Autoethnography of a Hard of Hearing Traveler

Dhruv Jain, Audrey Desjardins, Leah Findlater, Jon Froehlich
University of Washington, Seattle
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Before starting my PhD, I backpacked 21 countries.
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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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- Interviews about DHH people’s experiences in international conference (Friedner, 2014)
- 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)
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This method examines the lived experience from within, generating rich personal insights rarely available through other research methods.
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)

**Autoethnography**

But why did we choose to use autoethnography?
Autoethnography For Accessibility
Autoethnography For Accessibility

- Disability is highly personal; every person with disability is different.
Autoethnography for Accessibility

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• We wanted to amplify my first-person voice as a hard of hearing researcher in various contexts.
Autoethnography for Accessibility

- 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.
THE AUTOETHNOGRAPHER

- Severe to profound hearing loss
The Autoethnographer

- Severe to profound hearing loss
- Wears **hearing aids** in both ears
Severe to profound hearing loss
Wears hearing aids in both ears
Relies on facial cues to communicate, thus communication is difficult if speaker’s face is not visible
The Autoethnographer

- Severe to profound hearing loss
- Wears **hearing aids** in both ears
- Relies on **facial cues to communicate**, thus communication is difficult if speaker’s face is not visible
- Beginner level signer
THE AUTOETHNOGRAPHER

• Severe to profound hearing loss
• Wears **hearing aids** in both ears
• 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
Masters at MIT 2016
Jun '16 21-country backpacking trip 2017
Sep '17 PhD at UW 2018
2019
TIMELINE

- **Masters at MIT**
  - 2016

- **21-country backpacking trip**
  - Jun '16
  - 2017

- **PhD at UW**
  - Sep '17
  - 2018
  - Jun '18
  - 2019

**Autoethnography research begins**
TIMELINE

- Masters at MIT
- 21-country backpacking trip
- PhD at UW

Autoethnography research begins
2016

Jun '16

21-country backpacking trip

2017

Jun '17

Sep '17

PhD at UW

2018

Jun '18

2019

Autoethnography research begins
Retrospective account

Field-notes
Retrospective account

Field notes
Thematic analysis

(22 events, 7312 words)

Retrospective account

(25 events, 7876 words)

Field notes

Thematic analysis
Thematic analysis

Emergent Themes

Retrospective account (22 events, 7312 words)

Field-notes (25 events, 7876 words)
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.
EMERGENT THEMES

1. **Environmental complexities**
EMERGENT THEMES

1. Environmental complexities
2. Cultural tensions
1. \textbf{Environmental} complexities
2. \textbf{Cultural} tensions
3. \textbf{Relationship} to assistive \textbf{technologies}
1. Environmental complexities
1. **Environmental complexities**

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

1. **Environmental** complexities
   - No line of sight
   - Background noise
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   - 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, landsides and stoppages in the Himalayas increased the total time to more than 12 hrs.

- 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. 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
EMERGENT THEMES

1. Environmental complexities
2. 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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- Boston, Sep ’17
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
Emergent Themes

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

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

I will detail two examples: hearings aids, and a transcription service (InnoCaption).
I depend heavily on my hearing aids to interact with the world.
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During travel, I observed that my relationship to hearing aids changed because their loss or damage would have caused increased discomfort.
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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.”
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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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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!
To place calls, I use a remote transcription service, called InnoCaption, which is only licensed to be used in the US. Thus, during travel, making calls were extremely difficult.

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.
Reflection
Reflection

Reflections from our travel findings
Reflection

Reflections from our travel findings

Methodological guidelines for performing autoethnography
Travel Reflections
Autoethnography revealed deep personal experiences

- My travel experiences highlighted **personal ways of interaction** with different cultures, environments and technology.
Travel Reflections

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- Given that disability is highly personal, these deeply situated insights are difficult to obtain through other research methods.
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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.
Travel Reflections
Travel Reflections

Personalized assistive technologies

• The varied environmental conditions during travel affected my communication.
Travel Reflections

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• Future designers should consider: How might we design personalized assistive technologies that adapt to different settings?
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• 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.
Travel Reflections

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• Results are in the paper.
Methodological Guidelines for Disabled Researchers to Perform Autoethnography
METHODODOLOGICAL 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.
Methodological Guidelines for Disabled Researchers to Perform Autoethnography

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- 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.
Privacy vs. Transparency:

- **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.
Methodological Guidelines for Disabled Researchers to Perform Autoethnography

Balancing Authority:
METHODOLOGICAL GUIDELINES FOR DISABLED RESEARCHERS TO PERFORM AUTOETHNOGRAPHY

Balancing Authority:

- Graduate students performing autoethnography may be intimidated to share their personal experiences with advisors.
Methodological Guidelines for Disabled Researchers to Perform Autoethnography

Balancing Authority:

• 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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Calling all researchers with disabilities!

Let’s together contribute our rich personal accounts to reveal how diverse scenarios and contexts affect our disability.