

Assessment of Patient Experience With Unilateral Vocal Fold Immobility: A Preliminary Study

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Summary: Objective. Systematically moving toward patient-centered care for unilateral vocal fold immobility (UVFI) requires comprehensive understanding of the variability of actual patient experiences. This rigorous qualitative study assesses UVFI-related disability and proposes a preliminary taxonomy of UVFI patient experience.

Study Design. (1) Semistructured interviews and (2) taxonomy development.

Methods. Consecutive UVFI patients presenting July to September, 2012, prospectively underwent open-ended interviews investigating how UVFI affected their quality of life (QOL) and had caused disability. Comments reported by >20% were synthesized into axes based on content similarity. Variables were arranged into a preliminary taxonomy of UVFI patient experience, which was evaluated for four attributes of face validity.

Results. The majority of 39 patients had “extensive” baseline voice use (56%) and an iatrogenic etiology (62%). Taxonomy of patient experience included three main axes of symptomatic classification: (1) voice, (2) swallowing, and (3) breathing—all with intrinsic (physical and emotional) and extrinsic (social) subaxes that describe major impacts on QOL. Voice complaints were 100% penetrant, whereas breathing and swallowing symptoms afflicted 76% and 66%, respectively, of interviewees. Of affected patients, solid and liquid dysphagia was experienced by 70% and 63%, respectively. Of dyspneic patients, shortness of breath existed with talking (97%) and exercise (72%). Persistent throat congestion (76%), weakened cough (62%), globus (62%), and dysfunctional valsalva (41%) were frequent.

Conclusions. Patient experience with UVFI has been incompletely characterized. This qualitative assessment and preliminary taxonomy highlight several related patient experiences not well documented in the literature or incorporated into currently available metrics.

Key Words: Unilateral vocal fold immobility—Unilateral vocal fold/cord paralysis—Quality of life—Patient experience—Dysphonia—Dysphagia—Dyspnea—Classification—Taxonomy—Patient-centered care.

INTRODUCTION

The Institute of Medicine prioritized patient-centered care in their blueprint for improving quality in the U.S. health care system.¹ An underrecognized barrier to achieving patient-centered care is the schism between what clinicians and patients perceive as the most troubling aspects of a medical condition.² Qualitative research captures actual patient experience and is the foundation for understanding how a disease or disorder affects a patient and is the core from which patient-centered outcome measures should be developed. It is recognized that the traditional focus on physiological manifestations of disease to the exclusion of total illness experience—behavioral, social, psychological, and emotional—offers a rather limited perspective on what it means to live with an illness.³ The patient perspective

must be combined with the physician’s diagnostic skills to drive treatment decisions in conditions that affect quality of life (QOL) and, to this end, qualitative research is required.

Amplifying the dissonance between patient and physician perspectives is the assumption by many otolaryngologists that unilateral vocal fold immobility (UVFI) is merely a voice disorder when in reality, it has more broad-ranging and significant physiological (eg, dysphagia,⁴ dyspnea⁵), psychosocial,⁶ and economic⁶ consequences. This misconception has been perpetuated by a relative lack of studies systematically assessing UVFI’s QOL implications related to all aspects of laryngeal function. Moreover, variability in patient values and demands of daily living transcend and complicate strict categorization of this disorder. For example, some dysphonic patients may be less bothered by their disordered voice production than the associated swallowing dysfunction. Personalized, patient-centered care requires a paradigm shift away from diagnostic compartmentalization by physicians toward individualization focused on those aspects of the UVFI experience that each person finds most detrimental to their QOL.

Understanding the UVFI patient experience is increasingly important as its burden grows with the expanding indications for head and neck, cervical spine, and cardiothoracic surgical procedures,^{7–9} complications of which account for half of all the UVFI cases.^{10–13} More patients’ at-risk means more will incur associated health and QOL consequences. Socioeconomically, UVFI-attributable voice disorders result in employment productivity losses comparable or worse than patients with asthma, acute coronary syndrome, and depression, leading a

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substantial portion of patients to file disability claims.⁶ From a health perspective, 60% of patients suffer from dysphagia and 75% have new onset dyspnea.⁵ These findings illustrate but do not fully capture a UVFI patient's limitations and experience. Systematically moving toward patient-centered care for UVFI requires a comprehensive understanding of the severity and variability of actual patient experiences. This study aims to qualitatively assess UVFI-related disability and proposes a preliminary taxonomy of UVFI patient experience using a semistructured open-ended interview design.

MATERIALS AND METHODS

The study was performed in accordance with the Declaration of Helsinki, Good Clinical Practice, approved by the Vanderbilt Institutional Review Board (IRB #111775), and conducted in two phases: (1) open-ended interviews with patients after an ambulatory laryngology appointment where they were diagnosed with or being followed for UVFI and (2) development of a taxonomy of patient experience with UVFI.

To achieve a representative sample, all consecutive patients presenting to the Vanderbilt Voice Center between July and September, 2012, with current or recent history of complete UVFI were identified. UVFI is used throughout this study for accuracy; however, most were presumed to have paralysis (unilateral vocal fold paralysis) based on etiology, examination, and degree of recovery (when applicable). UVFI was confirmed with a flexible laryngoscopy examination (*standard of care*). Candidate patients included those with (1) symptomatic UVFI, (2) a history of UVFI who had spontaneously developed synkinesis (ie, tone) or regained mobility, and/or (3) had previously undergone treatment (ie, speech therapy, laryngoplasty). The outcome of interest was patients' experience with UVFI when they were symptomatic (before recovery or treatment, if applicable). All patients had been symptomatic within the previous 2 years. Thus, heterogeneity was permitted because all patients diagnosed with complete UVFI had easy recall of their experience when they were maximally symptomatic and to capture potential temporal variability in experienced symptoms related to this disorder. Excluded were patients who (1) declined participation; had a (2) history of tracheal or laryngeal stenosis; (3) bilateral vocal fold immobility or movement abnormality; (4) known cricoarytenoid joint fixation; (5) current tracheostomy; (6) laryngeal carcinoma; or (8) were non-English speaking.

Open-ended interviews

In the first phase of the study, a trained research assistant (M.E.M.) approached eligible patients after their ambulatory visit. All patients meeting criteria underwent open-ended interviews either face-to-face or by phone (*patient choice*). Patients were asked about demographics (eg, age, gender, race), occupation, comorbidities, any history and type of head and neck, cervical spine, or cardiothoracic surgeries, and UVFI etiology. Open-ended questions were posed to investigate how UVFI had affected or was currently affecting their QOL and/or had caused disability. Patients were asked about particular circum-

stances that were impacted by UVFI and how it affected their health, emotional well-being, personal relationships, and employment. Interviews were 10 and 30 minutes in length as determined by patient responses.

Development and evaluation of taxonomy

This process was done using a well-documented, standardized epidemiologic approach^{2,14} and described briefly here. Individual comments of patients were transcribed and assembled independently by two authors (D.O.F. and M.E.M.). These same authors independently reviewed the raw data and arranged comments according to the similarity of content. Authors then met and reached consensus on a specific list of attributes or variables related to patient experience with UVFI. Variables were assembled into similar groups and arranged as a preliminary taxonomy of UVFI patient experience. This task required investigators' clinical judgment to combine variables within the categories or "axes" of related phenomena as shown in the *Results* section. The ability of the classification to describe patient experience was evaluated using four attributes of face validity: (1) the focus of interpersonal exchange, (2) the focus of basic evidence, (3) the biologic coherence of components, and (4) attention to personal collaboration.²

RESULTS

Of 46 consecutive UVFI patients interviewed, 39 met inclusion criteria. Excluded were those with concomitant laryngeal or tracheal stenosis (four), laryngeal cancer (one), tracheostomy (one), or who declined participation (one). Median age of participants was 61 years (interquartile range 46–70), 51% were male, and 85% were Caucasian (Table 1). Over half of the patients (56%) described their baseline voice use as "extensive." Most common UVFI etiology was presumed iatrogenic nerve injury (62%) caused by cardiothoracic surgery, thyroidectomy, and anterior cervical disc fusion procedures (Table 1).

TABLE 1.
UVFI Patient Characteristics

Characteristics (n = 39)	%
Age, median years (IQR)	61 (46–70)
Male	51
Race	
Caucasian	85
African American	15
Voice needs	
Minimal	10
Average	33
Extensive	56
Employed	56
Etiology	
Iatrogenic	62
Idiopathic	31
Neurologic	5
Infectious	2

Abbreviation: IQR, interquartile range.

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