Should Professionals be Looking at the Voices of People with Ehlers-Danlos Syndrome: An Initial Inquiry of Professionals Treating Voice Disorders

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What is Ehlers-Danlos Syndrome?

- Ehlers-Danlos Syndrome (EDS) is defined by the Ehlers-Danlos Society as a group of genetic disorders (inherited from parents) that affect the body’s connective tissues. It typically results in:
  - Joint hypermobility → Flexibility
  - Skin hyperextensibility → Stretchy skin
  - Fragile Tissue → Easy bruising and bleeding

Implications for Voice

- EDS affects connective tissue as found within the vocal folds, specifically collagen responsible for vocal fold stiffening with vocal fold elongation and pitch increase.
- The laryngeal joints may be affected, leading to possible joint dysfunction.
- The general prediction is that individuals with EDS may have voice problems relatable to EDS.

Methods

- Professionals who specialize in voice were asked to complete a survey about their experiences treating individuals with EDS for voice disorders, contacted through the American Speech Language Hearing Association Special Interest Group for Voice (SIG 3). Sixteen professionals responded.
- Some example questions:
  - How would you characterize voice problems in people you have seen with EDS?
  - Have you observed a change in average speaking pitch in people with EDS?
  - Did you observe an impairment in voice quality in people with EDS?

Examples of Clinician Responses

1. How would you characterize voice problems in people you have seen with EDS?
   a. “Fatigue, instability, breath support issues.”
   b. “Pain while speaking and singing.”
   c. “Reduced pitch range while singing.”
   d. “Difficulty talking after periods of voice use.”
   e. “Breathy, lower pitch, restricted pitch range”
   f. "Unstable phonation"

Table 2.1: Averages of responses from 6 professionals surveyed.

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Table 2.2: Averages of responses from 6 professionals surveyed about which pitch ranges individuals with EDS have difficulties producing.

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Clinical Implications

- Check pitch range of individuals with EDS who present with voice complaints. Specifically measure the lowest and highest notes these individuals can produce.
- Assess voice quality in patients with EDS.
- Assess possible laryngeal cartilage displacement on visual or imaging exam.

Discussion

- A majority of the professionals who responded stated that they did observe an impairment in voice in persons with EDS, and specifically a reduction in overall pitch range.
- Respondents also noted an impairment in the production of low notes and high notes for individuals with EDS.
- The study was limited in scope. Current findings might serve as a basis for future studies on voice impairments in EDS and the mechanisms behind impairments.

References


Verdolini, R. I., & Titze, I. R. (2018a). The beta survey will be distributed to individuals with EDS, who present with voice issues. Using responses from 5 professionals surveyed about potential voice problems in EDS.

Next Steps

- Individuals with EDS from local support groups will be interviewed about their voices.
- Using responses from clinicians and individuals with EDS, a beta questionnaire will be developed on potential voice problems in EDS.
- The beta survey will be distributed to persons with EDS and control groups to determine its validity for further investigation.

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