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

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Abstract

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) Semi-structured interviews, 2) taxonomy development

Methods—Consecutive UVFI patients presenting July - 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 3 main axes of symptomatic classification: 1) voice, 2) swallowing, and 3) breathing - all with intrinsic (physical, emotional) and extrinsic (social) sub-axes that describe major impacts on QOL. Voice complaints were 100% penetrant, while breathing and swallowing symptoms afflicted 76% and 66% of interviewees. Of affected patients, solid and liquid dysphagia was experienced by 70% and 63%. Of dyspneic

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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.

Conclusion—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.

Keywords

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 under-recognized 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 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 physiologic (e.g. dysphagia [4], dyspnea [5]), psychosocial [6], and economic [6] consequences. This misconception has been perpetuated by a relative lack of studies systematically assessing UVFI's quality of life 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 quality of life.

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 UVFI cases [10-13]. More patients' at-risk means more will incur associated health and quality of life 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 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 semi-structured 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 unilateral vocal fold immobility (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 (UVFP) 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 (i.e. tone) or regained mobility and/or 3) had previously undergone treatment (i.e. speech therapy, laryngoplasty). The outcome of interest was patients' experience with UVFI when they were symptomatic (prior to recovery or treatment, if applicable). All patients had been symptomatic within the previous 2 years. Thus, heterogeneity was permitted since 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 (MEM) 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 (e.g. 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 or was currently affected their quality of life and/or had caused disability. Patients were asked about particular circumstances that were impacted by UVFI and how it affected their health, emotional wellbeing, 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 (DOF, MEM). These same authors independently reviewed the raw data and arranged comments according to 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*. 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 (4), laryngeal cancer (1), tracheostomy (1), or who declined participation (1). Median age of participants was 61 years (IQR 46 - 70), 51% were male, and 85% were Caucasian (Table 1). Over half of 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).

Taxonomy of Patient Experience

When variables were suitably organized, the overall taxonomy of patient experience included 3 main axes of symptomatic classification: 1) voice, 2) swallowing, and 3) breathing. Each main axis was divided into sub-axes, with or without categories containing the specific attributes (variables) that emerged from raw data. Constructing the taxonomy required combining related phenomena encountered in patient experience with UVFI. This classification is outlined in Table 2 and described in greater detail in the Appendix.

Frequency of Specific Comments

Experiential comments described by at least 20% (n=8) of UVFI patients qualified them for inclusion in axes. Representative patient responses in each axis are listed in the Appendix.

Axis I: Voice—Voice change or dysphonia was universal in this cohort (39/39). Patients characterized their voice as breathy (82%) and strained (77%), with an inability to project (69%) and reported vocal fatigue (49%). They described throat pain or irritation (38%) along with general communication difficulties (95%) particularly using the phone (41%). Social situations (74%) and background noise (51%) were the hardest circumstances for communication. Most patients tried to conserve their voice by resting it (72%). Many felt

UVFI negatively impacted their family dynamics (49%), ability to do everyday tasks (56%), ability to do activities they enjoyed (41%), and caused emotional or psychological strain (62%). Of the 56% of patients who were employed, UVFI-attributable dysphonia limited their effectiveness at work (86%) causing many to worry about loss of income (41%). Acquaintances responded to patients' dysphonia by asking them to repeat themselves (41%) and inquiring whether they had a “cold” or upper respiratory infection (28%).

Axis II: Swallowing—New onset swallowing symptoms were experienced by 69% of UVFI patients (N=27). Of those affected, this was characterized as coughing or choking with swallowing food or liquid (100%) often combined with a sensation that food was “sticking” in their throat (52%). They reported the need for increased concentration during the act of swallowing (63%) and more thorough chewing (36%) during deglutition. Solid and liquid dysphagia was described by 70% and 63%, respectively. Effective coping strategies identified by patients included eating slower (56%), neck posture maneuvers (41%), and taking smaller sips of thin liquids (33%). Several felt their dysphagia had affected meal partners and eating out made patients self-conscious due to the fear of choking (59%) and because of the extra time needed to finish their meal (56%).

Axis III: Breathing—New onset breathing symptoms were common (74%; N=29) and described as a general shortness of breath; specifically when talking (97%) and with physical activity (72%). This condition caused reduction in physical activity in 28% of respondents. Many also indicated that they “can't hold [their] air/breath” (72%). Dysfunctional valsalva maneuver was reported (41%), described as new onset difficulty carrying and lifting heavy objects and/or bearing down. Also common was new onset throat “irritation” symptoms relayed as a constant globus sensation (62%), persistent throat congestion (76%), inability to clear secretions (52%), and an inefficient cough (62%). Shortness of breath affected their ability to comfortably converse with others (41%). These symptoms caused significant anxiety and fear in this population (56%).

Evaluation of Taxonomy

Face validity of the taxonomy was evaluated for four features (2). 1) Focus of interpersonal exchange. Questions in this study were phrased in a personal manner and inquired about patients' prior and current experience with UVFI. In contrast, many instruments ask patient in general terms about predetermined aspects of their disability at the time of administration. They do not permit patients to openly share experiences or symptoms outside of specific topics surveyed. 2) Focus of basic evidence. The questions were also focused on directly assessing patients' experiences. This approach is superior to selecting items based on what the investigator rather than the patient considers important [2]. 3) Biologic coherence of components. The aggregated categories are logical groupings and are available for the reader to evaluate in the taxonomy and the Appendix. 4) Attention to personal collaboration. The patients' understanding and effort were directly observed during interview administrations. This strategy reduces problems that often arise in self-administered instruments especially if the patient does not comprehend the question or does not really try to give proper answers [2].

Based on these parameters, the classifications' face validity was deemed appropriate for identifying important components surrounding patients' experience with UVFI.

Discussion

We had two reasons for performing this analysis. First, there is a growing population of patients at risk for unilateral vocal fold immobility (UVFI) most commonly due to neurogenic injury; and second, actual patient reported quality of life concerns have been incompletely characterized in this specific population, thus limiting clinicians' ability to adequately address them both therapeutically and in counseling. UVFI consistently affected three main axes of laryngeal function: voice, swallowing, and breathing; signifying the larynx's central role in the aerodigestive tract. Our cohort also communicated three clear sub-axes of dysfunction within each primary axis. Two are intrinsic to the patient affecting their self-perception and identity (*physical, emotional*) and one extrinsic impacting others' perception and the patient's ability to interact and function in society (*social*).

Despite the relatively small cohort size, we believe the described taxonomy has **face validity** based on: 1) focus of interpersonal exchange, 2) focus of basic evidence, 3) biologic coherence of elements, and 4) attention to personal collaboration[2]. Therefore, it is of particular interest that several pervasive concepts identified are absent from contemporary patient reported outcome measures; thus demonstrating the importance of qualitative research in uncovering quality of life parameters necessary for optimizing patient care. UVFI can have substantial health consequences related to aspiration and pneumonia[4], but this study reinforces that the vast majority of patient reported concerns are related to quality of life. Clinicians must be astute in understanding how UVFI affects patients' personality, emotional wellbeing, interactions with society, and their work environment as described in the taxonomy.

UVFI is a largely neurological condition causing glottic insufficiency or the inability of vocal folds to approximate thereby affecting the primal laryngeal functions – respiration and airway protection. In fact, from a health and evolutionary biological perspective, voice is the third most critical axis of larynx function behind breathing and swallowing[15]. However, voice is among the most humanizing of traits and one that helps define our personalities and shape our ability to interact and function in society[15]. Thus, it is not surprising that UVFI-associated dysphonia affected all interviewees (100%) albeit with varying severity. The characteristic dysphonia profoundly affects communication eliminating a patient's ability to connect and interact with family, friends, and participate fully in their work environments. Emotionally, patients described a “loss of control” in their lives, a feeling of seclusion, frustration, anxiety, fear, and depression. Our findings emphasize how intertwined intrinsic and extrinsic affects of dysphonia are in the UVFI population.

Contrary to expectations, breathing complaints were more frequent than those related to swallowing in this cohort: 74% versus 69%. Besides a study by Brunner et al. that similarly found 75% of UVFI patients had associated breathing complaints[5] and a few others[16; 17], this primary axis has been largely ignored in the UVFI literature. Therefore, it is not surprising that no validated patient reported outcome measures, to date, assess the severity,

natural history, and intervention responsiveness of UVFI-associated dyspnea. The most common complaints were shortness of breath during phonation or exercise, which was quite disconcerting especially for patients who described themselves as active prior to developing UVFI. Many patients reduced their amount of exercise and felt limited in their ability to carry on conversations because of dyspnea.

Other respiratory-type complaints were also prominent. In particular, many described new-onset globus or throat congestion sensation and the inability to effectively clear secretions through throat clearing or cough. Another common complaint was inefficient valsalva that reduced their ability to bear down or carry heavy objects. These dysfunctions directly relate to an inability to achieve and maintain adequate glottic closure. It is likely that under-recognition of respiratory complaints related to UVFI results in unnecessary referrals, testing, and imaging. It also heightens patient anxiety and fear especially when clinicians fail to validate and explain how dyspnea is related to UVFI.

Dysphagia complaints were frequent in this population (69%) manifested primarily with coughing or choking with deglutition. From a clinical perspective, dysphagia is perhaps the most concerning because it is often a harbinger of aspiration and pneumonia[4; 18]. Therefore, dysphagic patients often undergo functional swallow studies to assess these risks. Most objective studies have identified thin liquids as most difficult for this patient population[18]. However, patient complaints in this cohort were mixed. Nearly equal percentages of patients described difficulty with liquids and solid foods that, in many cases, required dietary changes. Clearly, the fear of choking and coughing affected patients psychologically, but also in terms of their social interactions. Patients recognized that others were outwardly concerned about them when sharing meals and that they were self-conscious about the need to eat slower, take smaller sips, and how their consciously increased effort delayed meal completion. Those affected were disconcerted that a normally automatic swallow reflex now required active concentration.

Interestingly, the qualitative assessment and taxonomy demonstrate that, despite some overlap in concerns, there is also a divergence between what clinicians and patients find most relevant and debilitating about the UVFI condition. Patients often ask whether their swallowing and breathing complaints will improve with treatment. The answer is equivocal. Clinicians appropriately focus on the health consequences, in particular, reducing the risk of aspiration and subsequent pneumonia. Some data is available to prognosticate and direct therapy in this arena[4]. In contrast, patients may be more concerned that “food sticks in their throat” or a feeling of “not getting enough air”. Currently available studies are inadequate to answer this question definitively, requiring physicians to rely on anecdote and experience. Further studies are required to determine whether there is objective improvement – reduced aspiration and pneumonia – after vocal fold augmentation. Equally important from the patient's perspective, is whether their subjective experience of dysphagia or dyspnea improves.

Several patient-reported outcome measures exist for assessing dysphagia including the DHI[19] and EAT-10[20]. In contrast and to date, no non-pulmonary dyspnea scales have been published in the otolaryngology literature. These and most validated voice

questionnaires are not disease specific. Instead, most are designed to capture generalized handicap related to voice[21-23], swallowing[19; 20; 24], cough[25], or reflux[26] individually. Furthermore, very few popular measures, including the Voice Handicap Index[23], directly derived questions from prospective patient interviews or focus groups (excepting, for example, VRQOL[22], VOS[27], VOiSS[28; 29]); rather, initial item development has relied primarily on consensus expert experience and retrospective chart review. Many centers, including ours, use these well-validated outcome measures to assess voice-, swallowing-, and other-attributable disabilities. However, there are important symptoms, as demonstrated in this study, that are systematically overlooked when we solely rely on these measures, which emphasizes the importance of carefully listening to patients complaints and measuring non-voice related patient reported outcomes in the assessment of those presenting with laryngeal conditions.

This study has study design limitations that require mention. Patients captured were heterogeneous in relation to their current UVFI-status. Some were recently diagnosed, others were symptomatic or had recovered function spontaneously, and still others had undergone corrective interventions. However, all patients were asked to share their experience when they were symptomatic prior to spontaneous recovery or treatment. While there is the possibility of recall bias, all had extensive recollection of their symptoms in interviews. This is not surprising since they had been symptomatic from vocal fold immobility in the 2 preceding years. Moreover, the sample may not be representative of the entire population with this condition (i.e. racial, socioeconomic, geographic), thus skewing responses and findings. It is for these reasons that the taxonomy developed herein is considered *preliminary*.

Despite these limitations, this study contains useful information that future prospective research can build upon to more fully characterize the UVFI patient experience. The importance of these future studies is underscored by our findings that several parameters consistently described by affected patients have yet to be directly reported in the literature. We are currently undertaking a prospective study that should hopefully overcome some the limitations mentioned above. Once “quantity-of-life” consequences have been ruled-out (i.e. aspiration risk), patient-centered care should be directed toward optimizing quality of life. But in order to do so, clinicians must understand and study those aspects that matter to the patient. Moving toward better outcomes measures and therapeutics requires us to engage our patients and carefully examine their experience with this condition. Non-voice (e.g. dysphagia, dyspnea) related measures are critically important and should routinely be used in assessing disability related to UVFI and other laryngeal conditions. Further, future patient reported outcome should consider all domains of laryngeal function rather than the current approach that is focused on singular aspects. This would allow for rigorous comparative effectiveness research to assess different treatment effects on relieving symptoms associated with voice, swallowing, breathing, and other laryngeal-related dysfunction.

Conclusions

Patient experience with unilateral vocal fold immobility 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. More qualitative research is necessary to confirm and expand upon these preliminary findings in a larger cohort of patients. This and future data will provide critical information for all clinicians who care for patients with unilateral vocal fold immobility and provide a platform from which to investigate how and whether current interventions improve these patients' overall disorder-specific quality of life.

Appendix: Exemplary patient comments by domain and subcategory

Voice

I. Physical

Comments about physical aspects of UVFP voice experience sub-classified into:

- a. *Change in Quality* divided into:
 - i. *Breathiness*: voice “weak”, “raspy,” and “breathy”, “could not get voice above whisper even though was trying to talk loudly”
 - ii. *Strain*: unable to generate loud voice without “extreme strain”, “to speak in a loud manner causes vocal strain and it takes a lot of effort to generate any sound”
 - iii. *Vocal fatigue*: loss of vocal endurance, “could not talk for any period of time without voice giving out”, “voice was shot in afternoon after a full day of working”
- b. *Inconsistency*: vocal inconsistency was difficult, “never know if going to be talking to someone and voice would change”, “most speech just didn't sound right”, “sounded like cartoon character” or had “hit of helium”
- c. *Pain/Irritation with use*: using voice was physically uncomfortable, unable to generate voice without “lots of pain and scratchiness”, “pushing through pain to talk made throat feel raw”
- d. *Voice rationing/rest*: preserved voice by rationing, “limiting voice use is best way to prevent strain”, “take hours out of day where stayed home and rested voice”, “tried to ration voice throughout the day”

II. Social

Comments about social aspects of UVFP voice experience sub-classified into:

- a. *Change in family dynamic*: “difficult when family comes to visit and cannot communicate with them”, “negatively impacted my family”, “difficult for mother not be able to converse with her children”
- b. *Social limitation* divided into:
 - i. *Difficulty in background noise*: hard to be heard above noise in room of people, “cannot be heard ordering food above background restaurant

noise”, “with music, TV or clients talking in background... voice gets drowned out”

- ii. *Limitations in daily activities*: “no longer goes out to eat because can't be heard”, “vocal troubles have hindered and limited social activities”, “limits amount of social situations she puts herself in
- iii. *Phone difficulties*: using telephone is difficult and admits “not talking on phone because difficult to understand”, increasingly difficult to use phone at job because strain on voice to be heard
- iv. *Use of alternative communication*: Prefer electronic communication instead of phone calls, resorted to writing notes because people can understand those, prefer to text rather than talk
- c. *Decreased work efficiency*: telecommunications consultant so this has been bad for job... has gone to part-time, “did not return to work until got voice back”, “since development, has limited sermons duration”
- d. *External reactions*: person on other end get frustrated and hang up because could not understand”, people often ask whether he was sick or had laryngitis, “constantly asked to repeat himself”

III. Emotional

Comments about emotional aspects of UVFP voice experience sub-classified into:

- a. *Feeling of seclusion*: “Secluded himself because of shame of his voice”, “feels ignored by others because of inability to effectively communicate”, “stopped talking to everyone except her husband”
- b. *Worry about loss of income*: main reason opted for surgical correction, “could not sustain career if unable to communicate”, “symptoms are bad enough to where is at risk for losing his job”
- c. *Changed “way of life”*: never went out alone because she could not effectively communicate with people, very social person... problem severely affected outgoing personality, affected how lived on day-to-day basis, “difficult to live life”
- d. *Frustration*: constantly being asked to repeat self, people become frustrated and uninterested in conversation, gets extremely frustrated with combination of children misbehaving and her vocal difficulties, “people did see me like they used to”
- e. *Anxiety/Fear/Depression*: “trying to talk loudly to get someone's attention is difficult”, makes her anxious/nervous about meeting new people, issues exacerbated her anxiety and depression, patient too scared to go to places on her own

Swallowing

I. Physical

Comments about physical aspects of UVFP swallowing experience sub-classified into:

- a. Coughing/Choking divided into:
 - i. *Thin liquids*: water shoots down too quickly and it was a problem that would make her cough and choke, felt was “drowning” with thin liquids, “strangled” easily on liquids
 - ii. *Solids*: can drink better than can eat, problems with food because felt as though it would often get stuck in throat or wouldn't even go down
 - iii. *Pills*: “taking medicines was the hardest”, chokes when takes pills, difficulty swallowing multiple pills – now had to swallow one at a time
- b. Required diet change: altered eating habits to avoid anything with coarse or crumbly exterior (e.g. cornbread), use thickener for liquids, resorted to eating “mashed solids” that were easy to swallow
- c. Use of head maneuvers: tucks chin when eating and drinking to make it go down easier, if turns head to right was able to swallow easier, would choke easier if tilted head back to swallow
- d. Smaller sips and bites: “taking small sips and bites like a child... only thing that seems to help”, couldn't take a normal bite, and had to make sure chewed thoroughly or it would go down wrong way”

II. Social

Comments about social aspects of UVFP swallowing experience sub-classified into:

- a. Affect social interactions: stopped eating and drinking in front of others, did not eat or drink in front of people for a long time, others notice him wincing when eating and doing funny head turns when eats
- b. Choking in public: people would watch with “almost bated breath” because thought she might get choked, avoids eating around people for fear would have a choking fit and cause a scene
- c. Slowed meals: eats slower than did before, people noticed how slow he was eating, last to finish all meals now, almost always orders a to-go box so people wouldn't have to wait for him to finish eating

III. Emotional

Comments about emotional aspects of UVFP swallowing experience sub-classified into:

- a. Fear of choking/aspiration: worried about choking in restaurants in front of others, very conscious of possibility of getting choked, fear of choking made him self-conscious about eating and drinking habits

- b. *Hesitancy to eat and drink*: embarrassed about swallowing difficulties and very worried about inability to swallow foods and liquids, lost weight because of hesitancy to eat
- c. *Increased concentration*: has to concentrate to swallow, “swallowing more involved than it used to be to make sure I don't choke”, “swallowing should be natural, shouldn't have to worry about choking”

Breathing

I. Physical

Comments about physical aspects of UVFP breathing experience sub-classified into:

- a. *Shortness of breath* divided into:
 - i. *Phonatory*: “it was like playing catch-up... amount of air I could hold in my lungs did not equal amount I was talking”, “constantly felt need to take big gulps of air to could catch up”, couldn't talk and breath at same time
 - ii. *Exercise-induced*: significantly decreased physical activity due to feeling short of breath during exertion, feeling of not having enough breath greatly increased whenever move around or try to go up stairs
 - iii. *Sensation that “can't hold enough air”*: body could only hold fraction of air it used to, no matter what she is doing “just doesn't get enough air into chest so gets winded easily...I had to totally readjust my breathing”
- b. *Throat irritation*: cannot cough effectively, feels needs to “forcefully cough for several minutes” in order to bring up phlegm, increased drainage and congestion since onset – “it felt like I had a pool of mucus sitting at the bottom of my throat all the time”
- c. *Inefficient valsalva*: difficult bearing down to use restroom or lift heavy objects, “like had leak and couldn't hold air in chest”, increased shortness of breath when carrying loads, “like something is causing air to leak out when tries to lift something”

II. Social

Comments about social aspects of UVFP breathing experience sub-classified into:

- a. *Difficulty in conversation*: spend a lot of time taking deep breaths in order to communicate out loud, always clearing his throat several times during conversations and that it is very disruptive, limit amount talks because of how out of breath he gets
- b. *External reactions*: “people noticed how much breath it took to talk and would stop conversation early”, people have commented that he seems “like he just ran a marathon and is trying to catch his breath even when at rest”

III. Emotional

Comments about emotional aspects of UVFP breathing experience sub-classified into:

- a. *Anxiety about breathing*: at night when laying flat was very anxious about breathing, would wake up with feelings that could not catch breath, anxiety about inability to “catch breath”, anxiety about any exertion
- b. *Loss of control*: interfered with ability to pray and give sermons at church, felt constantly short of breath and could not be anything without exacerbating it, felt trapped and only not out of breath when sitting on couch

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Table 1

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%
	Neurological	5%
	Infectious	2%

Table 2
Preliminary Taxonomy of Patient Experience with Unilateral Vocal Fold Paralysis

Sub-Axes	PRIMARY AXES		
	I. Voice	II. Swallowing	III. Breathing
A. Physical	<p>1 1. Change in Quality</p> <p>Breathiness</p> <p>Strain</p> <p>Vocal Fatigue</p> <p>2 Inconsistency</p> <p>3 Pain/irritation with use</p> <p>4 Voice rationing/rest</p>	<p>1 Coughing/Choking</p> <p>Thin liquids</p> <p>Solid food</p> <p>Pills</p> <p>2 Require Diet Change</p> <p>3 Use of head maneuvers</p> <p>4 Smaller sips and bites</p>	<p>1 Shortness of Breath</p> <p>Phonatory</p> <p>Exercise-Induced</p> <p>Sensation that “can’t hold air”</p> <p>2 Throat Irritation</p> <p>Constant throat congestion/globs</p> <p>Inefficient cough</p> <p>Cannot clear secretions</p> <p>3 Inefficient valsalva</p>
B. Social	<p>1 Changed family dynamic</p> <p>2 Social Limitations</p> <p>Difficulty in background noise</p> <p>Limiting daily activities</p> <p>Phone difficulties</p> <p>Use alternative communication</p> <p>3 Decreased work efficiency</p> <p>4 External reactions</p>	<p>1 Affect social interactions</p> <p>2 Choking in public</p> <p>3 Slowed meals</p>	<p>1 Difficulty in conversation <i>Extra breaths during phonation</i></p> <p>2 External reactions</p>
C. Emotional	<p>1 Feeling of seclusion</p> <p>2 Worry about loss of income</p> <p>3 Changed “way of life”</p> <p>4 Frustration</p> <p>5 Anxiety/Fear/Depression</p>	<p>1 Fear of choking/aspiration</p> <p>2 Hesitancy to eat/drink</p> <p>3 Increased concentration</p>	<p>1 Anxiety about breathing</p> <p>2 Loss of control</p>