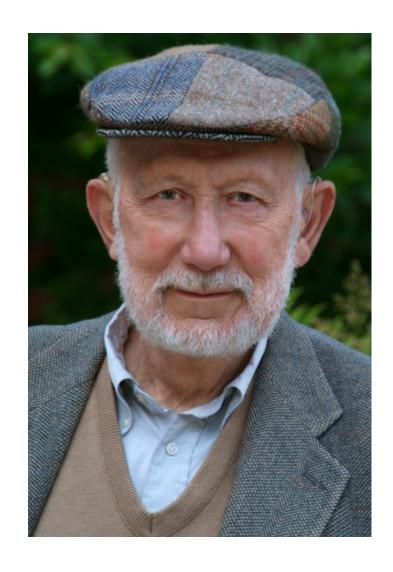
# My Ears are Tired! Subjective Reports of Fatigue in Adults and Children with Hearing Loss



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Pediatric Audiologist
Vanderbilt University Medical Center
Educational Audiology Association
February 22<sup>nd</sup>, 2018





"...I can attest to the **FATIGUE** caused by prolonged intensive listening in noise through hearing aids...so much **EFFORT** was being devoted to getting the signal that I missed part of the **MESSAGE**."

Mark Ross, Ph.D.
Pediatric Audiologist

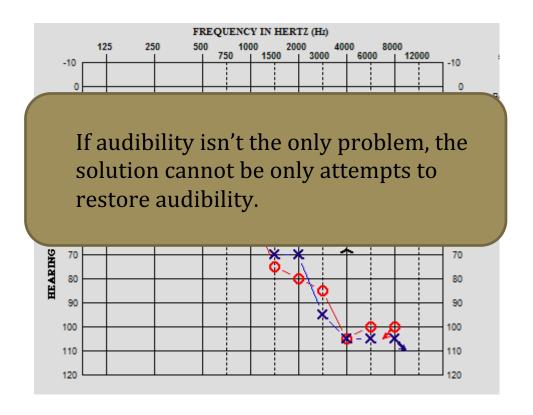


## Today's Goals

- Definitions
  - Fatigue, listening-related fatigue, listening effort
- Consequences of fatigue
- Subjective reports from adults and children with hearing loss
- Development of a fatigue scale for individuals with hearing loss



#### **Evaluation for Services**



Audibility isn't the problem—sounds are loud enough and they can understand speech BUT it is tiring and "too hard" to listen



# What is fatigue?

Lack of energy

Having no energy

#### Exhaustion

Lethargy

May be physical, mental, or emotional

Listless



WEARINESS OR EXHAUSTION FROM LABOR, EXERTION, OR STRESS

VANDERBILT UNIVERSITY

MEDICAL CENTER

**Tiredness** 

Difficult to describe

Lack of strength

Weariness

Worn out

## What is fatigue?

- Complex and multidimensional
- No universal definition
- Depends on the person describing and the context
- Can be considered a symptom or a consequence

"Fatigue is a lingering tiredness that is constant and limiting." --WebMD



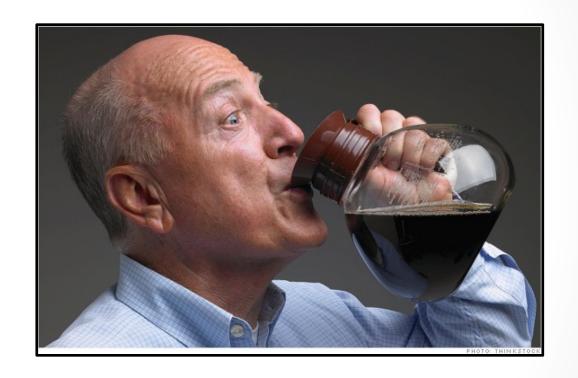


# Aren't we all fatigued?

Fatigue is one of the most common complaints reported in primary care settings

#### Cullen et al. (2002)

- 1428 participants in GP offices
- 25% reported fatigue
- 6.5% primary; 19% secondary
- 62% female





#### Acute Fatigue

- Protective physiological process in healthy individuals
  - Has a cause
  - Short in duration
  - Alleviated with intervention (rest, stress management)
  - Minimal impact



#### Hockey's Motivational Explanation of Fatigue

- Fatigue <u>protects</u> us
- Subjective experience of fatigue arises when there is conflict between current and alterative tasks.
- If a demanding task, over which the an individual has little control, is perceived as resulting in low success, the individual **experiences fatigue.** 
  - What will they do? Person may reduce effort toward the demanding task to avoid fatigue or prioritize a task that has less demands or is more rewarding.
  - Helps to determine if the effort applied toward a goal is worth the reward.



#### Severe Fatigue is the Problem!!

#### Recurrent, severe fatigue

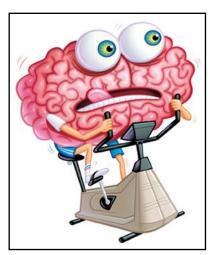
- <u>Uncommon</u> in healthy populations, but common in many chronic health conditions
  - Previous reports in individuals with cancer, HIV/AIDs, Parkinson's, Multiple Sclerosis
  - Very little work looking at fatigue and hearing loss, especially for children
  - Persists over time
  - Not relieved by common strategies
  - Significant negative effects on quality of life





- **Physical fatigue:** reduced ability or desire to perform a physical task
- Cognitive fatigue: reduced ability or desire to perform a mental/cognitive task
- **Emotional fatigue:** reduced ability or desire to perform a physical or mental task as the result of emotional or psychological demands









## What are "symptoms" of fatigue?

- Chronic tiredness or sleepiness
- Headache
- Dizziness
- Sore or aching muscles
- Muscle weakness
- Slowed reflexes and responses
- Impaired decision-making and judgement
- Moodiness, such as irritability
- Short-term memory problems
- Poor concentration
- Low motivation

**PHYSICAL** 

**COGNITIVE** 



#### Negative Consequences of Fatigue

- Adults with chronic conditions:
  - Loss of motivation
  - Difficulty concentrating
  - Loneliness
  - Irritability
  - Strong associations between fatigue and depression
  - Difficulties performing daily activities (socializing with friends and taking care of family)
  - Complex cognitive processing abilities, such as attention, processing speed, memory and decision making are negatively affected



#### Negative Consequences of Fatigue

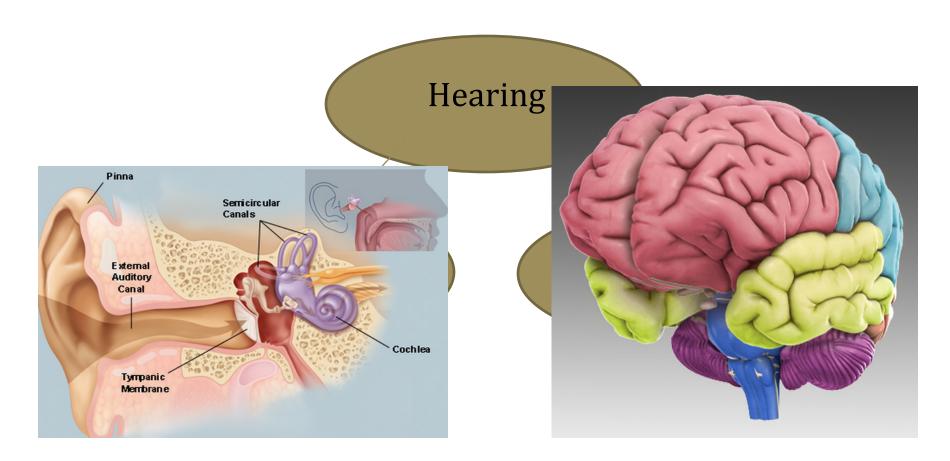


#### Children with chronic conditions:

- Difficulties with concentration and memory
- Inattention
- High distractibility
- Poorer school achievement
- Higher absenteeism
- Social effects



# What is listening?



## Effortful Listening

- For those with <u>hearing loss</u>
- Those with <u>declines in auditory processing</u> or cognitive processing (e.g., older adults)
- Any pers

   environr
   "In the long-term, if listening in everyday activities frequently demands more effort than listeners are able or willing to expend, they may develop chronic stress and withdraw from social interaction, with
- When in problem problem sounds of interest
- If a listener is unwilling or unable to maintain high levels of listening effort,
   fatigue may be experienced, or they may quit to avoid fatigue.



lre

#### Does effortful listening affect CHL?

"Effortfulness Hypothesis"











#### Framework for Understanding

Effortful Lictoning

Motivation performant

High effor

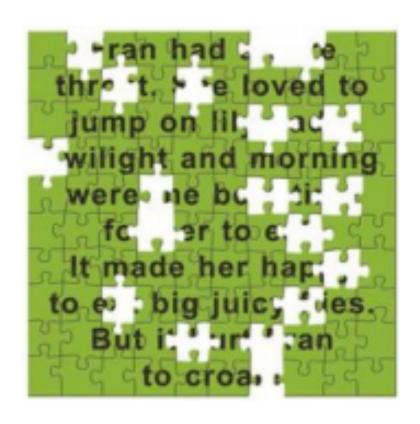
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Maintaining ef difficult or not



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Fran had a sore throat. She loved to jump on lily pads and twilight and morning were the best times for her to eat. It made her happy to get big juicy flies. But it hurt Fran to croak.

#### Factors Impacting Feelings of Fatigue

- Task specific factors
- Subject-specific factors
  - **time** on task
  - mental workload
  - mental **effort** allocated to the task
  - task importance
  - motivation
- These factors can impact how quickly (if at all) fatigue will develop.



#### Big Picture for our Students with HL

- How can audiologists better understand and find ways to counteract the factors underlying why listeners may decide to quit participating in activities because it takes too much effort to listen?
- How can audiologists help listeners to strategically employ their available cognitive capacity in situations when it is hard to listen?
- How can audiologists prevent listeners from avoiding situations and withdrawing from social participation because it is too hard to listen?



#### Measuring Fatigue

- Subjective Fatigue: Feelings
  - Describing fatigue as a feeling of weariness, tiredness, lack of energy, decreased motivation
  - Measured with questionnaires, rating scales
- Behavioral Fatigue: Performance Decline
  - Decrements in physical or cognitive performance as the result of a taxing task
- Physiological: Physical Changes
  - Changes in the body that can be used as an indirect marker of subjective and behavioral fatigue



# Physiologic Measures of Fatigue in CHL

Physiologic markers of stress can be reliably measured in children with hearing loss.

 Cortisol patterns in children with hearing loss are not "typical" and suggest increased stress.

Fatigue due to effortful listening can be induced in the laboratory and its effect on cognitive processing can be measured using auditory-evoked ERP.

• Children with and without hearing loss show reductions in cognitive processing secondary to speech-processing related fatigue.

Listening and Learning Lab Website: https://my.vanderbilt.edu/listeninglearninglab/

## Measuring Fatigue

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#### LISTENING FATIGUE

"I went to a great conference today. It was riveting and I was hooked on pretty much every word. And then I got home and collapsed on the sofa. I've had to turn my ears off to rest in silence and my eyes are burning. ..the impact of deafness doesn't just manifest itself in communication. It's about the energy involved in lipreading and being attentive all day long.



When I was younger, I was a little embarrassed to be so tired all the time. I would force myself to go out and be busy and out there when really al I wanted to do was crawl under the sofa and nap for a hundred years. Nobody ever really told me that being tired was "okay'.

an invariably random question.

It's like doing **jigsaws**, **Sudoku**, **and Scrabble** all at the same time."

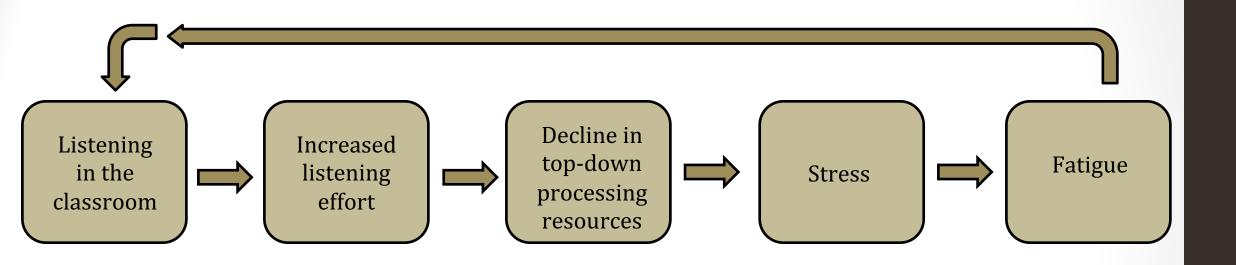




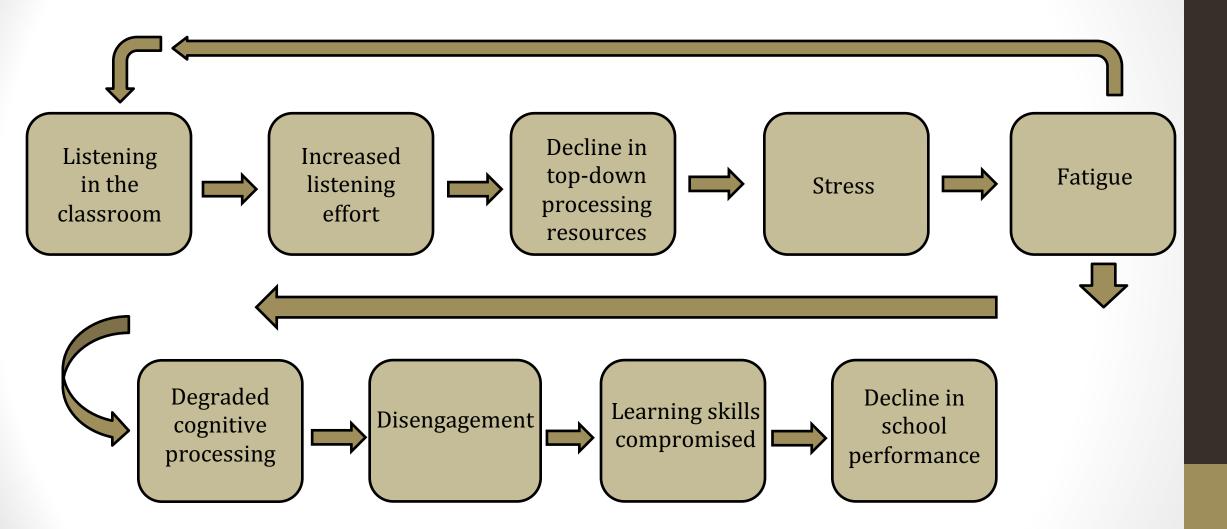
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6			1	9	5				
	9	8					6		
8				6				3	
8 4 7			8		3			1 6	
7				2				6	
	6					2	8		
			4	1	9			5 9	
				8			7	9	
						-			



#### What contributes to listening-related fatigue?



## Negative Consequences of Fatigue



#### Factors Influencing Subjective Fatigue in CHL

#### • Age

• typically developing older children/adolescents general report greater fatigue than younger children

#### Degree of HL

- more hearing loss = more difficulties communicating = more fatigue?
- not the case for adults
  - Hornsby and Kipp, 2016 and Alhanbali et al., 2017

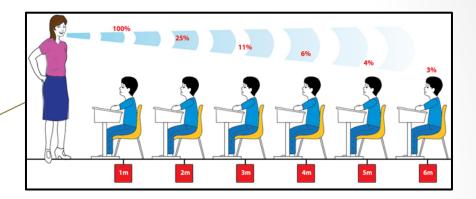
#### Other child-specific variables

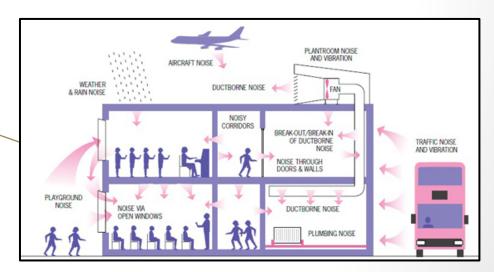
- language abilities
- immigrant status, family structure, parent education, speech perception, literacy level (Gordijn et al., 2011, Werfel 2016)
- SES



## Listening in the Classroom









#### Noise! Noise! Noise!

- Research has shown classrooms to be noisy and for noise to have a detrimental effect on learning for all children.
- Signal-to-noise ratios (-7 dB to + 5 dB)
- CNHL: +15 dB SNR; CHL: +20 dB SNR
- Noise affects children more than adults
- Those with hearing loss
- Language difficulties
- Learning difficulties
- Those not being taught in their first language (ESL/ELL)

## Multitasking: The Classroom Is Busy

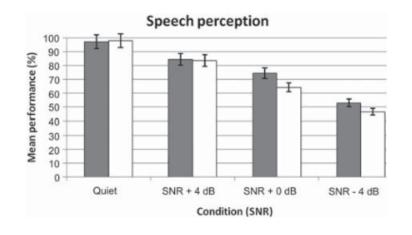
- Dual-task paradigm
  - Performance on a single task
  - Performance on the same task when performed in combination with a secondary task
  - Primary task demanding? Requires more effort?
    - Performance on the second task (or both) will plummet.

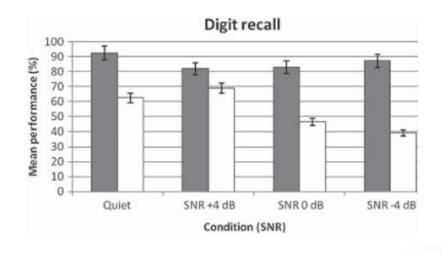
- Listen and take notes
- Listen to directions and look up something on the computer
- Listen to class discussion and think of their own answer
- Discuss information with a classmate and write down answers

#### Listening Effort in Noise

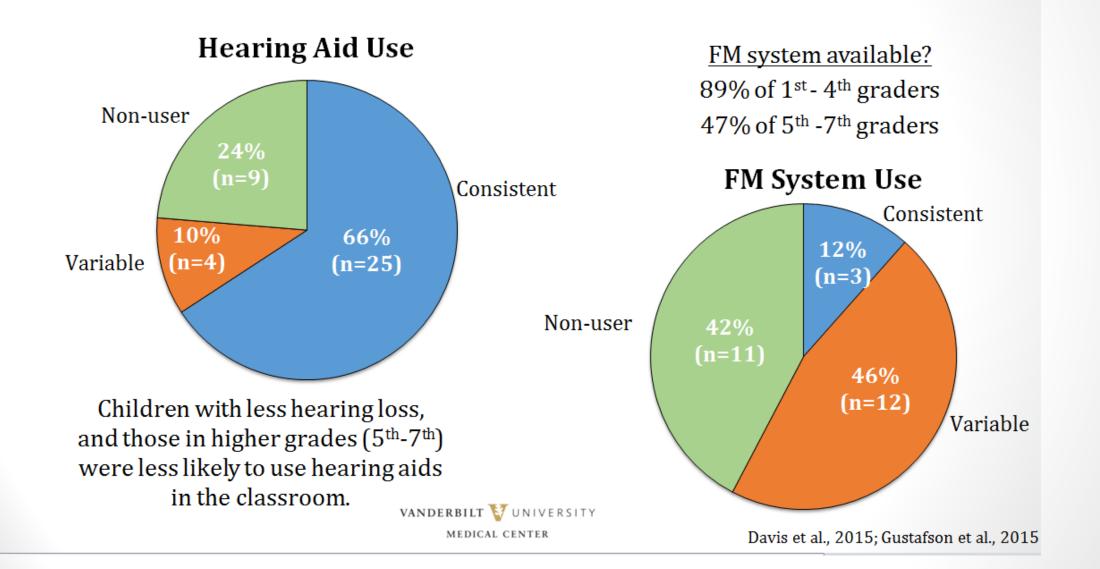
- 31 children without hearing loss
- Primary task
  - Repeat monosyllabic words in +4, 0 and -4 dB SNR
- Secondary task
  - Rehearsing digits and reciting them back later

In order to keep repeating words, greater effort was needed. This came at the expense of poorer scores on the digit recall task.





#### Device Use in the Classroom



"When you are hard of hearing you struggle to hear; when you struggle to hear you get tired; when you get tired you get frustrated; when you get frustrated you get bored; when you get bored you quit." (Pichora-Fuller, 2003)



#### Subjective Reports of Fatigue in AHL

- Metal Plant Worker Interviews (Hetu et al.)
  - Hearing loss difficulties (understanding speech, reduced awareness of environmental sounds)
  - Compensation strategies (increased concentration, attention and effort at work)
  - Result
    - Increased stress and fatigue
    - "too tired for normal activities"
- Working Adults (Kramer et al.)
  - Work duties require more effort in hearing than for those without hearing loss in similar jobs
  - Those with HL were four times more likely to take sick leave for "mental distress"
    - Fatigue, strain, or burn out
- Working Adults (Nachtegall et al.)
  - If person had more difficulties in the workplace related to hearing, they self-perceived their work productivity was more negatively affected
  - More likely to report being less able to complete all required work duties
  - Needed more time to fully recover from work-related stress (took more sick leave of >5 days)



#### Subjective Measures of Fatigue

- Subjective measures include surveys, rating scales, and questionnaires that ask about mood or feelings.
  - Uni-dimensional: assess "general" fatigue (composite score)
  - Multi-dimensional: assess various dimensions fatigue

Several scales exist to measure multiple domains of fatigue, but none are validated measures specific for hearing loss





#### General Measures of Fatigue

- Numerous measures looking at fatigue and energy in various clinical populations
  - The Fatigue Questionnaire
  - Multidimensional Assessment of Fatigue Scale
  - Short Form-36 Vitality Subscale
  - Fatigue Assessment Scale
  - Chalder Fatigue Scale
  - POMS

- No gold standard measure of subjective fatigue
- None specifically designed for AHL or CHL—stay tuned!

	NEVER	SOMETIMES	REGULARLY	OFTEN	ALWAYS
I am bothered by fatigue					
I get tired very quickly					



## Fatigue and Vigor in AHL

- Profile of Mood States (POMS; McNair et al., 1971)
  - Assesses multiple mood states
  - Respond based on the past week
  - Normative data available

	Not at all	A little	Moderately	Quite a bit	Extremely
Worn out					
On-edge					

- Multidimensional Fatigue Symptom Inventory-Short Form (MFSI-SF; Stein et al. 2004)
  - Assesses four domains of fatigue (general, physical, emotional, and mental)
  - Also assesses vigor

	Not at all	A little	Moderately	Quite a bit	Extremely
I feel refreshed					
My head feels heavy					

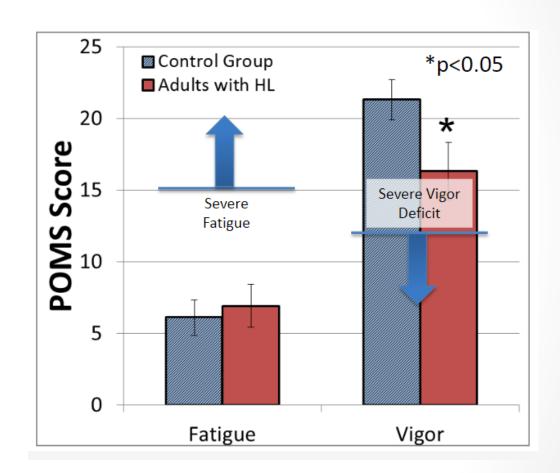


#### Fatigue and Vigor in AHL

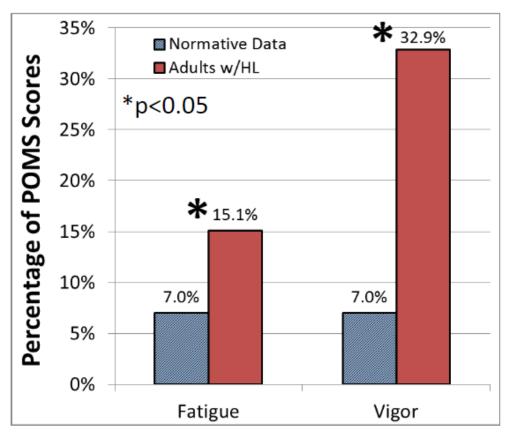
Adults age 55-94
 reported
 -similar fatigue
 -significantly less vigor

N = 116

POMS: Profile of Mood States (McNair et al., 1971)



#### Fatigue and Vigor in AHL



Hornsby, B. & Kipp, A. (2016)

- AHL were more than twice as likely to report severe fatigue
- AHL were more than four times as likely to report severe problems with vigor
- Severe = >1.5 st. dev from mean



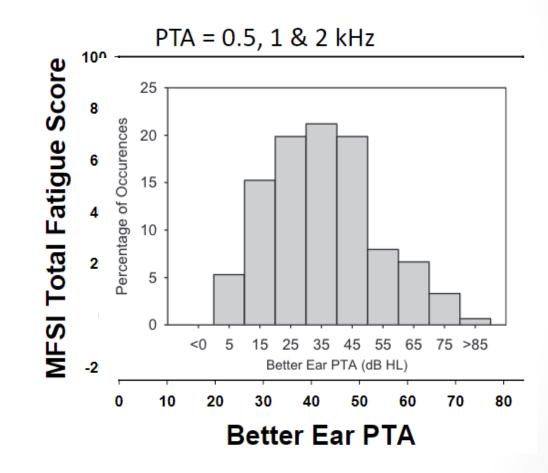
# Fatigue and Vigor in AHL Related to Degree of HL?

- No association
   between degree of
   hearing loss and any
   fatigue/vigor
   domains
- POMS and MFSI-SF

N = 143

Age range: 22-94

PTAs: 5-80 dB (median 33 dB)





#### Fatigue and Effort Reports in AHL

- Fatigue Assessment Scale (generic fatigue scale)
- Effort Assessment Scale (three effort-related questions from the SSQ)
- No correlation between selfreported fatigue and hearing thresholds

#### TABLE 2. FAS questions

- 1. I am bothered by fatigue
- I get tired very quickly
- I do not do much during the day
- 4. I have enough energy for everyday life
- 5. Physically, I feel exhausted
- 6. I have problems starting things
- I have problems thinking clearly
- 8. I have no desire to do anything
- 9. Mentally, I feel exhausted
- 10. When I am doing something, I can concentrate quite well

FAS, fatigue assessment scale.

#### TABLE 3. EAS questions

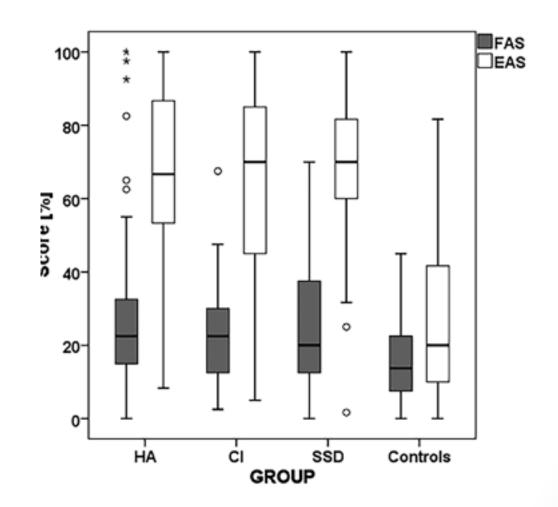
- 1. Do you have to put in a lot of effort to hear what is being said in conversation with others?
- 2. How much do you have to concentrate when listening to someone?
- 3. How easily can you ignore other sounds when trying to listen to something?
- 4. Do you have to put in a lot of effort to follow discussion in a class, a meeting, or a lecture?
- 5. Do you have to put in a lot of effort to follow the conversation in a noisy environment (e.g., in a restaurant, at family gatherings)?
- 6. Do you have to put in a lot of effort to listen on the telephone?

EAS, effort assessment scale.



#### AHL Self-Report of Fatigue

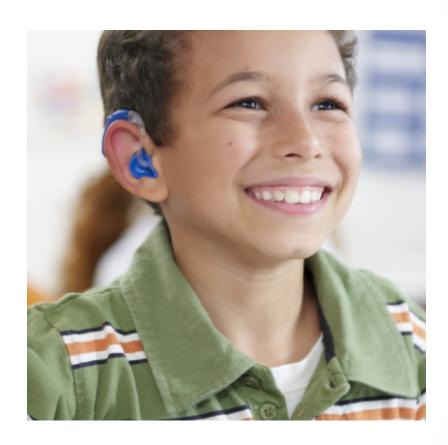
- Extreme listening effort
  - 46% HA
  - 54% CI
  - 52% SSD
- No difference in reports between HA, CI, and SSD
- AHL reported more listening effort and fatigue compared to controls.
- Extreme fatigue
  - 22% HA
  - 10% CI
  - 22% SSD





#### Vanderbilt Fatigue Study

- Participants
  - 60 CHL, 43 CNHL and one parent of each child
  - 6.0 and 12.9 years of age
  - no additional diagnoses (learning disabilities, autism spectrum disorder, diabetes, etc)
  - all English-speaking
  - all but one child fit with HA, no CI
  - mild to severe bilateral HL





### Subjective Fatigue in CHL

#### PedsQL Multidimensional Fatigue Scale

In the past ONE month, how much of a problem has this been for you...

Subscale	Item	Never	Almost Never	Sometimes	Often	Almost Always
General	I feel tired	0	1	2	3	4
Sleep/Rest	I sleep a lot	0	1	2	3	4
Cognitive	It is hard for me to keep my attention on things	0	1	2	3	4

SCORES: General, Sleep/Rest, Cognitive and Overall

Varni et al., 2002



### Subjective Fatigue in CHL

#### PedsQL Multidimensional Fatigue Scale

In the past few weeks, how much of a problem has this been for you...

Subscale	Item	Not at all	Sometimes	A lot
General	Do you feel tired?	0	2	4
Sleep/Rest	Do you sleep a lot?	0	2	4
Cognitive	Is it hard for you to keep your attention on things?	0	2	4

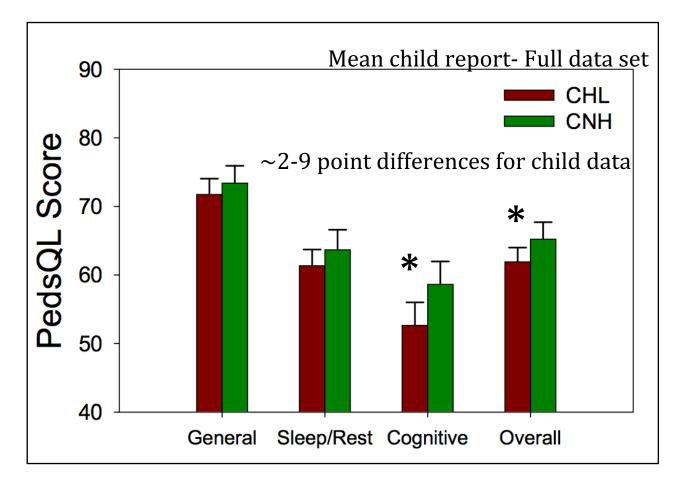
SCORES: General, Sleep/Rest, Cognitive and Overall

Varni et al., 2002



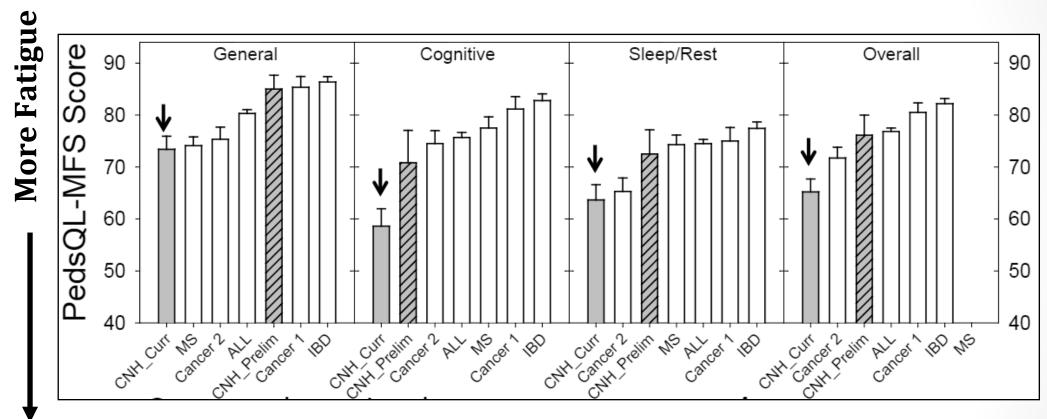
### Subjective Fatigue in CHL

# **More Fatigue**



 Current data shows main effect of HL, but small effect. Why?

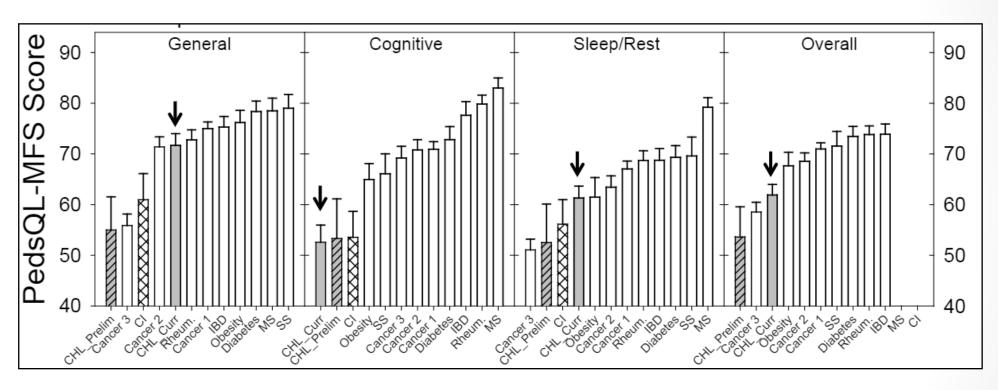
#### CNH and CHL PedsQL Reports



CNH reported higher fatigue compared to other control groups.



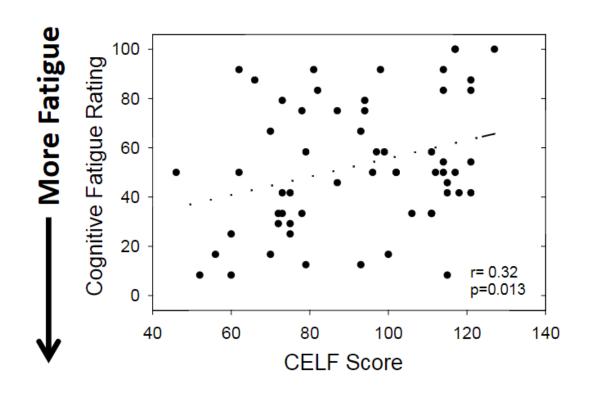
**More Fatigue** 



CHL reported more, or similar, fatigue across multiple domains when compared to other control groups AND children with other chronic conditions



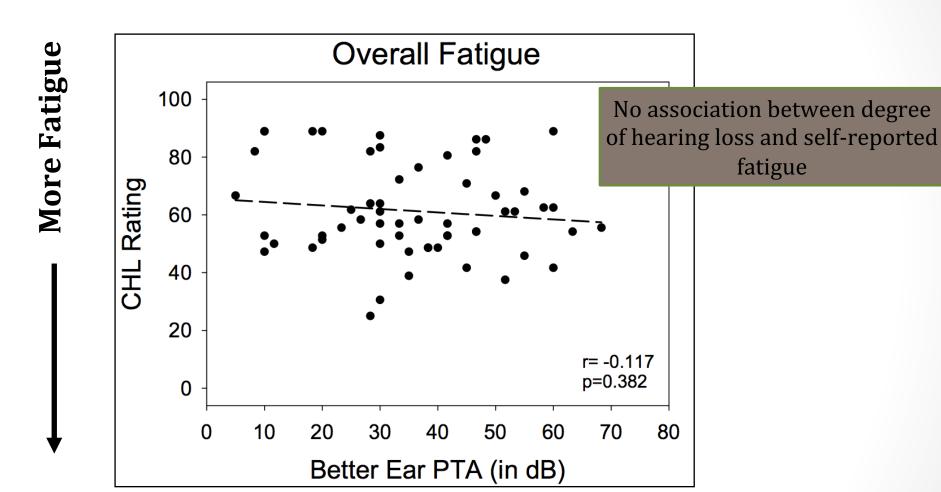
#### Peds QL and Standardized Scores



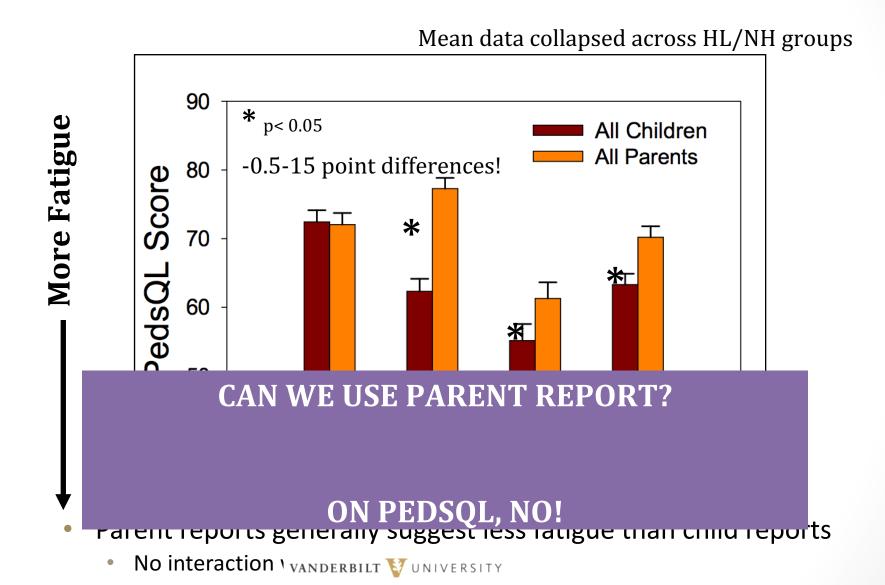
- Significant association with CELF (language) and PPVT (receptive vocabulary scores) and **COGNITIVE** fatigue.
- Similar, but weaker correlations for CELF and general fatigue
- And PPVT and Cognitive fatigue



#### More HL = More Fatigue?



#### Parent versus Child Fatigue Report



# Fatigue, Language Abilities, and Children with CI

- N = 19 children and parent groupings (9 girls)
- Grades 3 to 6 (mean age = 10.6)

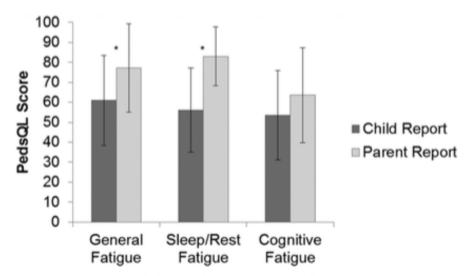
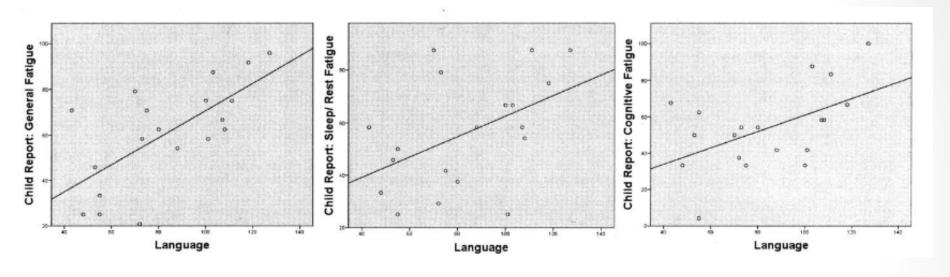
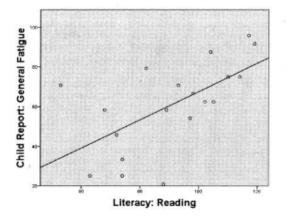


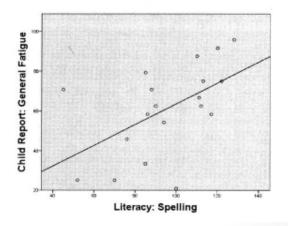
Fig. 1. Comparison of child and parent report of fatigue by category. Error bars indicate 1 standard deviation. Higher scores indicate lower fatigue.

# Children with CI & Fatigue Reports



- Language and literacy scores
  - TOWRE-2
  - CELF-5
  - TWS-5
- Speech perception (NU-6)





#### Self and Proxy Report

- In healthy populations, parents need <u>to underestimate</u> problems child is experiencing
- For children with chronic health conditions, parents tend to <u>overestimate</u> problems
- There are larger disagreements when responding to internal, subjective feelings (pain, sadness, fatigue) versus externalized behaviors (walking, aggression, running).



#### Need for Hearing Loss Specific Fatigue Scale

- No significant differences noted between CHL and CNH on overall scores for PedsQL MFS.
- Fatigue is a subjective experience
  - Inter-subject and inter-group variability



What was the PedsQL measuring? How do you quantify fatigue?



#### Listening-Related Fatigue Scales: Current Work

- Vanderbilt Fatigue Scale-AHL (Adults with Hearing Loss)
- Vanderbilt Fatigue Scale-CHL (Children with Hearing Loss)
  - Pediatric Version
  - Parent/Caregiver Version
  - Teacher/Service Provider Version

**GOAL**: create and validate a measure of fatigue in individuals with hearing loss with specific listening-related questions.



#### Fatigue Scale Development Process

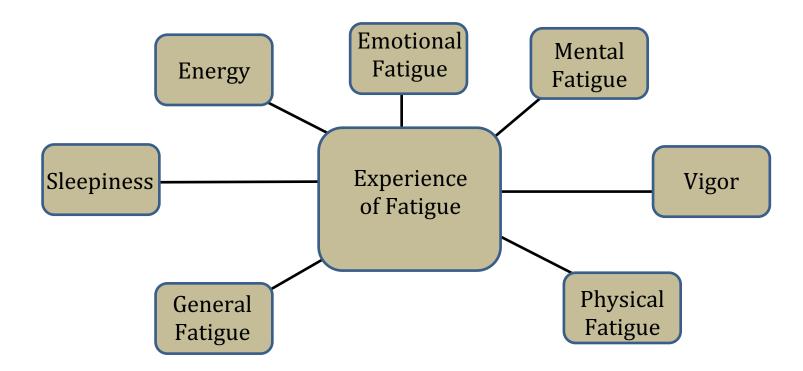
- Phase 1: Defining listening-related fatigue and issues
  - Literature Review: background theory and constructs
  - Focus Groups: individual experiences
- Phase 2: Item Development and Revisions
  - Focus group data review
  - Expert review
  - Cognitive interviews
    - AHL, CHL, parents, and teachers
- Phase 3: Initial Psychometric Evaluation







#### Dimensions of Subjective Fatigue





#### Focus Group Process

- Focus groups and individual interviews with parents, teachers, and children with hearing loss
- Transcribed and reviewed the focus group discussions
- Items written directly from quotes

#### SCHOOL SERVICE PROVIDER MODERATOR'S GUIDE

Does your student seem to exert more energy to participate in certain activities?

What behaviors/emotions do you note in your student that alert you that he/she may be fatigued?

What coping strategies do you/the student use to recover from fatigue?

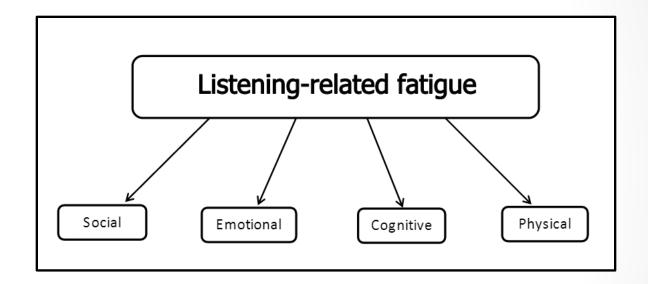
Is fatigue from listening a problem for your student?





#### Your thoughts!

- Do you note listeningrelated fatigue in your students with hearing loss?
  - If so, what behaviors are observed?





### Phase 1: Defining the Issues-CHL

"Fatigue sounds like phantom, so maybe a squid?"









#### Conceptualization of Fatigue

**CHILDREN** 

FATIGUE = PHYSICAL

**PARENTS** 

FATIGUE = PHYSICAL + COGNITIVE

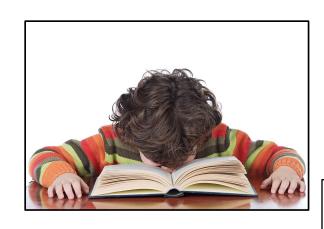
## Phase 1: Defining the Issues-CHL

Listening-Related Fatigue "...for me I feel more focused when there's a one-on-one conversation and I feel kind of more talkative when there's just a one on one conversation. But **when there's a lot of friends...that makes me more tired**. Trying to focus on conversations and then trying to think about it and process it makes me a little tired."

-teen with bilateral cochlear implants

"In the cafeteria, they try to listen but that's their starting time of "fading down" so they just kind of take it a break time. I've had my one student, she sometimes just takes her implant off and even turns the volume down on her hearing aid and that's like her time to just sit and not have to listen."

-Deaf education teacher



"Yeah, you wanna give up. You just don't want to try anymore because you know you won't actually get what they're trying to say or sometimes you think it's just you. Maybe I need to try a little harder to listen but when you do try, you put all of your focus on what they're trying to say and you still can't hear them."

-teen with bilateral hearing aids



"Yesterday we took a field trip - explored a museum. The gentleman was great, but he spoke so fast—she was still missing stuff. In a very hectic environment, and if things go really, really quick for her, I can tell her it's a lot for her. She has to make an effort, and it wears her out."

-Parent of a 10-year old with bilateral hearing loss

#### Phase 2: Item Development



It is a lot of work for me to focus on others when they are talking.

It takes a lot of work to focus on listening.

I have to try hard to focus on what others are saying.

I get tired trying to keep up with group conversations.

I have to focus hard to understand group conversations.

I get tired trying to process and understand in a group conversation.

I want to give up when I have difficulty understanding what someone is saying.

I have to focus all of my energy on listening to understand what others are saying.



#### Vanderbilt Fatigue Scale Sample Questions

Sometimes Often **Almost Always TEACHER** Rarely Never My student stops participating in difficult listening situations. My student will give up trying to listen when it is difficult to hear. Rarely **Almost Always** Sometimes Often **PARENT** Never Trying to keep up in a conversation exhausts my child. My child gets frustrated when it is difficult to hear. **Almost Always** Often Rarely Sometimes Never CHILD

- I use a lot of energy trying to understand what others are saying.
- I get annoyed when I have to listen in a noisy place.



### Your thoughts!

- If your student with hearing loss shows signs of fatigue, what does he/she do to cope?
- What are strategies/modifications/goals the classroom teacher, SLP, deaf educator, educational audiologist, etc. can use to help the student with hearing loss dealing with fatigue in the educational setting?





#### Suggestions for IEPs

#### ACCOMMODATIONS/MODIFICATIONS

Provide notes ahead of class time to reduce need to multi-task during lecture/discussion

Provide a space and/or scheduled break time for listening/quiet breaks

Consider schedule of day and timing of auditory tasks, including therapies or other pull-out sessions

Consistent personal amplification and FM system use

Preferential seating to potentially reduce listening effort

Visual information available in the classroom

Classroom acoustic modifications

**ADDITIONAL SUGGESTIONS?** 



#### Take Home Points about Fatigue

- May be a problem for <u>some</u> children with hearing loss
  - Perhaps those with lower language abilities?
- Child may not have the language to explain fatigue
- Behaviors to look for:
  - Tiredness
  - Inattentiveness
  - Mood changes
  - Changes in play activity (decrease in stamina)







#### Next Steps: Phase 2

The Vanderbilt Fatigue Scale – <u>Children</u> with Hearing Loss is in Phase 2. This version has parent, school service provider, and child components.

If you're interested in helping to distribute this scale to children with hearing loss, parents, and school professionals during the validation stage, please email hilary.davis@vanderbilt.edu



#### School Service Provider Proxy

- Examining the differences between student's self-perceived fatigue and that noted by the teacher.
- Teacher is with the student for the majority of the day and is asking the child to complete complex listening tasks.
- Child may not be aware or have the language to discuss this topic.





#### Questions? Comments?







Visit the Listening and Learning Lab's website at <a href="http://my.vanderbilt.edu/listeninglearninglab">http://my.vanderbilt.edu/listeninglearninglab</a>

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