Psychosocial and Quality of Life Effects of Spasmodic Dysphonia

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Background

- Spasmodic dysphonia is typically characterized by its physical presentation and voice symptoms: strain/strangled voice quality, voice breaks, effortful voicing, breathiness
- Management of SD is currently primarily based on a medical model to assess and address voice symptoms
  - Clinicians will assess the sound quality/symptoms that one hears and assess what patients perceive in the sound and feel of his/her voice
  - Voice Handicap Index (VHI) often used to measure level of voice handicap
  - Gold Standard of treatment is Botox injections to minimize voice symptoms (i.e. voice breaks, roughness)

Looking beyond voice symptoms

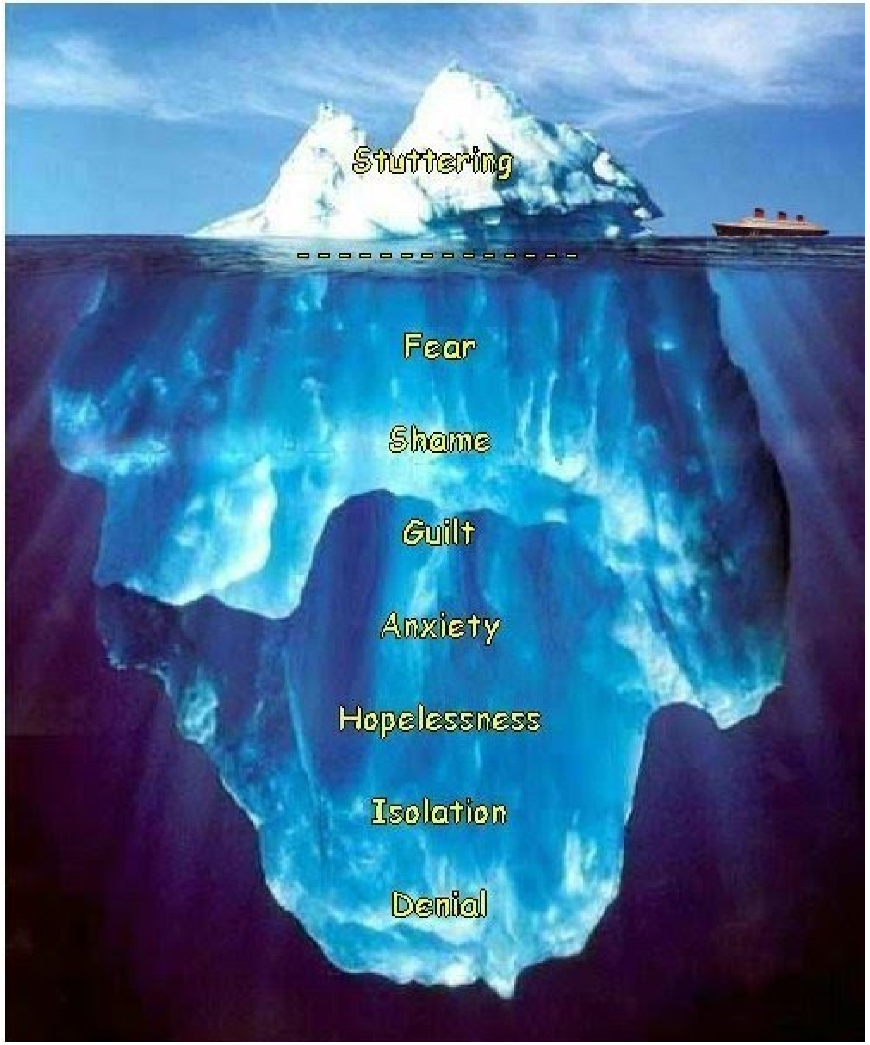
- What about the quality of life impact?
  - Emotional distress, loss of job or salary, reduced social participation, inability to complete daily tasks, avoidance of situations, and negative changes in personal relationships
- Individualized
- Can be at any stage
  - Pre-diagnosis, diagnosis, post-diagnosis
  - Treatment may lead to further psychosocial symptoms for some (cost, ineffective or variable results, physical negative side effects, need for repeated treatment)

(Baylor, Yorkston, Eadie, & Maronian, 2007) (Baylor, Yorkston, & Eadie, 2005) (Baylor, Burns, Eadie, Britton & Yorkston, 2011)(Isetti, Xuereb, & Eadie, 2014; Morzaria & Damrose, 2010)(Vanryckeghem, Ruddy, & Lehman, 2016) (Whurr & Lorch, 2016)

Why examine Psychosocial Symptoms?

- Individualized treatment goals with knowledge of psychosocial impact
  - Choice of treatment options (or no treatment)
  - Planning of Botox injections (weighing side effects with duration benefit)
  - Voice therapy
  - Referrals to appropriate professionals to target significant emotions experienced?

The Iceberg Analogy of Stuttering



Study

- Data collected in 2016 at New York University in collaboration with Celia Stewart, PhD, CCC-SLP
- Goal: Investigate the effects of spasmodic dysphonia in more detail beyond voice symptoms, beyond what the standard VHI-10 and current voice handicap and quality of life scales evaluate
- Survey based research study

Questions to Answer

- What are the most prominent psychosocial symptoms that exist in those with spasmodic dysphonia along with voice changes?
- What role do these psychosocial symptoms play in the individual’s perception of “voice handicap”?
- Is an individual’s experience and perceived handicap with SD appropriately captured by the current standard voice handicap scale (i.e. VHI-10)?
- What symptoms are most important for professionals managing those with SD to understand when assessing and treating spasmodic dysphonia?

Sample studied

- 127 participants with confirmed diagnosis of adductor spasmodic dysphonia (ADSD)
- **Age**: 21 to 81 years old
- **Sex**: 30 males and 97 females
- **ADSD diagnosis:**
  - Age at diagnosis: 11 to 74 years
  - 28% Early onset, 72% typical onset
  - Varied times since diagnosis ranging from less than a year to more than 20 years
- **Treatment**:
  - **Past treatment**
    - 78% received Botox injections and 71% received speech/voice therapy at one point
  - **Current treatment**
    - 41% receiving Botox injections
    - 39% not currently receiving treatment
    - 21% taking medications for symptoms
    - 9% receiving speech/voice therapy at the time of the survey
    - 4% had laryngeal surgery

Biopsychosocial Categories

BODY STRUCTURE & FUNCTION (VOICE SYMPTOMS)	ACTIVITY/ PARTICIPATION	ENVIRONMENTAL FACTORS	PERSONAL FACTORS
Perceptual Voice Symptoms • Strain, roughness, breaks, effort, overall severity **Direct Impact of Voice Impairment** • Dislike of voice sound • Dependability of voice • Control over voice	**Interference** • Reduction in participation in daily activities • Change in roles of society – professional, cultural, familial • Change in relationships **Enjoyment** • Decrease in enjoyment of daily activities or relationships	**Communication Situations** • Evaluation of speaking situations to weigh pros/cons of speaking • Speaking in different situations (i.e. small vs. large groups) • Speaking with different people (i.e. authority figures)	**Affective** • Emotions experienced **Cognitive** • Acceptance of disorder • Thoughts about one's voice • Thoughts about speaking • Self-view **Behavioral** • Avoidances • Hiding voice problem

Personal Category

EMOTIONS

- **Self conscious (M = 4.3)**
- Frustrated: (M = 4.27)
- Annoyed: (M = 4.06)
- Less confident: (M = 4.06)
- Angry (M = 3.5)
- Anxious: (M = 3.93)
- Anxiety in preparation of speaking (M = 3.86)

THOUGHT/COGNITIVE PATTERNS

- **I feel like I cannot always express my thoughts/opinions in the manner that I want (M =4.60)**
- It was hard to accept a life long disorder upon initial diagnosis (M = 4.09)
- I feel that my voice does not represent personality (M = 3.99)
- My personality has changed due to my voice disorder (M = 3.99)
- I believe that strangers perceptions of my personality are based primarily on how my voice sounds (M = 3.95)
- I can’t always use the words I want to say freely (M = .390)
- I am not able to focus on the message I am saying because I am focused on the sound of my voice (M = 3.83)
- I often rehearse what I want to say in my head before saying it out loud (M = 3.70)

BEHAVIORAL CHANGES

- **When my voice is bad, I avoid socializing with acquaintances or people who I don't know well (M = 4.02)**
- I avoid certain places where I know I will have to speak (M = 3.82)
- When my voice is bad, I avoid socializing with friends (M = 3.65)

Environmental Category

- Not as comfortable doing the following activities now as before the voice problem began:
  - Speaking in large groups (M = 4.35)
  - Speaking to authority figures (M = 4.20)
- In most instances, I evaluate the situation around me and the potential effects of speaking before I talk. (M = 4.17)

Activities/Participation Category

"I enjoy ___________ less now than before the voice problem began"

  - Restaurants : (M =4.12)
  - Communicating/socializing with friends (M = 3.73)
  - Speaking on the phone (M=3.50)

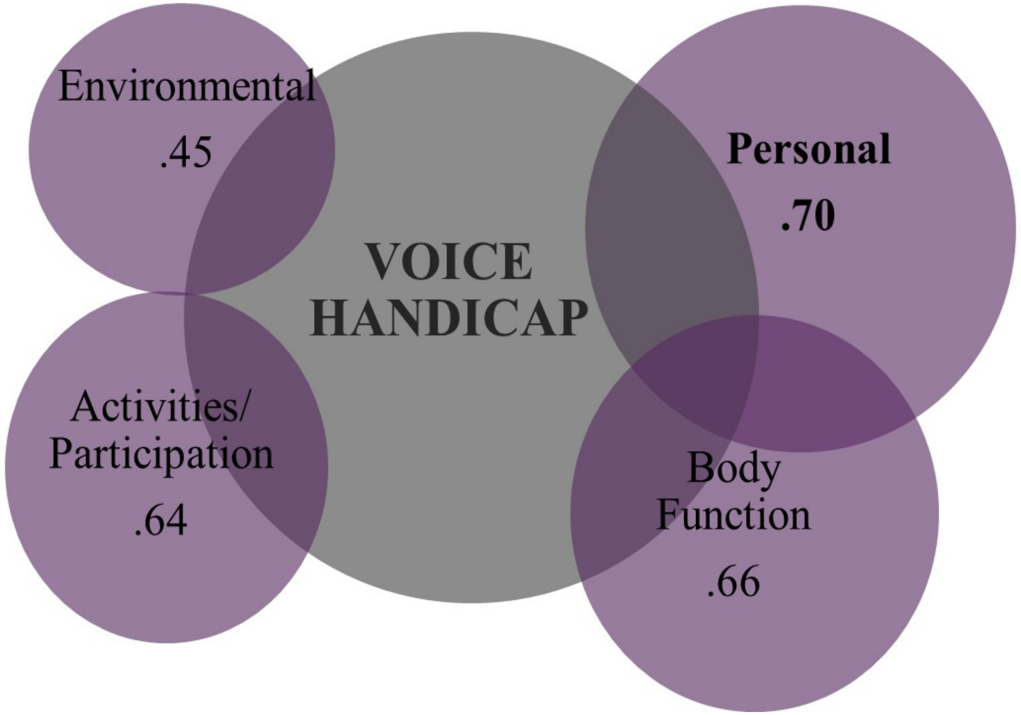
- My voice interferes with my success in work/school (M = 3.56)

Voice Symptoms in Body Structure & Function Category

- **Dislike the sound of the voice (*M = 4.75)**
- Having think about the process of talking (M = 4.32)
- Overall severity of the voice symptoms (M = 3.65)
- Phonation breaks (M = 3.61)
- Vocal effort/pushing (M = 3.52)
- Vocal strain (M = 3.82)

FINDINGS

- The **Personal** category (i.e. emotional and behavioral effects, and shifted thought patterns) was the category most strongly related to voice handicap
- More strongly related to voice handicap than physical voice symptoms (breaks, strain etc).



Relationship of items to VHI-10

- Powerful negative emotions; feeling hopeless, overwhelmed, angry, and helpless moderately correlated to vocal handicap scores
- **Hopelessness** was single biopsychosocial factor across all biopsychosocial categories that most correlated to voice handicap (including physical voice symptoms)
- 4 items related more highly to voice handicap than any physical voice symptom

BIOPSYCHOSOCIAL FACTOR	STRENGTH OF RELATIONSHIP TO VOICE HANDICAP (VHI-10)
Hopelessness* (P)	.560*
Helplessness (P)	.554
Belief that others treat them as less intelligent (P)	.547
Anger about his/her voice (P)	.539
Voice breaks (B)	.537

P= Item from Personal Domain, B= Item from Body Structure/Function Domain, *= Strong correlation

Results: Prediction of Handicap

- The **Personal** category was the best predictor of voice handicap of all four categories
- Emotional effects, behavioral responses, and negative thought patterns can predict voice handicap more strongly than voice symptoms alone

Biospsychosocial Category	Strength of Prediction
Body Structure and Function	4.27
Personal*	**5.76**
Activities and Participation	3.45
Environmental	2.60

Insider’s Experience

- **“What do you want treating professionals to know about your disorder?”**
  - “Handicapping”, “frustrating”, “hopeless”, “isolating”, “exhausting”, “life altering”
  - Changes personality
  - “It affects my whole being. It's not about the voice alone”
  - Desire for a cure/long term solution, need for a more “holistic” approach
  - Variability in symptoms
  - “How it impacts me emotionally”
  - “My voice does not reflect who I am”
  - “Being able to talk is being alive! Being a person!”
  - “While it is a disability it does not affect intelligence!”
  - “That losing the ability to communicate easily and comfortably changes so much about how one interacts in all facets of his life. Speaking with ease is something we take for granted until it is gone”
  - “The grief and loss, the fact it seriously affects loved ones”

Summary of Findings

1. Spasmodic dysphonia results in a significant psychosocial impact for many individuals
2. Psychosocial symptoms exist in those with ADSD even in those getting treatment in this study (more than 60% of participants in this study)
3. Emotional, behavioral, and cognitive effects of living with SD may be more debilitating than the physical voice symptoms alone
4. Psychosocial symptoms of spasmodic dysphonia may not be adequately captured by current quality of life or voice handicap scales

Questions to Consider

- How can we better address psychosocial symptoms in the SD population?
- Why do psychosocial symptoms exist despite treatment?
  - Cost, negative side effects, variability of treatment results, need to travel for treatment, temporary nature of treatment?
- Is the Voice Handicap Index-10 (VHI-10) sensitive enough to capture all of the psychosocial and quality of life impairments in those with SD?
  - VHI-10 mean was 28, indicating a significant voice handicap overall of the participants
  - The psychosocial items found in this study go beyond what the VHI-10 measures

Reframing the Stuttering Iceberg

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Coping Mechanisms

- **“What has helped you most dealing with this disorder?”**
  - Support groups, NSDA symposium and website, Facebook support groups
  - Having a trustworthy/competent treating otolaryngologist and speech language pathologist/voice therapist
  - Accepting it
  - Humor
  - Having accepting and understanding employers, friends and family members
  - Trying to decrease life stressors

Conclusions

- This study highlights importance of education, counseling, and expansion of treatment options for SD population
    - Increased treatment options to decrease significant feelings of hopelessness
- Professionals treating the disorder should recognize and consider the significant psychosocial symptoms in management of disorder
- Consideration of benefit of voice therapy to help manage symptoms, better target unaddressed psychosocial symptoms
    - Methods to increase participation in daily activities like speaking on the phone or in groups
    - Providing more control over the voice and self empowerment of individuals
    - Strategies to minimize avoidance in social situations
    - Acknowledgment and validation of the difficulty of living with the disorder
- Promote education and understanding amongst family members, friends, medical community

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Thank you!

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