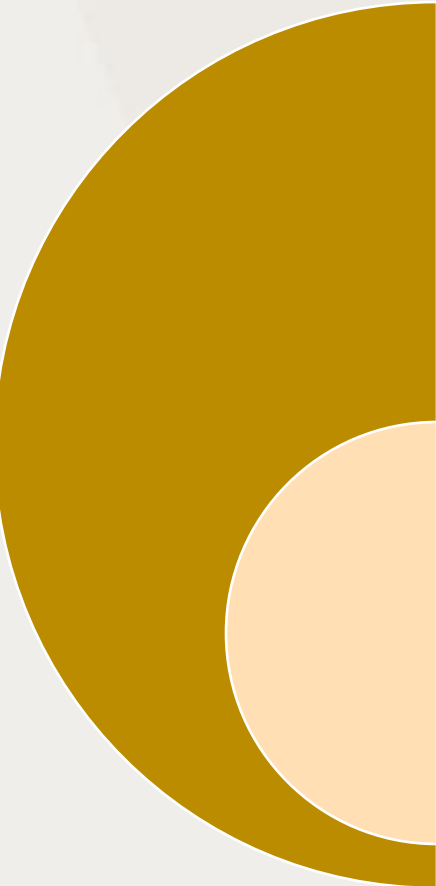


Patient-Reported Barriers to Diagnosis and Treatment in Non- Flaccid Facial Paralysis

Kelly Vittetoe, MD

VANDERBILT  UNIVERSITY
MEDICAL CENTER

Introduction



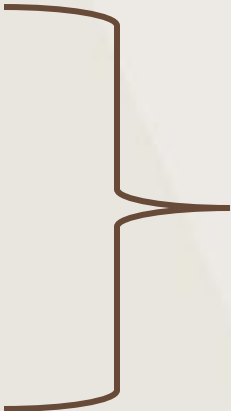
Non-flaccid facial paralysis (NFFP) is a common sequela of facial nerve injury, yet access to timely diagnosis and care remains a challenge.

Objective: characterize the NFFP patient experience regarding diagnosis, counseling, provider communication, and barriers to specialty facial nerve care.

Methods



Methods



SYNKINESIS ASSESSMENT QUESTIONNAIRE (SAQ)

Name: _____ Date: _____

Please answer the following questions regarding facial function, on a scale from 1-5, according to the following scale:

- 1 = seldom or not at all
- 2 = occasionally, or very mildly
- 3 = sometimes, or mildly
- 4 = most of the time, or moderately
- 5 = all the time, or severely

	Question	Score (1-5)
I	When I smile, my eye closes	
II	When I speak, my eye closes	
III	When I whistle or pucker my lips, my eye closes	
IV	When I smile, my neck tightens	
V	When I close my eyes, my face gets tight	
VI	When I close my eyes, the corner of my mouth moves	
VII	When I close my eyes, my neck tightens	
VIII	When I eat, my eye waters	
IX	When I move my face, my chin develops a dimpled area	
	Office use only Sum of Scores I-IX	
	Office use only SAQ Total Score	

Summate scores for questions 1-9 /45 x 100 = SAQ Total Score

Laryngoscope 117: 923-26, May 2007 Mehta et al.: Validation of the Synkinesis Assessment Questionnaire

Results

Facial Paralysis
History

NFFP severity
via the
Synkinesis
Assessment
Questionnaire
(SAQ).



Results



N=157
(60% response rate)

Age (median)	53 years	Etiology	
Gender		Bell's	84
Female	137	Lyme	5
Male	20	Post-procedural	9
Race		Ramsay Hunt	20
Asian	1	Trauma	12
Black or African American	20	Synkinesis Assessment	
White	125	Questionnaire Score	24 [9-44]
Ethnicity		(median [range])	
Hispanic	7		
Non-Hispanic	150		

Results

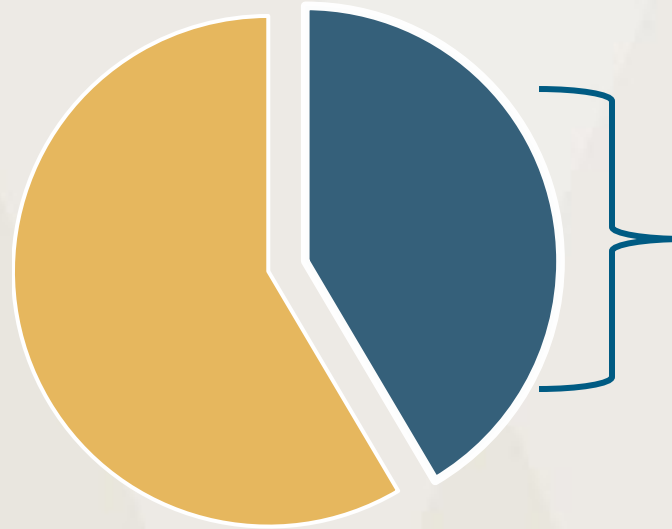
Access to Care

Provider
Communication



Results

On average, patients lived with NFFP for **4.25** years before receiving treatment.



Only 41.5% of patients recall being warned about the potential for NFFP during recovery.

50% of patients told there was “nothing else to do”



Patients told there was no treatment for NFFP had significantly higher SAQ scores (27 vs 22, $p=0.006$)

Results



19.5% first learned about NFFP treatment online



89.6% traveled over 2 hours for specialty care



92.6% of patients are willing to pursue long-term treatment



56.3% would pay out of pocket for chemodenervation therapy

Limitations & Future Directions

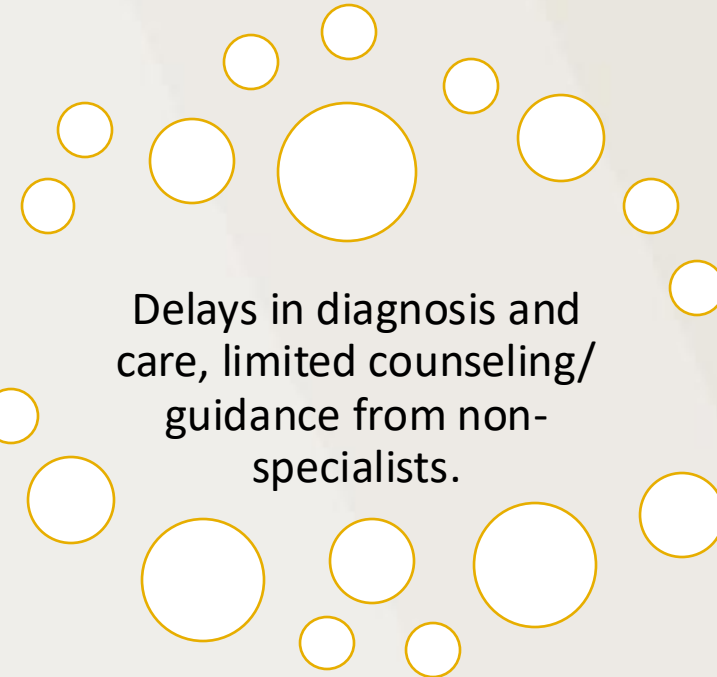
Limitations	Selection bias (single large institution in southeastern US)
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	Response bias
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Future Directions	Seek additional patient input on best counseling and referral practices
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	Implement survey results into outreach for non-facial nerve specialists
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Conclusion



Delays in diagnosis and care, limited counseling/guidance from non-specialists.



Patients are motivated to pursue treatment and report improvement once they reach specialized care.



Need for greater investment in outreach & awareness for non-flaccid facial paralysis



Alexander Barna, MPH

VANDERBILT  UNIVERSITY
MEDICAL CENTER