

Psychosocial and Quality of Life Effects of a Chronic Voice Disorder

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Psychosocial Symptoms of a Chronic Voice Disorder

Personal Factors	Environmental Factors	Activities/Participation Factors
<p>Affective</p> <ul style="list-style-type: none"> • Emotions experienced <p>Cognitive</p> <ul style="list-style-type: none"> • Acceptance of disorder • Thoughts about one’s voice • Thoughts about speaking • Self-view • Negative “self talk” <p>Behavioral</p> <ul style="list-style-type: none"> • Avoidances • Hiding voice problem 	<p>Communication Situations</p> <ul style="list-style-type: none"> • 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) 	<p>Interference</p> <ul style="list-style-type: none"> • Reduction in participation in daily activities • Change in roles of society – professional, cultural, familial • Change in relationships <p>Enjoyment</p> <ul style="list-style-type: none"> • Decrease in enjoyment of daily activities or relationships

Results from survey study conducted by Christie DeLuca and Celia Stewart in 2016:

Highest rated symptoms from patients:

- Dislike the sound of the voice (*M = 4.75)
- I feel like I cannot always express my thoughts/opinions in the manner that I want (M = .460)
- Feel less comfortable speaking in groups (M = 4.35)
- Feel self conscious (M = 4.30)
- Feel frustrated: (M = 4.27)

Conclusions from study conducted by Christie DeLuca and Celia Stewart in 2016:

- Powerful negative emotions exist in relation to the voice disorder; feeling hopeless, overwhelmed, angry, and helpless moderately related to vocal handicap scores
- *Hopelessness* was single biopsychosocial factor across all biopsychosocial categories that most correlated to voice handicap
- Psychosocial symptoms exist in those with ASD even in those getting treatment
- Emotional, behavioral, and cognitive effects of living with SD may be more debilitating than the physical voice symptoms alone
- Psychosocial symptoms of spasmodic dysphonia may not be adequately captured by current quality of life or voice handicap scale

Subjective reported experiences from those with SD:

- Affects one's whole being and is not just about the voice alone
- Affects one emotionally
- It does not affect intelligence, only the sound of one's voice
- Can be frustrating, life altering, isolating, hopeless, and exhausting
- It is associated with grief and loss

Coping strategies reported by individuals with SD:

- 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

Thoughts for moving forward:

- Importance of education, counseling, and expansion of treatment options for SD population
 - Increased treatment options to decrease significant feelings of hopelessness
 - Perhaps a model based on targeting cognitive, affective, and behavioral symptoms like stuttering treatment
- 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
- Individuals finding sources of empowerment & passion
- Psychosocial symptoms are normal and valid and are experienced with many with a chronic communication disorder
- Remember that each individual's journey is different and explore what works for you!

Visit the [NSDA](#) website to learn more about psychosocial symptoms of spasmodic dysphonia and related voice conditions, read inspiring stories of others with SD, explore treatment options, or to seek a virtual support group near you.

For more on my thoughts or personal experiences in navigating psychosocial experiences of a chronic voice disorder, or for more resources in coping with psychosocial symptoms visit speakingboldly.com/blog-1 or email christiejdeluca@gmail.com with any questions.