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## Patient Reflections on Decision Making for Laryngeal Cancer Treatment

**Andrew G. Shuman, MD<sup>1,2,3</sup>, Knoll Larkin, MPH<sup>3</sup>, Dorothy Thomas, MPH<sup>1</sup>, Frank L. Palmer, MBA<sup>1</sup>, Joseph J. Fins, MD, MACP<sup>2</sup>, Shrujal S. Baxi, MD, MPH<sup>4</sup>, Nancy Lee, MD<sup>5</sup>, Jatin P. Shah, MD<sup>1</sup>, Angela Fagerlin, PhD<sup>3,6,7</sup>, and Snehal G. Patel, MD, FRCS<sup>1</sup>**

<sup>1</sup>Head and Neck Service, Department of Surgery, Memorial Sloan-Kettering Cancer Center, New York, New York, USA

<sup>2</sup>Division of Medical Ethics, Weill Cornell Medical College, New York, New York, USA

<sup>3</sup>Center for Bioethics and Social Sciences in Medicine, University of Michigan, Ann Arbor, Michigan, USA

<sup>4</sup>Head and Neck Oncology Service, Department of Medicine, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

<sup>5</sup>Department of Radiation Oncology, Memorial Sloan-Kettering Cancer Center, New York, New York, USA

<sup>6</sup>Department of Internal Medicine, University of Michigan, Ann Arbor, Michigan, USA

<sup>7</sup>VA Ann Arbor Center for Clinical Research Management, Washington, DC, USA

### Abstract

**Objective**—To describe the reflections of patients treated for laryngeal cancer with regard to treatment-related decision making.

**Study Design**—Cross-sectional survey-based pilot study.

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Corresponding Author: Andrew G. Shuman, MD, Department of Otolaryngology–Head and Neck Surgery, University of Michigan Medical School, 1904 Taubman Center, 1500 E Medical Center Drive, Ann Arbor, MI 48109-5312, USA. shumana@umich.edu.

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#### Author Contributions

**Andrew G. Shuman**, original conception, data acquisition, analysis, and interpretation, drafting/critically revising and final approval of manuscript; **Knoll Larkin**, data analysis and interpretation, critically revising and final approval of manuscript; **Dorothy Thomas**, data acquisition, analysis, and interpretation; critically revising and final approval of manuscript; **Frank L. Palmer**, data acquisition, analysis, and interpretation; critically revising and final approval of manuscript; **Joseph J. Fins**, original conception, data analysis, and interpretation; critically revising and final approval of manuscript; **Shrujal S. Baxi**, original conception, data analysis, and interpretation; critically revising and final approval of manuscript; **Nancy Lee**, data analysis, and interpretation; critically revising and final approval of manuscript; **Jatin P. Shah**, data analysis, and interpretation; critically revising and final approval of manuscript; **Angela Fagerlin**, original conception, data analysis, and interpretation; critically revising and final approval of manuscript; **Snehal G. Patel**, original conception, data acquisition, analysis, and interpretation, drafting/critically revising and final approval of manuscript.

#### Disclosures

**Competing interests:** None.

**Sponsorships:** None.

**Setting**—Single-institution tertiary care cancer center.

**Subjects/Methods**—Adults with laryngeal carcinoma were eligible to participate (N = 57; 46% treated surgically, 54% non-surgically). Validated surveys measuring decisional conflict and regret explored patients' reflections on their preferences and priorities regarding treatment-related decision making for laryngeal cancer and how patient-reported functional outcomes, professional referral patterns, and desired provider input influenced these reflections.

**Results**—When considering the level of involvement of surgeons, radiation oncologists, and medical oncologists in their care, patients were more likely to believe that the specialist whom they saw first was the most important factor in deciding how to treat their cancer (Fisher's exact,  $\sim\chi^2 = 16.2$ ,  $df = 6$ ,  $P = .02$ ). Patients who were treated for laryngeal cancer who reported worse voice-related quality of life recalled more decisional conflict ( $P = .01$ ) and experienced more decisional regret ( $P < .001$ ). Of the patients for whom speech was a top priority prior to treatment, better voice-related quality of life overall scores were correlated with less decision regret about treatment decisions ( $P < .02$ ). Of the patients for whom eating and drinking were top priorities prior to treatment, better MD Anderson Dysphagia Inventory global scores were correlated with less decision regret about treatment decisions ( $P < .002$ ).

**Conclusion**—Patient priorities and attitudes, coupled with functional outcomes and professional referral patterns, influence how patients reflect on their choices regarding management of laryngeal cancer. Better understanding of these variables may assist in ensuring that patients' voices are integrated into individualized laryngeal cancer treatment planning.

## Keywords

larynx cancer; patient-reported outcomes; shared decision making; quality of life

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The optimal treatment of laryngeal cancer continues to be the subject of intense debate. Surgery and radiation therapy have traditionally been used with equal effectiveness in curing early-stage laryngeal cancer. In 1991, the publication of the Veterans Affairs larynx trial demonstrated equivalent outcomes of nonsurgical treatment with chemoradiotherapy as compared with traditional surgical approaches in selected cases of advanced laryngeal cancer, introducing a promising wave of so-called organ-sparing therapy.<sup>1</sup> A litany of treatment protocols and scores of prospective and retrospective research concerning treatment of early- and late-stage laryngeal cancer ensued, as clinicians attempted to maximize oncologic efficacy while preserving function and maximizing quality of life.<sup>2,3</sup> In addition, the advent of endoscopic surgical procedures that have proven efficacious from an oncologic and functional standpoint is again changing the paradigm of treatment options.<sup>4</sup>

There remains no true consensus regarding the comparative oncologic and functional outcomes of surgery versus radiotherapy as a primary treatment modality. As a result of this lack of consensus, the National Comprehensive Cancer Network guidelines indicate the acceptability of multiple treatment regimens for laryngeal squamous cell carcinoma.<sup>5</sup> In general, institutional and practitioner preference and the availability of resources, coupled with clinical factors and patient preference, continue to dictate treatment decision making.

Given the research to date and the variable treatment options available, laryngeal cancer treatment can be particularly confusing and difficult to reconcile. It is thus critical to (1) help patients make very difficult decisions based on the best available medical evidence and (2) carefully describe the associated risks and benefits of proposed treatments. In addition, we recognize that decisions made in the turbulent and emotionally laden interval shortly after diagnosis may be considered very differently after completion of treatment and that such reflections are also important to evaluate. As a result, we hypothesize that consideration of patient-specific preferences in the context of their current reflections on the decision-making process will foster the development of an individualized model to assist in decision making.

Despite prior attempts to address these questions, rudimentary issues remain unexplored, such as how patients weigh potential side effects when making treatment-related decisions. This analysis must reflect the robust body of literature focused on quality of life, utilizing patient-reported outcomes that consider the physical, emotional, and functional consequences of laryngeal cancer and its treatment.<sup>6-8</sup> Specifically, an understanding of how patients who have undergone treatment reflect on their treatment decisions in the context of their current health and symptom burden remains elusive.

Moreover, while multidisciplinary care is the sine qua non of contemporary head and neck cancer management, the cacophony of multiple consultants with varying recommendations may be more confusing than helpful; thus, we seek to understand how patients' interactions with medical, surgical, and radiation oncologists affect and influence their decisions and reflections thereof.

The objective of this pilot study is to describe how patients who have undergone treatment for laryngeal cancer reflect on their priorities and preferences regarding prior treatment-related decision making. This is prefaced on the null hypothesis that patients' treatment preferences and reported symptom burden are independent of decisional conflict and regret. The overarching goal of this research is to better understand the perspectives of patients with laryngeal cancer, to conceive a decision aid that is facile, flexible, and patient centric.

## Methods

### Subject Recruitment

This cross-sectional survey-based pilot study was conducted in a single-institution tertiary care cancer center (Memorial Sloan Kettering Cancer Center). The protocol was approved by the center's institutional review board, and informed consent was obtained from potential subjects, with precautions to ensure confidentiality and privacy. Inclusion criteria stipulated English-speaking adults with biopsy-proven laryngeal carcinoma (all stages) diagnosed between 6 months and 3 years prior who returned to the institution for clinical follow-up. Exclusion criteria indicated patients who did not speak English, those with other head and neck malignancies, and those who did not complete treatment in the designated time interval.

## Survey Administration

A survey was administered to patients who completed treatment for laryngeal cancer, to explore their attitudes regarding treatment modalities for laryngeal cancer and associated side effects, their relative priorities regarding treatment in terms of specific oncologic and functional outcomes, and the degree of provider involvement that they believe is optimal in the decision-making process. Our goal was not to ask patients to recall their symptoms from long ago; rather, it explicitly focused on how they presently felt. Thus, our intent was to control for their current feelings on how they reflected on their treatment in light of their current symptom burden. Included within the instrument is an established measure of how head and neck cancer patients prioritize specific treatment outcomes.<sup>9</sup> The compilation of surveys was designed by clinicians who treat head and neck cancer, social scientists with expertise in decision-making science, and medical ethicists.

Two well-established validated survey instruments were utilized to assess speech and swallowing function. The 10-item voice-related quality of life (VRQOL) measure is an easily administered instrument designed to evaluate dysphonic patients and their treatment outcomes.<sup>10</sup> The MD Anderson Dysphagia Inventory (MDADI) is a reliable self-administered questionnaire that evaluates the impact of dysphagia on the quality of life of patients with head and neck cancer.<sup>11</sup>

A traditional decisional conflict scale was also administered to elicit patients' uncertainty in making health-related decisions, the factors contributing to the uncertainty, and the patients' perceived effectiveness of their decision making. The scale was tested among individuals who were deciding about influenza immunization or breast cancer screening, and it demonstrated good reliability, validity, and psychometric properties and has been widely used thereafter in diverse settings.<sup>12</sup>

Patients also completed a decision regret test. This 5-item scale was originally administered and tested among discrete patient groups making different health care decisions. Validity was confirmed by examining the scale's correlation with measures of satisfaction, conflict, and health outcomes, leading the authors to conclude that the scale is a useful indicator of health care decision regret.<sup>13</sup>

Patients who were scheduled for appointments in multidisciplinary outpatient clinics were prescreened for eligibility, and a consecutive sample of potential study patients were contacted in person at the time of their clinic appointments by a clinical research study investigator and asked to participate. Subjects were instructed on how to complete each questionnaire, given opportunities to clarify any confusion, and allowed to return the surveys in person in real time or by mail. The questionnaire order was as follows: clinical and treatment history, treatment priorities, MDADI and VRQOL, and decision conflict and regret. This order was not counterbalanced, and intrarater reliability was not measured.

## Data Management and Analysis

Data were compiled with Caisis 6.0 (BioDigital, New York, New York), an open-source web-based cancer data management system, and verified by manual chart abstraction. Demographic, clinical, and survey data were stored within a password-protected institutional

computerized database. Analysis of data commenced with descriptive statistics for all measures: frequencies and percentages were presented for categorical variables and means and standard deviations for quantitative measures. The surveys (MDADI, VRQOL, decisional conflict, and decision regret) were analyzed and scored in the same manner in which they were developed and validated. The data set was transferred into Excel to summarize and calculate frequencies. Data were uploaded and statistical analyses performed with STATA 10.0 (Stata Corp, College Station, Texas).

## Results

Demographic variables and clinical data are summarized in Table 1. In general, patients represented the expected profile of laryngeal cancer demographics based on age, sex, and smoking history. Of the cohort, 54% of patients presented with early-stage disease (I–II), of whom half were treated surgically and half nonsurgically. Of the 33% of patients with advanced-stage disease (III–IV), 66% were treated with surgery—including initial surgery, followed by adjuvant treatment and salvage surgery after nonsurgical treatment—and 33% were treated nonsurgically with multimodality therapy.

Patients had variable perspectives regarding their most and least important treatment priorities (Table 2). The 4 most important priorities for patients with laryngeal cancer were oncologic cure (91%), maximizing survival (66%), being able to swallow (44%), and maintenance of natural voice (41%). The 4 least important priorities were having a comfortably moist mouth (59%), keeping one's appearance unchanged (45%), returning to one's activities as soon as possible (45%), and keeping one's normal sense of taste and smell (33%).

When considering the level of involvement of surgeons, radiation oncologists, and medical oncologists in their care, patients were more likely to believe that the specialist whom they saw first was the most important factor in deciding how to treat their cancer (Fisher's exact,  $\sim\chi^2 = 16.2$ ,  $df = 6$ ,  $P = .02$ ). Patients thought that the specialist whom they saw first was most involved in deciding how to treat their cancer (Fisher's exact,  $\sim\chi^2 = 14.2$ ,  $df = 6$ ,  $P = .01$ ). The study was underpowered to test if treatment modality and/or stage influenced these associations.

Patients who were treated for laryngeal cancer who reported worse VRQOL recalled more decisional conflict ( $P = .01$ ) and experienced more decisional regret ( $P < .001$ ). Of the patients for whom speech was a top priority prior to treatment, better overall VRQOL scores ( $-0.55$ ;  $P < .02$ ) and social/emotional subscores ( $-0.66$ ;  $P < .006$ ) were correlated with less decisional regret about treatment decisions. Of the patients for whom eating and drinking were top priorities prior to treatment, better MDADI global scores ( $-0.61$ ;  $P < .002$ ), emotional subscores ( $-0.76$ ;  $P < .001$ ), and functional subscores ( $-0.65$ ;  $P < .001$ ) were all correlated with less decisional regret about treatment decisions.

## Discussion

This study addresses questions that are at the core of head and neck oncology, directly from the patient's perspective. It is the first of its kind to utilize a survey that specifically

addresses how laryngeal cancer survivors reflect on their treatment choices. The survey was designed to address the relevant clinical questions as well as the underlying ethical issues and tenets of existing research on medical decision making.

Input from physicians and patients is integral to make informed medical decisions regarding treatment of serious diseases. A seminal report presents specific criteria necessary to this interaction, including the input of at least 2 participants (physician and patient), the sharing of information, the creation of a consensus about the preferred treatment, and a formal agreement on an established plan.<sup>14</sup> This model displaces paternalism while respecting the integral role of the medical provider as a part of the decision-making process, thereby granting patients necessary autonomy and expert guidance. Our data corroborate the importance of this partnership and suggest how interactions between patients and multiple care providers may mold and influence decision making. This work fits nicely into the mandate of the Patient-Centered Outcomes Research Institute, focused on improving the quality and relevance of evidence available to help involved stakeholders make informed health decisions.

Given the similar outcomes of varied treatment modalities for specific situations, laryngeal cancer treatment is a good example of *preference-sensitive care*, a term from the decision-making literature that describes clinical equipoise: the treatments are equally effective, and thus the decision about which treatment to undergo is based mostly on the values and opinions of individual patients.<sup>15</sup> In many examples of preference-sensitive care, the relationship that yields the most satisfactory decisions is one between clinician and patient in which decision making is a shared activity.<sup>15</sup> That said, physician involvement and input are always important and often strong determinants of the ultimate choice of treatment. Our data suggest that patient preferences, along with their impressions of how choices were made, will directly influence their perspectives downstream. Indeed, patient-reported symptoms at the time of survey completion directly correlated with how they reflected on their prior treatment choices.

Our data are consistent with prior findings and affirm that survival is the primary—but by no means only—consideration when patients contemplate cancer treatment. Recent data from France clarify that few patients are willing to sacrifice survival even when faced with laryngeal preservation and that discussion of acute and chronic toxicities is critical to the decision-making process.<sup>16</sup> The findings presented herein suggest that this finding is durable long after treatment completion. Moreover, validation of the head and neck cancer priorities instrument demonstrated that survival is the most important priority and suggested that patients are frequently willing to accept acute treatment-related side effects in the interest of long-term goals.<sup>9</sup> Our data nuance this finding by reporting how their function, long after acute toxicities resolve, still influences their reflection on treatment choices.

Recent data suggest that patient satisfaction is closely linked to the correlation between their preferred degree of involvement and their actual level of involvement; patients who prefer not to make their own decisions are less satisfied when they are asked to do so.<sup>17</sup> Not surprising, a study examining the role of pretreatment consultation and informed consent confirmed that pursuit of larynx-preserving treatment was closely associated with a



documented discussion of available treatment alternatives.<sup>18</sup> This reinforces the seminal findings of the Fireman Study, which concluded that when tradeoffs such as laryngeal preservation versus survival are considered, treatment choices should be based on patients' attitudes toward the quality of survival as well as its duration.<sup>19</sup> Our data build on these findings and provide a more nuanced viewpoint, incorporating patient-centric perspectives on both priorities and actual functional abilities after treatment.

Prior attempts have been made to model laryngeal cancer decision making. An early study examining a decision tree model for pharyngeal cancer determined that quality of life–related outcomes are crucial to this decision; remarkably, this study was published years prior to the seminal studies that reinforced this very point, and its conclusions still ring true.<sup>20</sup> A mathematical decision analysis model utilizing confidence intervals for utility measurements in deciding between primary radiation and laryngectomy was unsuccessful due to the significant variability and uncertainty concerning specific oncologic and functional outcomes.<sup>21</sup> Another study created a software system designed to utilize a provider's prior clinical decisions for laryngeal cancer patients to make future decisions.<sup>22</sup> This was limited by the need to explicitly define successful outcomes and by the inherent bias of the model. In essence, these exercises help demonstrate that laryngeal cancer decision making is inherently patient specific.

An observational multisite study of decision making among head and neck cancer patients was recently published.<sup>23</sup> The authors presented a qualitative description of how decision making is unique among head and neck cancer patients, and they argued that a conventional model of shared decision making should be replaced by an amorphous discussion of diagnostic and therapeutic options that integrates risks, benefits, and alternatives without necessarily utilizing a stepwise approach or culminating in one salient “decision.” The authors concluded that caregivers treating head and neck cancer are behooved to carefully integrate patient-specific facts into their overall approach in helping to reach individualized decisions.

As with any retrospective single-institutional study, there are inherent limitations of our data. There is also concern for recall bias given the variable interval from treatment among subjects, although this reflects the reality of clinical practice and evolving perspectives over time. Given that each subject was reflecting on one's experience from the present time and asked to consider one's current symptom burden, we believe that this association remains valid. In studies examining prostate and breast cancer, data suggest that measurements of decisional conflict and regret in cancer-related decision making remain relatively stable over years.<sup>24,25</sup>

In addition, our study was not large enough in either scope or size to adequately control for the many confounders, including stage, comorbidities, social status, ethnicity/race, socioeconomic factors, and others that invariably influence interpretation of the data. Given our data, we estimate that a robust and adequately powered multivariate calculation that can fully control for these variables in an analysis of decisional regret would require a minimum of 20 patients per variable studied and thus a sample size of at least 200. Our pilot data are hypothesis generating and provide the preliminary data to inform such a study.

In addition, we report data at 1 point in time, and there is a critical absence of longitudinal patient-reported quality-of-life outcomes, which would require a prospective assessment from the time of diagnosis. However, we believe that these data paint the landscape of how an unselected group of patients reflect on their cancer treatment. Our goal is to provide a cross-sectional snapshot of how patients feel at a moment in time after they have completed treatment, and we recognize that this does not equate to how they feel when making an initial treatment choice or how they may feel in the years to come. We believe our data support that current patient-reported symptoms and preferences directly relate to how patients reflect on their decisions.

We anticipate that the development of a decision aid would be a major milestone in the management of laryngeal cancer. The data collected and information gleaned from this pilot study are designed to allow for this decision aid to be formulated. We expect the results of this study to provide the necessary perspective to proceed with the next phase of research, and they may also provide clinicians with insight into how patients make and reflect on critical choices in their laryngeal cancer treatment.

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**Table 1**Demographics and Clinical Data (N = 57).<sup>a</sup>

	n	Mean or % (Range)	SD
Age, y		61.2	
Sex			
Male	43	80	
Female	11	20	
Declined to answer	3		
Smoking history			
Current	5	9	
Former	38	72	
Never	10	19	
Education			
High school or less	19	38	
Some college or more	31	62	
American Joint Committee on Cancer stage			
I	17	34	
II	14	28	
III	9	18	
IV	10	20	
Treatment received <sup>b</sup>			
Surgery	26		
Radiation	44		
Chemotherapy	31		
Voice-related quality of life			
Overall		70.1 (0–100)	30.8
Social/emotional		74.7 (0–106)	
Physical functioning		66.9 (0–100)	
MD Anderson Dysphagia Inventory			
Global		68.9 (20–100)	28.2
Emotional		78.0 (20–100)	
Functional		94.3 (40–140)	
Physical		62.2 (20–88)	
Decision conflict		25.6 (0–78)	20.1
Decision regret		16.2 (0–60)	17.3

<sup>a</sup>Numbers may not add to total due to missing data or declined survey answers.<sup>b</sup>Includes all treatments received, not mutually exclusive.

**Table 2**

Treatment Priorities of Patients with Laryngeal Cancer.<sup>a</sup>

	Ranked as Top 3 Most Important Treatment Goals		Ranked as Top 3 Least Important Treatment Goals	
	Yes	No	Yes	No
Being cured of my cancer	49 (91)	5 (9)	30 (59)	21 (41)
Living as long as possible	34 (66)	18 (34)	23 (45)	28 (55)
Being able to swallow all foods and drinks	24 (44)	30 (56)	23 (45)	28 (55)
Keeping my natural voice	22 (41)	32 (59)	17 (33)	34 (67)
Keeping my normal sense of taste and smell	5 (9)	49 (90)	12 (24)	39 (76)
Having my speech understood easily	5 (9)	49 (90)	10 (20)	41 (80)
Keeping my appearance unchanged	4 (7)	50 (93)	8 (16)	43 (84)
Returning to my activities ASAP	4 (7)	50 (93)	8 (16)	43 (84)
Having a normal amount of energy	4 (7)	50 (93)	5 (10)	46 (90)
Being able to chew normally	3 (6)	51 (94)	4 (8)	47 (92)
Having no pain	3 (6)	51 (94)	4 (8)	47 (92)
Having a comfortably moist mouth	1 (2)	53 (98)	1 (2)	50 (98)

<sup>a</sup>Based on a validated survey instrument as described in List et al.<sup>9</sup> Values are presented as n (%).