and neck region. The senior author (UCM) noted frequent complaints from patients regarding the wait times for biopsy results, and the need for additional clinic visits to discuss biopsy results. This led to the initiation of a quality improvement project to improve communication of biopsy results to patients. Given the recent move towards more patient-centered care and shared decision-making, understanding the patient's perspective is important. Consequently, the goals of the initial phase of the project were to determine the preferred methods of communicating biopsy results for

Abbreviations: analysis of variance, (ANOVA); Brief Health Literacy Screen, (BHLS); confidence interval, (CI); fine needle aspiration, (FNA); head and neck cancer, (HNC); odds ratio, (OR)

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patients in our comprehensive otolaryngology clinic, and to examine factors associated with preferring remote vs. in-person communication of results. We report our findings in this study. To our knowledge, this is the first study to examine patients' preferences for communication of biopsy results in otolaryngology patients.

2. Methods

This study was exempt from review by the Stanford University Institutional Review Board due to its status as a quality improvement project. This was a cross-sectional study of adult patients (older than 18 years old) undergoing fine needle aspiration (FNA) biopsies in Stanford Health Care's Comprehensive Otolaryngology clinic from March 1, 2017 to April 30, 2018. Patients were excluded if they were not proficient in English because the electronic health record's online patient portal is only available in English. Patients were administered a questionnaire in English asking them to select their primary preferred method of receiving the biopsy result. Patients were asked if they would prefer to receive communication from the provider in person, from the provider over the telephone, or from their online patient portal account. The patients were asked to rate their level of worry regarding the biopsy result on a 5-point Likert scale ("extremely," "quite a bit," "somewhat," "a little bit," or "not at all") and to list the factors that were most important to the patient when receiving the biopsy result if it were positive for malignancy. The options for these factors important to the patient included: getting the result quickly, receiving emotional support from the provider (showing her/his concern, providing comfort), receiving clear explanations about the result, or other (the patient was allowed to elaborate using free text). The patients were also asked to choose the longest acceptable time they should have to wait for their results (1 day, 2 days, 3–5 days, 6–10 days, 10–14 days, or > 14 days).

Data were collected on demographic factors such as age, gender, marital status, and education level. Highest level of education achieved was recorded as: a) less than high school diploma, b) high school diploma or GED, c) bachelor's degree, or d) graduate or professional degree. Health literacy was assessed using the Brief Health Literacy Screen (BHLS), a validated 3-item self-reported measure of health literacy [8]. The BHLS was developed to rapidly detect patients with inadequate health literacy. It has been formally validated against the Short Test of Functional Health Literacy in Adults [9] and Rapid Estimate of Adult Literacy in Medicine [10] two previously validated and widely used measures of health literacy, and has been found to be reliable in detecting patients with inadequate health literacy. The BHLS questions are as follows:

1. How confident are you filling out medical forms by yourself?
2. How often do you have someone help you read hospital materials?
3. How often do you have problems learning about your medical condition because of difficulty understanding written information?

For the first question, the response options were: "extremely," "quite a bit," "somewhat," "a little bit," or "not at all." For the other two questions, the response options were: "all of the time," "most of the time," "some of the time," "a little of the time," or "none of the time." Patient BHLS responses were recorded on a 5-point Likert scale. The first question was reverse-coded. The score for the three questions was summed to equal between 3 and 15 points, with higher scores indicating higher health literacy. A response of ≤ 3 (i.e., "somewhat" or "some of the time") on the Likert scale was considered indicative of inadequate health literacy for each question, and a summative score of ≤ 9 was considered indicative overall inadequate health literacy [11,12]. Data on the biopsy site, prior history of head and neck cancer (HNC), and whether the patient had an active online patient portal account were obtained from the patient's medical records.

R version 4.3.1 (R Foundation for Statistical Computing, Vienna, Austria) [13] was used for statistical analysis with the ggplot2 [14]

package for data visualization. Baseline characteristics were compared between patients stratified by their preference for communication. In our univariable analysis, we used the one-way analysis of variance (ANOVA) test or the Kruskal-Wallis rank sum test for continuous variables. For categorical variables, we used Pearson's chi-square test or Fisher's exact test as appropriate. Multivariable analysis was performed with logistic regression modeling the outcome of patient preference for in-person communication vs. remote communication. The following variables were included a priori in the models: age, gender, marital status, education level, BHLS score, biopsy site, prior history of HNC, active online patient portal account, the most important factor for communicating a malignant biopsy result, and the patient's level of worry. Continuous variables were evaluated to ensure linearity in the logit and were modeled categorically if they did not meet this assumption. A p -value of < 0.05 was considered statistically significant. The Bonferroni correction was used to adjust for multiple comparisons when making pairwise comparisons. The sample size for the study was based on the available subjects during the study period. Sample size calculations were not performed since there were no previous published or pilot data available to provide reliable estimates of the variability of the outcome and predictor variables.

3. Results

Of 110 surveys administered to eligible patients, 107 were available for analysis, a response rate of 97.3%. Two patients declined, and one completed the form incorrectly – this survey was excluded from analysis. Patient baseline characteristics are shown in Table 1, stratified by preference for communication of biopsy results. While there were no significant differences in age, sex, marital status, type of procedure, or prior history of head and neck cancer between the three groups, health literacy metrics differed across the three groups. The median overall BHLS score was 12 (range 3 to 15). Patients who preferred in-person communication had significantly lower BHLS scores (median 10, range 7 to 13) than those who preferred to be notified by telephone (median 13, range 11 to 15, Bonferroni-corrected $p = 0.002$) or online (median 13, range 10.5 to 14, Bonferroni-corrected $p = 0.029$). Almost all (94.7%) patients who preferred to be notified online had active patient portal accounts compared to 69.7% of patients who preferred in-person communication and 50.9% of patients who preferred communication by telephone.

Patients were first asked which factors were important to them when receiving malignant biopsy results and were allowed to select multiple options. Overall, 76 (71.0%) patients selected "Getting the result quickly," 36 (33.6%) patients selected "Emotional support from the provider," 89 (83.2%) patients selected "The provider explaining the result clearly," and 11 (10.3%) patients selected "Other." Nearly all free text responses (90.9%) from patients selecting "Other" indicated a desire for clarification of the next steps or treatment plan. There were no significant differences in these responses between patients when stratified by their preferred method of communication except for timelines of results. There was a significant difference among the three groups in their response for "getting results quickly" ($p = 0.037$). Patients who preferred in-person notification (54.5%) were less likely on pairwise comparison to desire getting results quickly than their counterparts who preferred telephone notification (80.0%) or online notification (73.7%), but this relationship was not significant after correction for multiple comparisons [Bonferroni-corrected $p = 0.066$ (telephone), $p = 0.854$ (online)]. Patients were also asked which factor was *most important* to them when receiving malignant biopsy results (single option response). Most patients indicated the most important factor for them was the provider explaining the result clearly (53.8%) or getting the result quickly (39.4%). While there was some variation in expected wait time for biopsy results, most patients (49.5%) expected to have to wait 3–5 days for the results of their biopsy (Fig. 1).

The results of univariable analysis evaluating factors associated

Table 1
Baseline demographics, clinical characteristics, and health literacy metrics of patients stratified by preference for communication of biopsy results.

	Patient preference for communication of biopsy results			p
	From provider in person	From provider over the telephone	From patient portal account	
N	33	55	19	
Age (mean, SD)	56.55 (18.04)	51.31 (17.45)	50.58 (15.70)	0.327
Male (%)	10 (30.3)	14 (25.5)	7 (36.8)	0.628
Marital status (%)				0.300
Single	8 (24.2)	21 (38.2)	6 (31.6)	
Married	18 (54.5)	25 (45.5)	13 (68.4)	
Divorced	5 (15.2)	4 (7.3)	0 (0.0)	
Widowed	2 (6.1)	5 (9.1)	0 (0.0)	
Procedure (%)				0.784
Thyroid FNA	12 (36.4)	18 (32.7)	8 (42.1)	
Salivary gland FNA	8 (24.2)	13 (23.6)	3 (15.8)	
Lymph node FNA	10 (30.3)	12 (21.8)	4 (21.1)	
Neck mass FNA	2 (6.1)	10 (18.2)	4 (21.1)	
Other biopsy	1 (3.0)	2 (3.6)	0 (0.0)	
Prior head and neck cancer diagnosis (%)	1 (3.0)	2 (3.6)	1 (5.3)	1.000
Active patient portal account (%)	23 (69.7)	28 (50.9)	18 (94.7)	0.001
BHLS score (median, range)	10 (7 to 13)	13 (11 to 15)	13 (10.5 to 14)	0.002
Education level				0.430
Less than high school diploma	5 (15.2)	6 (10.9)	0 (0.0)	
High school diploma or GED	13 (39.4)	23 (41.8)	7 (36.8)	
Bachelor's degree (college degree)	10 (30.3)	17 (30.9)	5 (26.3)	
Graduate degree	5 (15.2)	9 (16.4)	7 (36.8)	
How worried are you about the result of your biopsy? (%)				0.467
Not at all	3 (9.1)	5 (9.1)	1 (5.3)	
A little bit	6 (18.2)	8 (14.5)	6 (31.6)	
Somewhat	7 (21.2)	22 (40.0)	7 (36.8)	
Quite a bit	8 (24.2)	12 (21.8)	2 (10.5)	
Extremely	9 (27.3)	8 (14.5)	3 (15.8)	
If the result shows cancer, what is most important to you when receiving your biopsy result? (%)				0.197
Getting the result quickly	8 (24.2)	22 (40.0)	11 (57.9)	
Emotional support from the provider	2 (6.1)	2 (3.6)	1 (5.3)	
The provider explaining the result clearly	22 (66.7)	28 (50.9)	6 (31.6)	
Other (please specify below)	0 (0.0)	2 (3.6)	0 (0.0)	
Question marked incorrectly	1 (3.0)	1 (1.8)	1 (5.3)	

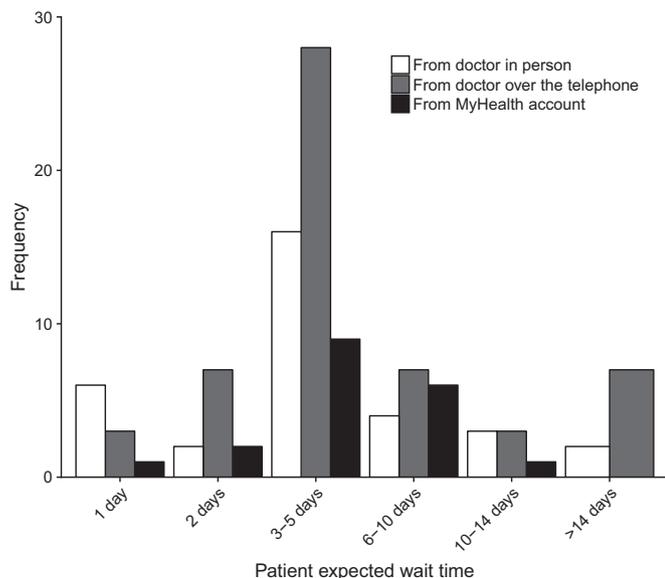


Fig. 1. Expected wait times for biopsy results stratified by patient preference for communication.

with preferring in-person communication of biopsy results are shown in Table 2. Patients who valued receiving a clear explanation of the results as the most important communication factor were more likely to prefer in-person notification [unadjusted odds ratio (OR) 2.35, 95%

Table 2
Univariable analysis of factors associated with preferring in-person communication of biopsy results.

	Odds ratio (95% CI)	p
Level of worry		
“Quite a bit” or “extremely” worried	2.08 (0.90 to 4.80)	0.083
“Not at all,” “a little bit,” or “somewhat” worried	1.00 (ref.)	–
Most important factors for communication		
Getting results quickly	0.40 (0.16 to 1.00)	0.046
Emotional support	1.53 (0.24 to 9.60)	0.643
Clear explanation	2.35 (1.00 to 5.54)	0.047
Health literacy		
Adequate	0.21 (0.08 to 0.54)	0.001
Inadequate	1.00 (ref.)	–
Level of education		
High school diploma or less	1.27 (0.56 to 2.88)	0.573
Bachelor's degree or higher	1.00 (ref.)	–

confidence interval (CI) 1.00 to 5.54]. In contrast, patients who valued receiving results quickly as the most important communication factor were less likely to prefer in-person notification (unadjusted OR 0.40, 95% CI 0.16 to 1.00). Patients with adequate health literacy were less likely to prefer in-person notification, compared with patients with inadequate health literacy (unadjusted OR 0.21, 95% CI 0.08 to 0.54). Level of worry, level of education, and preference for emotional support were not associated with a preference for in-person communication of results.

The results of the multivariable analysis are shown in Table 3.

Table 3
Multivariable analysis of factors associated with preferring in-person communication of biopsy results.

	Coefficient (SE)	Wald Z	Odds ratio (95% CI)	p
Age				
< 55 years old	0.00 (ref.)	–	1.00 (ref.)	–
≥ 55 years old	–0.29 (0.6)	–0.48	0.75 (0.22 to 2.40)	0.633
Gender				
Female	0.00 (ref.)	–	1.00 (ref.)	–
Male	0.87 (0.63)	1.38	2.39 (0.71 to 8.63)	0.166
Marital status				
Single	0.00 (ref.)	–	1.00 (ref.)	–
Married	0.43 (0.62)	0.70	1.54 (0.47 to 5.44)	0.483
Divorced	1.73 (1)	1.74	5.63 (0.83 to 44.39)	0.083
Widowed	0.79 (1.26)	0.63	2.21 (0.15 to 25.38)	0.530
Education level				
Bachelor's degree or higher	0.00 (ref.)	–	1.00 (ref.)	–
High school or less	0.22 (0.62)	0.35	1.25 (0.37 to 4.35)	0.724
Health literacy				
Inadequate	0.00 (ref.)	–	1.00 (ref.)	–
Adequate	–2.17 (0.66)	–3.28	0.11 (0.03 to 0.39)	0.001
Biopsy site				
Thyroid	0.00 (ref.)	–	1.00 (ref.)	–
Salivary gland	0.45 (0.74)	0.60	1.56 (0.36 to 6.86)	0.546
Lymph node	0.78 (0.69)	1.13	2.17 (0.57 to 8.77)	0.260
Neck mass	–1.44 (0.97)	–1.48	0.24 (0.03 to 1.38)	0.139
Prior history of head and neck cancer				
No	0.00 (ref.)	–	1.00 (ref.)	–
Yes	–1.48 (1.48)	–1.01	0.23 (0.01 to 3.22)	0.314
Active patient portal account				
No	0.00 (ref.)	–	1.00 (ref.)	–
Yes	0.50 (0.61)	0.82	1.65 (0.51 to 5.75)	0.412
Most important factor for news delivery				
Getting the result quickly	0.00 (ref.)	–	1.00 (ref.)	–
Emotional support from the provider	1.36 (1.25)	1.08	3.89 (0.26 to 43.35)	0.279
The provider explaining the result clearly	1.42 (0.61)	2.32	4.13 (1.31 to 14.88)	0.020
Level of worry				
“Not at all,” “a little bit,” or “somewhat” worried	0.00 (ref.)	–	1.00 (ref.)	–
“Quite a bit” or “extremely” worried	0.83 (0.6)	1.37	2.30 (0.71 to 7.76)	0.170

Adequate health literacy was significantly associated with lower odds of preferring in-person communication (adjusted OR 0.11, 95% CI 0.03 to 0.39). Compared with patients who prioritized receiving the results quickly, patients who prioritized clear explanation of the results were more likely to prefer in-person communication (adjusted OR 4.13, 95% CI 1.31 to 14.88). Prioritizing emotional support was not associated with odds of preferring in-person communication, compared with prioritizing receiving the results quickly (adjusted OR 3.89, 95% CI 0.26 to 43.35). Age, sex, marital status, education level, biopsy site, prior history of HNC, active patient portal account, and level of worry were not found to be significantly associated with preference for in-person communication.

4. Discussion

Our study showed that approximately 70% of patients undergoing head and neck FNA biopsy in our comprehensive otolaryngology clinic preferred to receive their biopsy results remotely, either over the telephone or through an online portal. Most patients indicated that the most important factor for them, when communicating a malignant result, was the provider explaining the result clearly. Patients preferring in-person notification of their biopsy results had lower health literacy than patients who preferred online or telephone communication. Preference for in-person notification was not found to be associated with age, sex, education level (adjusted for health literacy), biopsy site, prior history of head and neck cancer, or level of worry. However, patients who prioritized clear explanation of malignant biopsy results had approximately four times the adjusted odds of preferring in-person notification of biopsy results compared to those who prioritized receiving their results quickly. Additionally, patients with adequate health literacy had about nine-fold lower odds of preferring in-person

communication compared to those with inadequate health literacy. Finally, the majority of patients expected to have to wait 3–5 days for the results of their biopsy.

To our knowledge, this is the first study to examine patients' preferences for communication of biopsy results in otolaryngology patients. Our results are consistent with other studies published recently on patient preferences for biopsy result communication. Choudhry et al. [6] surveyed 301 patients undergoing skin biopsies, finding that approximately 65% preferred remote (either online or telephone) notification of their results. They found that younger age and higher education were associated with preferring online notification, but notably did not adjust for patient health literacy in their analysis. Additionally, the same study included the results of a survey of almost 50 practicing physicians, finding that they overall preferred telephone notification of biopsies as well. Brazeal et al. [7] surveyed patients undergoing biopsies in a breast cancer clinic. Similarly, they found that approximately 70% of patients in their study preferred to receive their results over the telephone. In their study, the majority of the patients (about 80%) prioritized learning their results as soon as possible. Interestingly, both our results and those from these more recent studies from 2015 and 2018 stand in contrast to survey findings reported in the 1990s. Both Sardell and Trierweiler [15] and Butow et al. [16] found in 1993 and 1996, respectively, that patients overwhelmingly preferred to receive biopsy results showing malignancy in person, but they did not examine factors that were associated with this preference. This may represent a shift in patients' perspectives and expectations for how news should be delivered, possibly reflecting the increased prevalence of electronic communication tools in daily life.

Because the discussion of a cancer diagnosis can be stressful and difficult for patients, one potential argument against delivering bad news remotely is the inability to provide adequate emotional support to

the patient. However, our study showed that most patients (93.2%) indicated the most important factors for them when receiving a malignant biopsy result were clear explanations from the provider or receiving the result quickly. This is consistent with findings from Parker et al. [17], which surveyed 351 patients with a wide range of malignancies. Patients were asked to rate factors that were important to them when receiving news of a cancer diagnosis. The factors were grouped into three categories: (1) content (what and how much information was given); (2) facilitation (setting of delivery and context variables); and (3) support (emotional support during the interaction). They found that factors addressing content were the most important to patients, while factors addressing support were the least important. The results of our study suggest a potential disconnect between patient and provider perspectives regarding the delivery of bad news. Winget et al. [18] examined the views of oncologists about patient electronic access to radiology and pathology results that could potentially indicate disease progression. In a survey of 82 oncologists, they found that 87% believed it was somewhat or very harmful for a patient to receive abnormal imaging or pathology results before consultation with a physician. Because the patient is the one whose life will be most impacted by the diagnosis, the patient's perspective needs to be considered when developing a communication plan. Our study revealed that half of our patients expected to receive their results within 3–5 days. This expectation may be unrealistic for institutions that have longer turnaround time for cytology results. Patients should be informed of the expected interval for receipt of results when discussing the communication plan.

To our knowledge, our study is the first to investigate the association between health literacy and patients' preferred methods of receiving biopsy results in the otolaryngology population. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health [19]. Health literacy has been shown to impact patient understanding, treatment compliance, and health outcomes [20–25]. Our study showed that patients with lower health literacy were more likely to prefer in-person notification of their biopsy results. This is consistent with prior findings that patients with low health literacy prefer to receive information in verbal form rather than written form [26]. Interestingly, our study also showed that patients who prioritized clear explanation of the results were more likely to prefer in-person notification. This may be due to concerns regarding misunderstandings over the telephone or inability to interpret online results without the help of the provider. The introduction of electronic medical record systems with patient portals, in response to the 2014 requirements of the Centers for Medicare & Medicaid Services Promoting Interoperability Program [27], have increased the amount and complexity of medical information that patients have to process [28]. The current trend towards use of online patient portals for communication may place patients with low health literacy at a disadvantage.

The main strength of our study lies in our high survey response rate and the systematic collection and analysis of data. However, our study does have some limitations. Because we only administered the survey to English-speaking patients, the study's generalizability is limited to this population. We limited our study to English-speaking patients because the electronic health record's online patient portal is only available in English. Finally, the survey was administered at a tertiary academic medical center, located in an area with a highly educated population. Thus, our results may not be generalizable to other otolaryngology practices.

5. Conclusion

Our results showed that a significant proportion of patients in our comprehensive otolaryngology clinic undergoing a head and neck biopsy preferred remote (either telephone or online) communication of their biopsy results. Patients most valued clear explanations from the

provider and prompt receipt of the result when communicating malignant results. Patients with inadequate health literacy, and patients who prioritized clear explanation of the results were more likely to prefer in-person communication of results. These findings highlight the variation in patient preferences regarding communication of malignant findings and challenge the notion that patients prefer in-person communication of bad news. This suggests that individualized communication plans should be developed for patients undergoing tests, which may potentially reveal malignant findings. We have now incorporated this into our clinic work-flow for patients undergoing biopsies. The next phase of the quality improvement project will involve ensuring that all patients from our clinic undergoing biopsies have a mutually agreed-upon communication plan at the end of the visit.

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