Dhruv Jain, Audrey Desjardins, Leah Findlater, Jon Froehlich University of Washington, Seattle

Hard of hearing

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Hard of hearing

Before starting my PhD, I backpacked 21 countries.

This talk is about my experiences during the backpack tour and also occasional travel as a PhD student.

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But why are we examining my travel?

During travel, an individual interacts with different people, culture and environment.

For people with disabilities, examining travel experiences could reveal how **disability** affects **communication** and **navigation** in diverse contexts. We critically examined my travel to investigate **how deafness shapes my experience** in diverse contexts.

Prior accessible tourism studies have largely **investigated experiences** of people with visible disabilities (*e.g.*, vision or physical impairment).

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Interviews about DHH people's experiences in international conference (Friedner, 2014)

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Online survey of Deaf backpackers (Zajadacz, 2013)

### We offer a longitudinal exploration of a hard of hearing traveler's experiences from a highly personal view using

# We offer a longitudinal exploration of a hard of hearing traveler's experiences from a highly personal view using autoethnography

## **AUTO-ETHNOGRAPHY**

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A qualitative research method where **researcher adopts the role of participant** and uses "self-reflection to explore their personal experience and connect their story to wider **cultural**, **political**, and **social** meanings." (Ellis, 2010)

# **AUTO-ETHNOGRAPHY**

A qualitative research method where **researcher adopts the role of participant** and uses "self-reflection to explore their personal experience and connect their story to wider **cultural**, **political**, and **social** meanings." (Ellis, 2010)

This method examines the **lived experience from within**, generating **rich personal insights** rarely available through other research methods.

# Autoethnography

A qualitative research method where **researcher adopts the role of participant** and uses "self-refee" But why did we choose to use **autoethnography?** wider **cultural, political, and social** meanings." (Elis, 2010)

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- Disability is **highly personal**; every person with disability is different.
- We wanted to **amplify my first-person voice** as a hard of hearing researcher in various contexts.
- Our hope is to **diversify the array of methods** used in the ASSETS community.





• Severe to profound hearing loss



- Severe to profound hearing loss
- Wears hearing aids in both ears



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- Wears hearing aids in both ears
- Relies on **facial cues to communicate**, thus communication is difficult if speaker's face is not visible



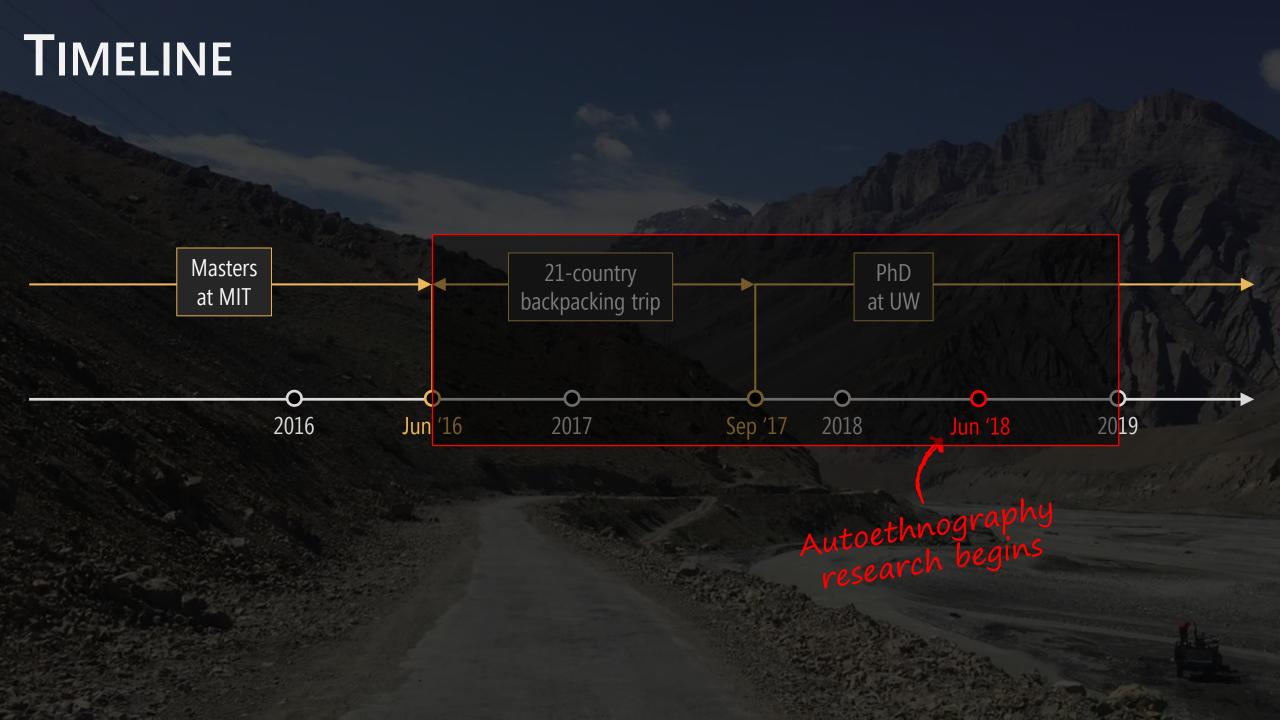
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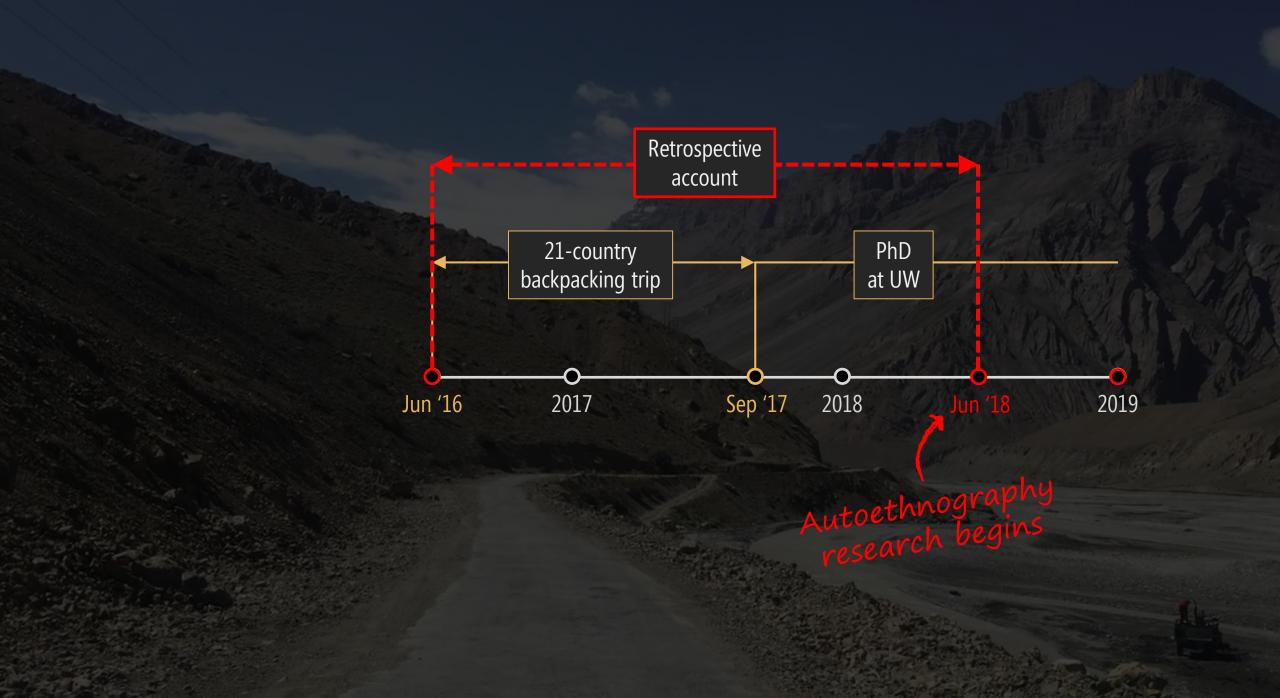
- Severe to profound hearing loss
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- Relies on **facial cues to communicate**, thus communication is difficult if speaker's face is not visible
- Beginner level signer
- Uses real-time **captioning** in lectures and group meetings

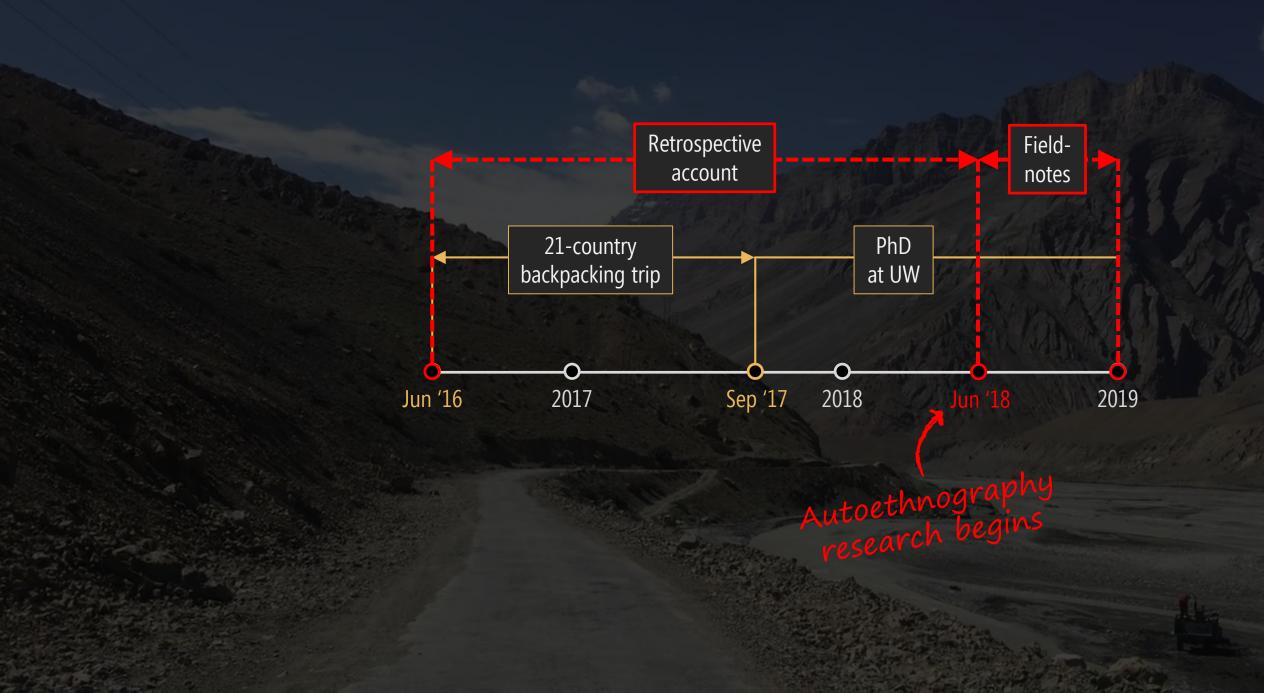












Retrospective account Fieldnotes

#### (22 events, 7312 words) Retrospective account

#### (25 events, 7876 words) Fieldnotes

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Thematic analysis

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Thematic analysis

#### **Emergent Themes**

Our findings detail my experiences in varying geographies, societies, cultures and also presents my relationship to technologies.

#### In today's talk, I will discuss three themes.

# 1. Environmental complexities

# Environmental complexities Cultural tensions

Environmental complexities
Cultural tensions
Relationship to assistive technologies

# 1. Environmental complexities

### 1. Environmental complexities

Environmental complexities included **no line of sight**, **background noise**, and **high frequency sounds**.

# 1. Environmental complexities

- No line of sight
- Background noise

## 1. Environmental complexities

#### • No line of sight

A major issue during travel was **no direct line of sight to the speaker's faces** which made communication difficult. "I was *sitting at the back of a shared vehicle* during the journey in the deep mountains.

- Spiti Valley, India, Jun '16

"I was *sitting at the back of a shared vehicle* during the journey in the deep mountains. Since the journey was slow, people were chatting in the car and *I wasn't able to lipread*. It was frustrating... The journey was supposed to be around 6 hours but multiple road blockages, landslides and stoppages in the Himalayas increased the total time to more than 12 hrs.

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"I was sitting at the back of a shared vehicle during the journey in the deep mountains. Since the journey was slow, people were chatting in the car and I wasn't able to lipread. It was frustrating... The journey was supposed to be around 6 hours but multiple road blockages, landslides and stoppages in the Himalayas increased the total time to more than 12 hrs. I felt spatially lost, like having no knowledge of where I am and how much time it would take to arrive at the destination. It felt disorientating and suffocating. I felt trapped."

- Spiti Valley, India, Jun '16

# 1. Environmental complexities

- No line of sight
- Background noise

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- No line of sight
- Background noise

Areas with background noise (which are frequent during travel) were **very hard for me to communicate in.** 

"[When I was on a plane] it was terribly difficult to communicate drinks or food choice due to background noise.

- Flight from Milan to Sharm el sheikh, Mar'17

"[When I was on a plane] it was terribly difficult to communicate drinks or food choice due to background noise. I couldn't hear the attendant very well. [...] And since I can't hear my own voice well, I did not know how loud I was speaking. Thus, the crew also had a hard time understanding me.

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"[When I was on a plane] it was terribly difficult to communicate drinks or food choice due to background noise. I couldn't hear the attendant very well. [...] And since I can't hear my own voice well, I did not know how loud I was speaking. Thus, the crew also had a hard time understanding me. Somehow, through gestures and repetitions, we made it work but I skipped one meal and compromised with cold water instead of the hot water (which I wanted)."

- Flight from Milan to Sharm el sheikh, Mar'17

# Environmental complexities Cultural tensions

# 1. Environmental complexities

# 2. Cultural tensions

I faced tensions due to varying cultural perceptions of disability across regions.

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- Leh, India, Aug '17

In India, people were extremely sympathetic of my disability:

"[On finding that I am hard of hearing], the [gate agent at the airport] shook my hand and escorted me in person to the plane... I was really embarrassed to be given special treatment in front of other people who looked amused."

- Leh, India, Aug '17

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#### While in the US, the airport agent was overly polite, which was also an issue:

"[After a long while of waiting], I heard what seemed like my name being called multiple times for boarding. [Feeling very guilty,] I asked the airport staff member if they were really calling out my name. She appeared unhappy (not knowing that I am Deaf) but said: 'yes sir, but it's okay!" I figured social niceties conflict with accessibility here. If she had asked the cause of the delay, I would have clarified—my deafness."

- Boston, Sep '17

# Environmental complexities Cultural tensions Relationship to assistive technologies

- 1. Environmental complexities
- 2. Cultural tensions
- 3. Relationship to assistive technologies

I will detail two examples: **hearings aids**, and **a transcription service** (InnoCaption).





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"I became obsessed with *cleaning my aids regularly, storing them safely,* and *keeping enough batteries*. As an example, while sleeping in shared dorms, I kept the aids under my pillow and woke up multiple times at night to check if they did not drop to the floor or got lost.



During travel, I observed that my relationship to hearing aids changed because their **loss or damage would have caused increased discomfort.** 

"I became obsessed with *cleaning my aids regularly, storing them safely,* and *keeping enough batteries*. As an example, while sleeping in shared dorms, I kept the aids under my pillow and woke up multiple times at night to check if they did not drop to the floor or got lost. Similarly, I *panicked when my aids became wet* with rain or sweat, and stayed up the night with a hair dryer to dry them." To place calls, I use a remote transcription service, called *InnoCaption*, which is **only licensed to be used in the US**.

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Federal law prohibits anyone but registered users with hearing loss from using this service.

Thus, during travel, making calls were exteremely difficult.

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Thus, during travel, making calls were exteremely difficult.

For example, once I lost a credit card in Mexico. Because I usually traveled alone, *it took me two weeks to find someone* who I can trust to make a phone call for cancelling and ordering a new card!

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#### InnoCaption

In summary, being away from the support network at home meant that I had to be more self-reliant, which changed my relationship with the ATs. usually traveled alone, *it took me two weeks to find someone* who I can trust to make a phone call to my bank in the US for cancelling my card!

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# Reflection

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**Reflections from our travel findings** 

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Methodological guidelines for performing autoethnography

#### Autoethnography revealed deep personal experiences

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- My travel experiences highlighted personal ways of interaction with different cultures, environments and technology.
- Given that disability is highly personal, these deeply situated insights are difficult to obtain through other research methods.
- Future work should further investigate experiences of other disabled people in diverse contexts.

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- Future designers should consider: How might we design personalized assistive technologies that adapt to different settings?
- To examine this question, we investigated two highly personalized technology explorations to aid communication during my travel *in-situ*: a speech to text translating app, and a customized quote speaking app.
- Results are in the paper.

### METHODOLOGICAL GUIDELINES FOR DISABLED **Researchers to Perform Autoethnography**

### Privacy vs. Transparency:

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- **Disabled researchers may feel compelled to hide facts** that could negatively affect them.
- In fact, some of my negative experiences are during travel with my family members, which were very hard to talk about.
- While hiding intimate facts may be necessary, deep and evocative insights only result when **intricacies are disclosed** and discussed.
- So, take the time to access what balance between disclosure and privacy makes you comfortable.

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• Graduate students performing autoethnography may be **intimidated to share** their personal experiences with advisors.

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- Graduate students performing autoethnography may be **intimidated to share** their personal experiences with advisors.
- Their advisers should **ensure a healthy, constructive environment** for personal expression.

### DISCUSS YOUR IDEAS WITH US...





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Jon Froehlich Professor, CSE jonf@cs.uw.edu

**Calling all researchers with disabilities!** Let's together contribute our rich personal accounts to reveal how diverse scenarios and contexts affect our disability.