Travel and cost as barriers to care in subglottic stenosis

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Abstract

Introduction

- Idiopathic subglottic stenosis (iSGS) is a chronic, progressive, scarring process of the upper airway for which delay in diagnosis leads to worsening symptoms. Researchers sought to investigate the international experience. The primary objectives of this study were to examine the 1) relationship of access to care on diagnosis and 2) amount of travel for care and associated healthcare costs.

Methods

- A 26 question survey was distributed to 2,657 participants in a laryngotracheal stenosis online community.
- Chi-square tests and Fisher's exact tests were used to compare dichotomous healthcare access outcomes. Bonferroni correction was then used for multiple comparisons.

Results

- Participants from all countries in cities had a streamlined experience regarding travel time and receiving a diagnosis.
- USA and Australia had a significantly higher percentage of travel cost.
- Australia had a higher percentage of total airway stenosis procedures.

Conclusions

- Patients with SGS often face delay in diagnosis due to rarity and provider familiarity with their disease process. This study aims to prove that access to care is an issue for patients as it relates to travel and cost internationally. Further studies can evaluate how this access to care affects disease progression, symptomatology, and overall quality-of-life. This supports the need for wider distribution of specialty care internationally.

Introduction

- Idiopathic subglottic stenosis is a progressive narrowing of the upper airway. Symptoms can include shortness of breath, hoarseness, cough, and even voice changes. It almost exclusively affects women. Middle aged Caucasian women are the common demographic (1).
- Diagnostic workup can take years as it can often be misdiagnosed (2). Efforts have been made to quantify the delay in diagnosis, but there have been no studies to determine how travel and cost are associated with subglottic stenosis. The purpose of this study was to examine access to care based on patient location (1,2).

Materials and Methods

- A 26-question survey was distributed to 2,657 research participants in an international laryngotracheal stenosis online Facebook community, *Living with Idiopathic Subglottic Stenosis*, from December 20th 2023 to January 22nd 2024.
- Data Collection included multiple choice and write-in responses about demographics, length to diagnosis and treatment, average time traveled for office visits and procedures, estimated cost of office visits and procedures, reason for travel, type of provider managing care, and health insurance status.
- Chi-square tests were used to compare dichotomous healthcare access outcomes.
- Fisher's exact test was used when 25% or more of the cells had expected counts less than 5.
- Bonferroni correction was used to adjust for multiple comparisons.
- Ordinal variables were dichotomized mainly based on their median (for the robustness of statistical findings), along with considering domain knowledge for ease of interpretation (3-5).

Access to Care	Rural	Town	City	P-value
Time to diagnosis within 1 year symptom onset	28.9%	31.2%	**39.8%**	0.010
Time to first treatment within 1 month of dx	47.6%	46.1%	45.8%	0.918
< 1 hour travel for office visit	22.7%	32.4%	**63.3%**	<.0001
< 1 hour travel for surgical care	20.0%	**31.3%**	**61.2%**	0.008
Total # of airway stenosis surgical procedures 6+	51.3%	44.2%	**38.4%**	0.008
Travel cost $500+	22.0%	21.9%	17.1%	0.208

Table 1: Access to care by place of living.

Results

- There was a 33% response rate. Compared to those in rural areas, participants across all countries in city areas reported a quicker time to diagnosis of SGS (40% vs. 35%,), less than an hour's travel from home for an office appointment in the last 3 years (63% vs. 23%), and less than an hour's travel for surgical care in the last 3 years (61% vs. 20%).
- Compared to participants from the USA, those from Australia had a significantly higher percentage of travel for surgical care 3+ times (58% vs. 31%) and more airway stenosis surgical procedures 6+ (63% vs. 42%); those from Canada had a significantly lower percentage of time to first treatment (35% vs. 48%), less than 6+ airway procedures (29% vs. 42%), and travel cost $500+ (7% vs. 25%); those from UK had a significantly lower percentage of travel cost $500+ (4% vs. 25%).

Discussion

- Participants in rural areas had a higher percentage of 6 or more surgical procedures. Procedures in our study were defined as dilations and major procedures such as reconstructions, Maddern procedures, and tracheal resections.
- One study of patients with a delay in diagnosis of idiopathic subglottic stenosis reported more procedures that could have been avoided if there was earlier diagnosis (2). Rural residents having more procedures than those in cities may be due to procedure type. Endoscopic dilations have been shown to have a higher reintervention rate over an open surgery (6,7).
- There are no studies demonstrating if rural patients prefer less- invasive procedures for SGS, but there is evidence that the need for repeat procedures is important when deciding on SGS management (7).
- These findings could be due to more unnecessary procedures as well as limited resources in rural areas.
- The need for further investigation of severity of disease and increased airway procedures in Australia & rural populations is warranted, as rural SGS outcomes were not analyzed in this study.
- In this study, rural and town participants were more likely to drive greater than one hour for their SGS care. It is known that rural residents have a greater distance to travel to access healthcare than urban residents and often face more limitations due to lack of funds or public transportation (8).
- According to this study, high travel costs are a barrier to SGS care in Australia and USA.
- This study further provides proof that rural otolaryngology care and education should be expanded, especially regarding laryngology conditions such as SGS.

Conclusions

- This is the first study to examine access to care for subglottic stenosis globally regarding travel and cost.
- Participants that live in the city have a shorter time to diagnosis globally as well as less travel time for office and surgical visits, giving them a streamlined experience. Participants in the US and Australia had higher travel costs.
- This provides further proof that wider distribution of otolaryngologists are needed.

Access to Care	Australia (n=64)	Canada (n=101)	USA (n=569)	UK (n=99)	P-value
Time to diagnosis within 1 year symptom onset	29.7%	31.7%	37.4%	29.3%	0.245
Time to treatment within one month of dx	59.4%	**35.0%**	48.3%	45.9%	0.018
Travel for surgical care 3+ times	**57.8%**	34.0%	30.9%	41.4%	<0.001
Total # airway stenosis procedure 6+	**62.5%**	**29.0%**	42.2%	46.5%	<0.001
Travel cost 500+	18.8%	**7.0%**	24.7%	**4.1%**	<0.001

Table 2: Access to care by country.

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