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SEEING THE UNSEEN:
INTERACTIVE NARRATIVES AS A TOOL FOR
UNDERSTANDING INVISIBLE DISABILITIES

by

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ABSTRACT

Understanding invisible disabilities has become a more consistent conversation in recent years. While this conversation has included developing better medical treatment and legislative progress for accessibility requirements, there remains progress to be made in comprehending how these invisible disabilities impact a person's daily life. This dissertation research focuses on how informal learning tools such as interactive narratives could be developed to provide insight into the ways an invisible disability influences a person's day that otherwise goes unnoticed by the mainstream population. To provide this insight, an advanced prototype of an interactive story titled *Under the Rock* was developed and based upon the researcher's experiences growing up and living with advanced hearing loss. The narrative used for *Under the Rock* was drafted using an autoethnography methodology to capture key moments from the researcher's memories and translate them into a game narrative. Following a choose-your-own-adventure story format, users are asked to guide the main character through a series of situations that are directly influenced by her hearing loss and learn about the impact of each choice. To test the efficacy of *Under the Rock*, a survey study was conducted to determine what users most commonly took away from the game experience. This survey study found that a majority of users began with an expected baseline of minimal knowledge about hearing loss, and after completing the study many reported a deeper understanding of hearing loss within the context of everyday life. While there is a great deal of work to build upon within this research, this advanced prototype of *Under the Rock* and accompanying survey study show promising initial results in developing effective informal learning resources for educating mainstream populations about invisible disabilities and their impact on daily life.

To the family I love and depend on every day:

Lisa Gray: my patient and beautiful mom, thank you for choosing me

Karolina Theophilo: my best friend and sister, a woman with the kindest and strongest heart I

have ever known

Zofia and Florence Theophilo: my nieces and fairy goddaughters who fill my heart with love and

purpose every single day

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INTRODUCTION

Invisible disabilities such as hearing loss have remained a challenge to understand without having firsthand experience with the diagnosis. An invisible disability is defined as “conditions, illnesses, and structural or biomechanical anomalies that are life limiting but not readily discernable to others” (Davis 2005). Throughout mainstream media, there have been examples of deaf and hard-of-hearing characters in movies such as *Children of a Lesser God* and television shows such as *Switched at Birth*. These movies and television shows provide the chance for viewers with hearing loss to feel seen, but they do not provide an understanding to individuals without it any insight of what daily life with hearing loss is like. Rather, the most common objective of these viewing experiences is to create a heartwarming tale where the character with hearing loss to find acceptance in the hearing world, thus continuing an ableist narrative (Tarvainen 2019, Campbell 2009).

This dissertation explores the process of using an autoethnographic methodology to document the researcher’s personal experiences growing up with severe hearing loss and translate those experiences into an interactive experience. This experience is comprised of several scenarios based on the researcher’s documented moments with hearing loss that has been organized into a coherent path organized into three levels to reflect childhood, college, and adulthood. The prototype of this game, titled *Under the Rock*, offers the user the ability to guide the main character through these scenarios, make choices about how to react to each scenario, and learn about the potential outcome of these choices. An autoethnographic methodology was used in documenting the researcher’s 20 years of living with progressive hearing loss and translating those into the interactive narrative of *Under the Rock*. This interactive narrative is

meant to provide users with an opportunity to gain a deeper understanding of how an invisible disability impacts a person's daily life. Ideally, this use of interactive media exposes the user to otherwise undetectable information without having firsthand experience with the invisible disability.

Autoethnography is defined as “a theoretical, methodological, and (primarily) textual approach that seeks to experience, reflect on, and represent through evocation the relationship among self and culture, individual and collective experience, and identity politics and appeals for social justice” (Holman Jones 2007). This methodology was applied to the researcher's experiences living with hearing loss to analyze these entries and understand how these moments fit within and contrast with mainstream culture.

In constructing *Under the Rock*, Twinery.org (further referred to as Twine) was used to create a choose-your-own-adventure-style narrative game. This structure presents users with a series of choices that guide the user's narrative experience as they learn more about the ways hearing loss can impact a person's daily life. In utilizing this interactive narrative, the researcher is utilizing the user experience (UX) design of *Under the Rock* to create a new connection in the user's knowledge base regarding hearing loss. Through applying UX design principles to ensure the user would be continually engaged with *Under the Rock* manually (by clicking through the narrative), auditorily (by utilizing sound files throughout the narrative), and visually (by using images to provide further context for the narrative).

This prototype of *Under the Rock* is intended to be used as an informal learning tool that will add an awareness of hearing loss to a person's network (Latour 2007) without the person needing to have personally experienced hearing loss. The survey study results (found in Chapters 4 and 5) indicate that this prototype was successful in creating new connections in the survey

participants' networks regarding hearing loss. Traditionally actor network theory (ANT) describes an individual's social webs being one way a person learns about their environment and form connections between personal experiences. In this dissertation, the researcher endeavored to test if an individual can form new connections to hearing loss and its impact on one's daily life by playing the interactive narrative game *Under the Rock*. Through navigating the main character through *Under the Rock*, the user could potentially develop new connections to their webs regarding the understanding of hearing loss without either being diagnosed with hearing loss or personally knowing an individual with hearing loss. The next section states the main research questions that will guide this dissertation.

Research questions

To test the effectiveness of *Under the Rock*, a prototype of the interactive narrative game had to be drafted, and the prototype needed to be tested. In creating the prototype of *Under the Rock*, there are two main research questions related to this portion of the research:

1. How does an interactive narrative structure help in teaching users about invisible disabilities?
 - a. How does an interactive narrative help users gain an understanding of another's experience that differs from their own daily experiences?
 - b. How can the reflections and insights gained through autoethnography be translated into a game narrative?

With this research question, the primary focus is to determine if the autoethnographic methodology used to create the interactive narrative of *Under the Rock* is effective in creating an informal learning experience for users regarding invisible disabilities. Additionally, this research

question also touches on the importance of users maintaining an understanding of the “Other” experience while playing through *Under the Rock*. The term “Other” refers to a perspective separate from one's own (Bollmer 2017). Bollmer (2017) discusses the importance of maintaining an awareness of the “Other” when learning about different perspectives as it enables the user to better understand how these differing perspectives compare with their life experience.

2. How can an interactive narrative created in Twine be used to improve a user’s understanding of hearing loss’s effect on daily life?

This research question focuses on *Under the Rock*’s ability to educate the user specifically about the invisible disability of hearing loss. While there are several invisible disabilities, this research is focused on increasing the user’s knowledge of hearing loss. This research question was assessed through a survey study that gathered information from the survey participants regarding their experiences playing *Under the Rock*. By using a pre-survey/post-survey structure, this study was able to measure how participants’ attitudes shifted throughout the study. The next several sections provide a brief overview of the contents of each chapter throughout this dissertation.

Chapter 1 Summary

This chapter reviews the key scholarship being utilized from the fields of autoethnography, Deaf culture, actor network theory, and user experience design. Deaf culture is briefly discussed to highlight the types of research that have been done in this field to help further efforts to educate the public about the Deaf experience. Autoethnography is reviewed as the main methodology utilized within this research. This section reviews several examples of how autoethnography has been used to document researchers’ experiences and observations in a variety of cultural experiences. ANT is discussed next to establish key ideas from this research

area and discuss how other researchers have also begun exploring new ways connections in one's social web can be created. In the final part of this chapter user experience design is reviewed to better understand the many ways UX design has been used to create informal learning resources.

Chapter 2 Summary

This chapter will review the creation of the prototype of *Under the Rock*. The prototype was built using Twine, an online story-building product that allows developers to create interactive narrative-based games. Additionally, this chapter will also briefly discuss the environmental scan of existing products that was conducted to better understand how invisible disabilities have already been addressed in similar forms of game design. In the remaining portion of the chapter the game design of *Under the Rock* will be detailed. This includes the story map, character creation, and the use of assets to improve the immersive nature of the experience.

Chapter 3 Summary

This chapter reviews the creation of the survey study used to test the efficacy of *Under the Rock* as an informal learning tool about an invisible disability. The structure of the pre-survey and post-survey questions will be discussed as well as the intention behind each section of questions. The parameters of the survey study are outlined, and the target survey population is detailed. As this study was conducted during the COVID-19 pandemic, the virtual nature of the study is briefly discussed. Finally, the IRB process for this study is reviewed.

Chapter 4 Summary

This chapter provides the results of the survey study including the pre-test and post-test results. The pre-survey results are provided first with graphs representing the survey data, with initial impressions of the survey participant being discussed. Following this, the post-survey results are provided as well as the graphs that have been created by the Qualtrics report of the data. The information in this chapter provides the information needed to better understand the discussion in the following chapter.

Chapter 5 Summary

Chapter 5 provides a discussion of the survey data. The shift in answers between the pre-survey and post-survey questions are reviewed, and the implications of these shifts are also discussed. The overall implications of the survey results are discussed in detail, as well as the implications for *Under the Rock*. The answers the survey data provides to the research questions are also discussed.

Chapter 6 Summary

This closing chapter provides an overview of the information presented in this dissertation. The inspiration for the creation of *Under the Rock*, key themes from the existing literature, development of Twine prototype, survey study design, and the implications of the survey study results are discussed in this summary. The final portion of this chapter discusses future applications of this research. The next chapter will discuss the main areas of academic debate related to this dissertation research.

CHAPTER 1: LITERATURE REVIEW

To best determine how to create an interactive experience that will informally educate users about the impact of an invisible disability on daily life, it is important to analyze the theory that influenced the product design and survey study used to test the prototype's efficacy. This chapter will examine the existing works within the fields of autoethnography, actor network theory, and user experience (UX) design. Each of these theoretical areas provides a framework for understanding the basics of each of these three areas and provides an understanding of how they can be combined to build a hybrid niche. The next section will highlight the research that has been conducted in the field of Deaf culture.

Deaf Culture

While the focus of this research dissertation is in understanding how autoethnography can be used to translate one's personal experiences into a playable narrative that can serve as an informal learning experience, because the narrative focuses on hearing loss, it is important to have a brief overview of Deaf culture research. This will provide context for this research to understand the new potential research avenues that are available after the completion of this work. Deaf culture research has included many ethnographies documenting Deaf communities around the world, studies within schools researching how deaf children are educated, and how numerous professionals are dedicating their time to documenting sign languages around the world. This research field encompasses several possibilities, and this dissertation could be seen as another avenue within Deaf culture because it offers a new way for someone outside of Deaf culture to gain a better understanding of someone living with severe hearing loss or deafness. The following paragraphs will provide a brief overview of Deaf culture research.

Deaf Culture research has focused on documenting sign languages (Kyle & Allsop 1997; Meier 2012; Nijmegen 2012; Nyst 2012; Peterson 2009), and the existence of Deaf Culture throughout the hearing world (Berbier 2002; Dunn 1989; Groce 1985; Lane 1993; Lane 1984; Lane, Hoffmeister, & Behan 1996). There has been a continual push to expand Deaf Culture research to continue impressing upon society that Deaf individuals have a cultural identity and have a place within society without needing to assimilate into it – rather adapting to daily life as needed (generally through lipreading conversations with individuals that do not use ASL (American Sign Language) and using accessibility technology such as alarms that vibrate or use lights) (Moore & Levitan 1993; Padden & Humphries 1988; Rosenthal 2009; Senghas & Monaghan 2002).

Documenting Deaf individuals within mainstream schools is one research area within Deaf Culture research that provides insight towards understanding how this cultural group functions within a dominantly hearing environment. Valente (2019) documented their research in documenting deaf kindergarten classrooms around the world to gain insight into how educating deaf children is handled in different countries. Additionally, Valente (2014) discussed the unique position a researcher connected to the Deaf community is in while conducting research. Valente adeptly captured the struggle one could go through by researching a cultural group that they also fit within but do not yet understand their place among.

Additionally, Hensley (2016) discusses the struggle a researcher must face when they are required to fill several roles; in this case, it included a research assistant, interpreter, cultural mediator, and linguistic consultant. Understanding a language also requires understanding the culture it is used within, and that can become a coveted skill in a researcher when they are the sole group member with those skills. Hensley (2016) accurately captures how this ability can

become a gateway towards being overloaded with additional requests and expectations. These struggles and historical information about hearing loss, Deaf culture, and American Sign Language was part of the information incorporated into *Under the Rock* to teach users about hearing loss from a pragmatic perspective. Developing this interactive narrative also serves as an example of how the fields of Deaf culture and game developers can collaborate in the future to develop informal learning tools. The next section will review the field of Autoethnography, and how its methodology can be used to document one's personal experiences for research purposes.

Autoethnography

As a field, autoethnography research focuses on documenting one's own experiences so others can either read about or gain insight into those moments and learn from the researcher's life as they attempt to make abstract and obscure information more concretely comprehensible (Holman Jones 2016). In this research project, an autoethnography methodology is being utilized to document the researcher's experiences growing up with progressive hearing loss from age 11 to an adult in her 30s. In this section, different elements of autoethnographic research will be reviewed and discussed to capture the diversity of the field and the importance of each element. While autoethnographic research has varied from written work, interpretive art pieces, and video game creation, the root of these works is a desire to make one's life experiences understood and seen. The next section reviews the use of autoethnography for documenting personal experience.

Translating Personal Experience

At the heart of autoethnographic research is a desire to document one's personal experiences within unique situations to provide context the rest of the population would miss.

Professionals within this field have produced numerous examples of how one can record personal experiences and present them in a way that can offer insight to others. For example, Chavez (2012) documented their experience as a Chicana to show the value of autobiography in ethnographic works, arguing that it is an invaluable educational tool. At the root of a majority of this research is the attempt to provide insight and understanding to one's personal experiences. This research can provide a valuable resource to someone trying to understand how a person is processing learning a new language, adapting to life with a medical condition, living through a pandemic, or countless other unique situations. Documenting one's personal experiences in any of these situations can provide a singular insight into how they reacted emotionally as well as physically to that situation.

Individual perspectives have also been documented by autoethnographers in situations of language learning (Werner 2020), early career researchers (Belkhir, Brouard, Brunk, Dalmoro, Ferreira, Figueiredo, Huff, Scaraboto, Sibai, Smith 2019), construction work (Grosse 2017), understanding idiosyncratic town humor (Markham 2005), interdisciplinary research about Polish Romani women (Kazubowski-Houston (2018), and medical research (Ellingson 2006). Each of these works attempts to document an individual perspective in such a manner that others that are outside of the experience can learn from those moments. While research is often treated as an entity that should be separate from personal experience, there is pragmatic value to be gained from autoethnographic research (Bochner 2018). First-person perspectives are often not viewed as valuable or valid as other branches of research, however, each of the examples discussed in this section proves that the individual narrative provides more detailed context that is often avoided in other fields.

Before the COVID-19 pandemic, autoethnography was being used to document individual experiences in the attempt to provide deeper context to the unique experiences of individuals. For example, physical and mental illnesses are usually difficult for individuals outside of the experience to comprehend all that they impact. Frank (2017) has made significant efforts throughout their career to document their experiences with illness, as well as document other individuals' experiences coping with illnesses, their journeys to understand those moments, and the impact it had on their lives afterward.

The COVID-19 pandemic provided an opportunity for both researchers around the world to conduct research from their own homes, as well as a chance for autoethnographic researchers to analyze their experiences critically (Harris & Jones 2020). While people around the world adjusted to this new normal, autoethnography researchers seized the chance to document their early experiences during this largely once-in-a-lifetime event. Markham & Harris (2020) outlined a 21-day prompt challenge to enable researchers to analyze their situations while being able to adapt to their new routines that were developed through these unique circumstances. This prompt challenge created an additional layer of analysis to an unprecedented situation and offered a new method for processing the experience. By sharing the daily prompts through social media posts, a sense of camaraderie and connectivity was created that allowed researchers completing this challenge an opportunity to connect through their work (Markham & Harris 2020).

As a creator of this challenge, Markham (2020) also took the opportunity to document and analyze their experiences in the early days of COVID-19. Markham (2020) expressed the importance of viewing one's knowledge of a subject and the idea that when one knows something it becomes a political act (p.1-2). Throughout the prompt challenge, their observations

focused on patterns and associations that can be made between the researcher and their surrounding environment. Markham (2020) documented the patterns they established to bring them comfort and their focus on methodology while coping with this global event. The use of the methodology to maintain a sense of focus, and to avoid emotional distress, reflects Markham's (2020) comfort in research while maintaining a dedicated analysis of the situation.

In addition to utilizing prompt-based challenges, fictional narratives based on one's experiences during the COVID-19 pandemic were also created. Thorndahl & Frandsen (2020) came together to blend the range of personal and shared experiences undergone in the initial months of the pandemic to create a series of layered fictional narratives that, though fiction, honestly portrayed their condensed experiences (p.2). While some would argue against using fictionalization as a research technique, it can be a valuable strategy in autoethnography to protect a participant's identity as well as to create a narrative that encapsulates numerous experiences in one narrative. This makes it possible to present one coherent narrative to readers after the autoethnographer has processed through all of the research data and has determined the key points of the research the user is meant to have as a takeaway.

One of the key populations that were highly depended upon throughout the COVID-19 pandemic has been teachers. These professionals have had to adapt while continuing to guide their students' education. Chemi (2020) used an autoethnographic methodology to document their experiences adapting their art and creative-based teaching style to the virtual teaching environment. Through this documentation and reflection, an insight into the obstacles this teacher had to overcome while learning new ways to reach their students provides context into the teacher's experience during the pandemic that many are aware of, but do not fully comprehend. Chemi's (2020) work also serves as an example of a way for one to take ownership

of their experiences within that unique context and ensures their experience has been documented for other populations to study and understand.

Besides prompt challenges, fictional narratives created from layered experiences, and journals comprised of personal experiences in a situation, what else can be done with this type of research? Tosca (2020) provides an example of translating one's experiences and observations during the COVID-19 pandemic into a video game narrative. After drafting their day-to-day quarantine observations, Tosca determined several recurring themes, thought patterns, and translated them into dialogue that could be used within a video game. Following the repetitious theme of the movie, *Groundhog Day*, where the main character relives the same day over and over, the dialogue Tosca outlined captures the feelings they experienced repeatedly while living through, and the videogame placed users in, that same repetitious environment (p.7).

Complementary with Frank's (2017) work, Irwin (2020) documented their observations as a disabled woman during the COVID-19 pandemic. Irwin (2020) was able to document how many Americans experienced undesired restrictions during the pandemic and parallel those unwanted restrictions to the experiences that disabled individuals experience daily (that usually go unnoticed). Throughout this work, Irwin (2020) can astutely detail the restrictions they handle in their everyday life living with an invisible disability, which was suddenly more easily noticed by mainstream individuals once they were also put under unwanted restrictions and outline how this similar comprehension should be used to understand and empathize with a wider range of often ignored populations. The next section highlights how autoethnographic work has been translated into coherent works for others to enjoy.

Interpreting Fieldwork into written work

Once fieldwork has been completed, the next task for one to consider is translating that research into a coherent work that can either be read or experienced by the reader. Some interpret their autoethnographic journals into interpretive art pieces, video games, or through summarizing the highlights of their findings in a research paper. Within most of these works is a driving passion to present observations and data that is often overlooked and present those findings with compassion. Oftentimes autoethnographic research is only the beginning to a larger set of possibilities as it can be connected to other works to have a larger impact and cause social change (Ellis 2017). Autoethnography work is meant to connect with the readers/users as well as other works when possible – seen by collaborations during the COVID-19 pandemic prompt challenge (Markham, Ellis, Luka 2020; Markham & Harris 2020; Markham 2020; Tosca 2020).

The works produced through autoethnography have grown and shifted as the field has become more known. Originally its methodology was utilized in indigenous ethnography in opposition to traditional ethnography's focus on the silent author and grew to its current space supporting vulnerable first-person authorship providing insight into research that is often overlooked in many traditional research fields that focus solely on conventional data collection methods (Bochner & Ellis 2016; Ellis, Adams, & Bochner 2011). Acknowledging the wealth of knowledge that can be provided from one's first-person experiences within a vulnerable situation can provide situational details that fill in the blanks that are not understood from a formal study, and this data can be utilized to determine how one can be a compassionate participant in a comparable situation (Ellis 2017).

A clear challenge in autoethnographic research is the challenge of subjectivity: is it best to treat it as testimonial material or as a condemning confession (De Freitas & Paton 2009)? Depending on the context of the material, authors can find empowerment in having their singular observations seen and acknowledged for their validity. Others may not have confidence that their words will have any impact. Autoethnographic works aim to be transparent while portraying the sense of self within that environment with accuracy (De Freitas & Paton 2009).

Finished autoethnographic works have expanded past written works and at times have inspired digital art and interpretive art pieces. These research methodologies have also been used with art students as an educational tool to make them aware of their design processes through written exercises, tutorials, and interviews (Neil 2019). This utilization of autoethnographic methodologies empowered students as they sought to understand their thought processes while completing design exercises. Utilizing autoethnography in this manner in other student capacities (i.e., student researchers, design students) could offer more students an internal scaffolding they may lack for understanding the context and processes of their work. Some groups of students are already utilizing this methodology to analyze and connect with other students around the world trying to make sense of their college experience during the pandemic (Wilson, Tan, Knox, Ong, Crawford, Rudolph 2020). The next section reviews the importance of maintaining a sense of ethics when conducting autoethnographic work.

Ethics in autoethnographic work

A key concern in any form of ethnographic research, including autoethnography, is protecting the anonymity of anyone included in one's research documents. While it is important to portray ethnographic research descriptively with as much specificity as the researcher is

capable of, maintaining the safety of all research participants is the priority. Within autoethnographic research, one may record interactions had with coworkers, teachers, and children. As a result, these interactions would need to be anonymized. This can be accomplished in several ways: changing the names used in the final work, excluding moments involving vulnerable populations, or fabricating the final narrative to protect research participants while still portraying the message of the autoethnographic work (Markham 2011; Markham, Tildenberg, & Herman 2018).

A second key concern within autoethnography research is the motivation behind conducting the research – why this research data is being gathered. Autoethnographic research is most often meant for gaining pragmatic insight into a situation or environment (Bochner 2018). Research using this methodology is most often focused on the practical information that it can provide (Bochner 2017; Bochner 2018). The next section discusses a researcher's narrative identity, an important entity to keep in mind when conducting autoethnographic research.

Narrative identity

Autoethnography provides the researcher with an opportunity to grow their narrative identity in their work. From its inception as an alternative approach to ethnographic research to a counter approach to traditional research methods (Bochner & Ellis 2016), autoethnography has given a platform to researchers whose personal observations within their research (whether that research focuses on minority cultural experiences, performance art, or experiences with disabilities) provide an opportunity for these researchers to discuss their insights into their work.

All researchers preparing work for publishing must determine the narrative voice of their published work. With the autoethnographic narrative identity, there is an opportunity to

humanize the researchers as well as to build greater connections between the research focus and the reader (Ellis & Bochner 2000). Creating a sense of connection to the research population, oftentimes a cultural niche can progress the process of linking the concrete to the abstract (Holman Jones 2019). This is accomplished through the effective use of the narrative identity. The next section discusses key areas of debate within autoethnography.

Key Areas of Debate in Autoethnography:

Now that the key areas of autoethnography have been discussed, it is time to review the key areas of debate within this field: the methodologies used, the types of narratives being documented, and additional ways autoethnography is being utilized beyond written research. The methodology is an area of key importance with any research, specifically how to do so effectively, managing personal bias within autoethnographic research, and its purpose. As the previous sections have shown, autoethnographic research is most effective when it is providing insight into a lesser-seen perspective within a culture or daily life environment that is often overlooked. For example, Irwin (2020) used the context of quarantine during the COVID-19 pandemic to help make the limitations they experience living with a disability less abstract to readers. Personal bias can be difficult to manage, especially in a research area that is a platform for personal insights, however research within this field does place a focus on the researcher seeking to understand their thought processes and observations in their endeavor to understand the causes and how they are being impacted by their environment (Werner 2020). Research produced in this area has been used to produce additional types of projects meant to supplement the original works: interpretive digital art (Neil 2019) and video games (Tosca 2020) are two examples of additional work that came from autoethnographic works.

Another area for discussion within autoethnography is the types of narratives that can be explored using this methodology. Throughout this literature review, the researcher has focused on examples of narratives during the COVID-19 pandemic, disability, language learning, teaching, and different college experiences. Research examples focused on COVID-19 were utilized to provide a research area that many potential readers could understand. This global experience was experienced in numerous ways by countless individuals, and these examples of autoethnography focused on COVID-19 provide different examples of how others experienced the pandemic. Arguably, a researcher could use the methodology to document any type of personal narrative within any experience if the researcher can find a research focus that provides new insight. The next section highlights the main research questions that often fuel autoethnographic research.

While autoethnography research can and has focused on a wide variety of perspectives, there are often several core research questions that are expanded upon. Those core research questions are:

1. How can the personal perspective add to this research area?
2. How can this research be accomplished ethically?
3. What is the value of this research being conducted with an autoethnographic research methodology versus another form of research methodology?

These core research questions provide a solid starting point for researchers. For example, in the COVID-19 quarantine prompt challenge discussed above (Irwin 2020; Markham & Harris 2020; Markham 2020; Thorndahl & Frandsen 2020; Tosca 2020, Chemi 2020) all of these researchers started out wanting to document the experiences each of them had while living through the pandemic quarantine. While each of these researchers was focusing on their experiences through

the same event, each researcher had quite different observations about themselves and their surroundings. The next section briefly reviews areas where future autoethnographic research could build upon.

Areas for Future Development

Autoethnographic research has been applied to a wide variety of situations, but there is room for additional research. As this literature review has discussed, this research methodology has been utilized for documenting individual perspectives in a variety of capacities and has resulted in a diverse collection of published written works, some examples of performance art, digital art, and a few video games.

Future research would benefit from utilizing this research methodology to document the experiences of those with invisible disabilities (i.e., depression, anxiety, hearing loss, diabetes). In general, investigation into how these invisible disabilities impact a person's daily activities has not been thoroughly documented in a formal research capacity. There are examples of independent game developers creating an online game experience that is meant to show users how one of these invisible disabilities impacts their lives, but there is an opportunity in academic research, specifically within autoethnography, for the practical impact of these invisible disabilities to be documented for others to learn about. Specifically, within autoethnography, there is the opportunity to provide a first-person perspective of what daily activities are impacted because the researcher must factor in one of these invisible disabilities. The following section reviews the areas of autoethnography that have been covered thus far in this literature review.

Summary

Throughout this section, the main goal has been to discuss the ways autoethnography research methodologies have been used to document a researcher's first-person observations within a unique environment or experience. It has been applied in a variety of experiences including the COVID-19 pandemic (Chemi 2020) and living with a disability (Frank 2017) and has been used to create interactive artistic experiences meant to help communicate the researcher's observations and experiences (Kazubowski-Houston 2018). The next section will discuss Actor Network Theory and how it is used to describe how a person grows their circles of connections to those around them.

Actor Network Theory

The heart of Actor Network Theory (ANT) argues that the actor (for example, a person) makes connections to other actors through personal interaction. This theory provides a reference structure for one attempting to understand the difference in various actors' knowledge bases: by understanding the numerous different social interactions one actor has had versus another actor, the difference in their awareness of different information can become clear. For this dissertation research, the researcher is endeavoring to find out whether a person (the actor) can add an awareness of hearing loss to their network by playing through an interactive digital narrative rather than physically meeting a person with hearing loss. In this next section, ANT will be described in detail as well as additional ways it is being utilized by other researchers.

The Origins of Actor Network Theory

Bruno Latour sketched out ANT to redefine the use of the term ‘social’ within the social sciences and reorient social connections in a constantly shifting network of relations outside of the individual’s network, and to the individual nothing else exists to that individual aside from the connections in their self-developed network (Latour 2007; Bruni & Teli 2007). ANT is a theory that is accompanied by its vocabulary that must be understood to be able to fully comprehend the potential impact of the theoretical framework (Law 2009). Within ANT there are a few key terms to keep in mind:

- “Actor: Both human beings and nonhuman actors such as technological artifacts
- Actor-network: Heterogeneous network of aligned interests, including people, organizations, and standards
- Enrolment and translation: Creating a body of allies, human and non-human, through a process of translating their interests to be aligned with the actor-network
- Irreversibility: The degree to which it is subsequently impossible to go back to a point where alternative possibilities exist” (Walsham 1997, p.468)

Through utilizing these terms, it can become possible for a researcher to categorize a person’s connections and interactions with their environment into a network. Then when analyzing multiple different individuals and their respective networks, it can become possible to see discrepancies between networks and analyze how each network was created. In a reflective piece, Latour discussed ANT using an example of NASA (National Aeronautics and Space Administration) and the Columbia shuttle (Latour 2011). Throughout this example, Latour pointed out that at the time of the launch NASA believed it had all the information needed for a

successful launch, then discovered it needed additional information – and needed to expand its network to have a successful launch in the future. This example shows that an actor’s network is continually changing and growing as they are exposed to new information.

One of the key elements of ANT, as was seen in the above NASA example, is within ANT the social does not exist separate from the actor or its environment of non-human actors (Whittle & Spicer 2008). This is important to remember when considering the number of technology people (actors) interact with daily in today’s society. Technology has infiltrated every element of a person’s day and every individual has a smartphone in their pocket ready to direct them towards new information. All of this technology creates new forms of interaction individuals can have with non-human objects that can advance their networks or limit their networks depending upon how the individual utilizes technology. Regarding this dissertation, the researcher will be evaluating the effectiveness of an interactive digital novel in adding an awareness of hearing loss to an actor’s ever-growing network.

Applying ANT to one’s research can lead to difficulties and misconceptions with the theoretical concepts. Latour (1996) identified a couple of common misconceptions in ANT including: 1) having an accurate contextual understanding of “network” (as this term can be defined in multiple ways) and 2) ANT is not solely focused on understanding social networks (p.369). Rather, Latour points out it is important to keep in mind that “network” does not mean the same as a technical network one would imagine if one were to picture an online network and its vast array of potential connections. It is more important to be able to identify the actor’s core network of strongest connections, which can be comprised of social, environmental, and technical factors (Latour 1996).

ANT has faced criticism over the years (Elder-Vass 2015), with arguments being made that ANT is nearly anarchic towards pre-existing sociological theories (Fine 2005). In his critique, Fine (2005) argues between macro and micro levels of understanding in people, pointing out the actor exists within the micro-level and by extension their network is also within the micro-level. Callon (1999) criticized ANT for not having a theory focused on the actor as much as the network around the actor, while simultaneously pointing out ANT's strength in describing and explaining the potential actions within networks. Specifically, Callon (1999) uses economic markets as an example to explain how ANT can be utilized for examining actions with a network. Amidst criticism for ANT are also critiques for additional opportunities for utilizing this theoretical model to bridge between research areas. Alcadipani & Hassard (2010) point out that while ANT has been seen as lacking a political critique, it can be used for analyzing those micro levels of understanding of individuals within organizations as they function within organizations. Mol (1999) also points out the potentially political nature of the ontology of word choice within ANT as actors determine how to cooperate amongst their respective and overlapping networks. The next section discusses new ways ANT is being applied to research.

Refocusing the creation of connections

One of the advantages of ANT is it lends itself to adaptability as researchers find new ways of using it to understand their environment, both their current environment and potential interactions that could happen in the future. For example, ANT can be utilized in analyzing nonhuman entities such as public policy and potential security threats (though created by humans), which are often analyzed as separate entities from the human actors that create these nonhuman entities. Salter (2019) makes the argument for employing ANT to understand

securitization theory to better understand those nonhuman subjects that are an active part of the securitization process without being at risk for oversimplifying the components involved (p.349). By applying ANT, Salter (2019) can provide a new form of analysis into security possibilities without belittling other nonhuman and human factors that influence the process.

One cannot ignore the growing influential role digital media has in today's society. There are numerous theories for understanding media's impact, and ANT has been proposed by Couldry (2008) as a methodology for documenting the roles various forms of media have today. As Couldry (2008) points out, ANT can address the roles nonhuman media has in contemporary society, specifically for identifying and mapping the sprawling nature of these media connections with the potential for power and impact media can cause. In addition to being applied to understanding media and other technological nonhuman-actors, ANT has also been proposed for developing a further level of understanding the maritime activity. Dolwick (2009) discussed an example in which ANT could be used for understanding how ANT can be used when studying maritime archaeology to studying all the elements involved as actors including a ship, a person, a government, or a virus to study how these are relationally linked together into networks (p. 45). Similarly, ANT has also been utilized in understanding the relationship between education standards and their results (Fenwick 2010). Similar to what was discussed in previous examples in this section, ANT is effective in mapping out the connections between an educational standard, the people who organize and facilitate these standards, the teachers who must carry out these standards, and the students who must be educated through these standards. The next section highlights the main research questions within ANT.

Within ANT research the recurring research questions often focus on include:

1. What is Actor Network Theory able to help researchers understand?

2. How have researchers utilized Actor Network Theory to create a deeper level of understanding of how human actors and nonhuman actors form networks of connections?

As it has been discussed throughout the above sections, ANT has been utilized by several researchers (Salter 2019; Couldry 2008; Dowick 2009; Fenwick 2009) to illustrate the wide variety of connections that can be drawn within different fields to see the networks. These networks are then able to be used to show how those specific series of actors can cause a variety of impacts on one another. The next section discusses areas that ANT research could expand upon in the future.

Areas for Future Development

One area in which ANT research is currently thin is utilizing it to analyze the impact of a disability or illness when it becomes a part of an actor's network and the impact it has on the network over time. Research could also be conducted that analyzes potential ways awareness of a disability could be added to an actor's network without the actor personally experiencing the disability. A part of this dissertation's research focuses on determining if the interactive novel experience developed for this dissertation is successful in adding an awareness of hearing loss (an invisible disability) to a user's network without them either experiencing hearing loss themselves or knowing someone with hearing loss. If it is successful, it could provide a new avenue for adding greater awareness of an array of invisible disabilities to a user's network. The next section summarizes the key ideas within ANT that have been discussed.

Summary

Throughout this portion of the literature review, the main components and applications of Actor Network Theory have been discussed and analyzed. Latour's construction of ANT was detailed (Latour 2007; Latour 2011; Latour 1996), criticisms and critiques were discussed (Whittle & Spicer 2008; Fine 2005), and additional applications researchers have used ANT for to develop a deeper understanding of their field (Salter 2019; Couldry 2008; Dolwick 2009; Fenwick 2009). In the next section, UX design research will be discussed. While this is a vast area of research, this section focuses on examples of digital media and immersive technology that have been used to increase a user's knowledge and awareness towards a vulnerable population. The next section reviews the research within user experience design relevant to this dissertation.

User Experience and Designing for Informal Learning

This dissertation is centered around the creation of an interactive narrative prototype, which means it is important to briefly review key concepts within user experience (UX) design. Through reviewing concepts of informal learning, online interactions, audience, interface design, and UX in video games we can better understand the impact of the UX design of this prototype and the factors that influenced its design.

Informal learning is often seen in games and products used in museums, schools, and medical offices to teach the user about a specific topic wherein they can interact with the product and discover new information themselves. *Under the Rock* employs game-based learning (GBL) to teach users about the impact hearing loss has on daily life through a series of choices in a game-based narrative (Hainey, Connolly, Boyle, Wilson & Razak 2016). As Hainey et al. (2016)

examined throughout their research, GBL can be applied to several educational topics including science, math, and language to enhance a child's learning experience. These products provide the user with a sense of agency and the power of their own choices to influence their learning experiences. This use of choice, as is seen in *Under the Rock*, is a tool in UX design that can increase the user's level of interest in participation (Schaller 2015). As Schaller (2015) outlined, creating meaningful choices in the gaming experience can lead to the user having impactful moments from their game. Through utilizing a framework of connecting the informal learning in the game to guided activities afterward, a game experience could be developed into a structured learning experience that incorporates informal learning techniques to learn about a specific subject area or place, such as a museum (Lawson, Cook, Dorn & Pariso 2018). An example of this type of learning development can be seen in Crowley & Jacobs (2003) description of "Islands of Expertise," a system in which families can connect engaging moments in museums with deeper learning. This example of informal learning is one example of how these experiences with a knowledge area can enhance the user's learning (Hainey et al. 2016, Schaller 2015, Lawson et al 2018, Crowley & Jacobs 2003).

The interface chosen for a product's UX can be a valuable element to its impact on the user. Whether a product uses a web-based interface, mixed reality (MR), augmented reality (AR), or virtual reality (VR) it makes an impact on the user experience (Billinghurst 2001; Hughes et al. 2005; White et al. 2007; Trunfio & Campana 2019; Nisi, Dionisio, Barreto Nunes 2018; Milgram & Kishino 1994; Kolstee & Eck 2011; He et al. 2018; Marques & Costello 2015). These product interfaces can be used to augment the user's immersion level by employing different stimuli such as clicking with a computer mouse to interact with a story, applying augmented reality to add an additional layer of visual stimuli to a game, or incorporating a VR

headset to create a level of visual and auditory immersion. Utilizing these diverse types of reality-manipulating interfaces can serve to ignite informal learning in new and creative ways (Harrington 2019, Harrington 2011). Each interface choice provides different forms of engagement for the user whether it encourages users to interact with both a digital interface and their physical environment, a virtual environment, or encourages a higher amount of engagement with the screen (Billinghurst 2001, Trunfio & Campana 2019, Marques & Costello 2015). For example, a web-based narrative could encourage consistent engagement with the screen by breaking the interactive narrative into chunks that require the user to consistently click on their choices. While the web-based interface is not as sensory immersive as AR, VR, or MR, by using a combination of clickability, visual cues, and audio files a web-based experience can be created so the information is memorable and a meaningful experience for the user (Not et al. 2019). The next section discusses the importance of remembering the role the audience plays in designing a user experience.

Understanding Audience and User Experience

In designing a digital experience, another essential element to consider is how potential audiences will react to the game and its interface, something that is often accomplished in museum environments through observation (Mears & Wintle 2014, Nisi et al. 2018). For example it is important to consider the emotional reactions an interactive narrative can inspire in users: hope, irritation, disgust, fulfillment or confusion. Oftentimes media that has been created around a disability is framed with an inspirational narrative showing how the individual rose above their difficulties – this was the opposite message the researcher wanted the audience to experience (Golos 2010, Valentine 2001, Foss 2014). Rather than creating another inspirational

narrative, the researcher wanted to encourage users to understand the endless frustration someone dealing with invisible disability experiences through an informal learning experience (Hainey et al. 2016, Schaller 2015, Lawson et al 2018, Crowley & Jacobs 2003). The ultimate perceived meaning of a game can be determined by the survey study results from the audience. The results show the game's social impact after interacting with the virtual environment of the game (Charitonos et al. 2012, Pietroni et al. 2018). With a game that is a web-based experience, it was important to consider how users would interact with the web-based interface through the use of interactive elements such as buttons, links, imagery, and sound (Walsh, Hall, Clough & Foster 2018). The next section reviews key ideas within interface design.

Interface Design

The interface design for an interactive experience incorporates the developer's ultimate design choices regarding how to impart information to the user (Wesson, Cowley & Brooks 2017). The interface design assists in providing context for the user as they are introduced to the game (Wesson et al. 2017). For example, when considering an interactive narrative experience or another web-based experience, the interface design can be most effective when played on a laptop or desktop computer rather than on a mobile device as the larger screen size will help to minimize the amount of scrolling required in the game narrative. A common goal of interface design in game development is to make an engaging virtual environment that helped the user to focus on the game narrative and use the game's assets to assist in maintaining the user's immersion into the story (Slater 1997; Tzortzi 2017; Cui, Wu, Liu, Wei, Zhou & Qu 2010; Heuwing, Mandl, & Womser-Hacker 2016).

UX in Game Design

To be able to design an effective game prototype, it is important to understand how several UX design principles are utilized within game design. Contrasting with other forms of interactive media such as websites, the UX principles applied to a game's design are far different. These principles include playability, usability, game documentation, and understanding the overall user experience one has during and after playing a game. Playability focuses on understanding the several factors that influence a user's play experience (Sanchez, Vela, Simarro, & Padilla-Zea 2012). Usability refers to the user's ability to play the game without being disconnected from the game experience (Álvarez-Xochihua, Muñoz-Merino, Muñoz-Organero, Kloos & González-Fraga 2017). Game documentation includes the documentation that is created while building the game that provides design notes and instructions for its prototypes, user interfaces, and other documentation information that provides needed information for the development of a game (Grünwied & Mustață 2020; Karabinus & Atherton 2018). Understanding user experience can be seen as a general goal of UX overall, within this literature review the researcher seeks to briefly touch on how researchers have sought to evaluate and understand user experiences within gameplay (Ardito, Costabile, Lanzilotti & Montinaro 2007). Throughout this section, these principles of UX in game design will be discussed in greater detail to better understand how each of these principles impact a user's game experience.

When considering the playability of a game, one needs to maintain an awareness of all the factors that comprise the game being created. As it was defined previously, playability focuses on understanding how the several factors that comprise a game come together to form a unified experience (Sanchez et al. 2012). These playability factors include the mechanics of how

the user will play the game, how the narrative has been broken up throughout the game, and the experiences the user will have throughout playing the game (Sanchez et al. 2012; Deterding, Sicart, Nacke, O'Hara, & Dixon 2011; Nareyek 2004; Law & Sun 2012). Regarding a game's mechanics, one of the most important factors to consider is the interactive narrative (if applicable), and how it would be broken up into small enough chunks throughout the game to ensure the user would be consistently engaged with the narrative. If the screen becomes too inundated with text that required continual scrolling, the user would become too distanced from the experience, so to avoid that the narrative was broken into chunks that would fit onto the screen with minimal or zero scrolling required (Deterding et al. 2011).

As described previously, usability is connected to the user's ability to play the game without being disconnected from the game experience (Álvarez-Xochihua, Muñoz-Merino, Muñoz-Organero, Kloos & González-Fraga 2017). This also includes evaluating how well the functionality of a game coincided with the learner's motivation when discussing games that are education based (Nagalingam & Ibrahim 2015; Álvarez-Xochihua, et al. 2017; Hussain, Mkpojiogu, Karmal & Lateef 2019). Within the context of crafting an interactive narrative, a developer can begin encouraging the user's learner motivation by introducing them to the main characters and the main objectives of the narrative on the initial screens. By creating this situation for the user in the beginning of the game, they are given a purpose for learning new information and maintaining a level of engagement with the game experience (Álvarez-Xochihua, et al. 2017).

For game developers and others seeking a deeper understanding of the game design process, a game's documentation can present valuable information about the developer's design choices as well as present learning opportunities for burgeoning developers (Karabinus &

Atherton 2018; Grünwied & Mustață 2020). The potential elements in a developer's design document can include outlines of the main character and minor characters, a description of the visual styling applied to the images used throughout the narrative, the sound files used, and the CSS (cascading style sheet) file if the developer is creating a web-based experience. By having access to game design documentation such as this game design documents, it encourages other developers to try the design processes and methodology utilized by one developer in their own game creation (Karabinus & Atherton 2018).

The final design principle in this section is evaluating the user experience and the effects it can cause to the user during and after gameplay. Society now incorporates technology into almost every facet of daily life, and researchers have developed research methodologies for understanding a user's experiences after interacting with these different forms of technology (Takatalo, Kawai, Kaistinen, Nyman & Häkkinen 2011; Diya, Prorna, Rahman, Islam & Islam 2019). These methods of evaluation originated in HCI (human computer interaction) though have shifted away from evaluating the product's productivity to instead evaluating its entertainment (Nacke, Mirza-Babaei & Drachen 2019). Within education-based games researchers have also extended their research into understanding the effects playing video games can have on a child's mind such as improving memory or their ability to notice details (Diya et al. 2019). Perhaps through the prolonged application of video games in daily life, researchers will be able to better understand the prolonged impact gameplay has on different populations (Poels, IJsselsteijn, De Kort & Van Iersel 2010; Gürkök, Hakvoort & Poel 2011; Vissers, De Bot & Zaman 2013). This research could lead to more informed research of how to best design an education game for specific subjects as well as different types of learners.

Conclusion

This literature review has surveyed autoethnography, actor network theory, and user experience design research. Within each of these areas of academic theory, key ideas were discussed in detail and will prove useful in future chapters for understanding how this dissertation fits within this research. An autoethnographic methodology was the primary influence in the production of *Under the Rock* for translating the researcher's 20-years of living with hearing loss into an interactive narrative. Key ideas from ANT were applied to *Under the Rock*'s story outline to increase the user's practical understanding of hearing loss without having to personally know an individual with hearing loss or experience hearing loss firsthand. Finally, themes from user experience design used in building informal learning experiences and the impact of these experiences were discussed. In the next chapter, the production process of *Under the Rock* will be detailed.

CHAPTER 2: THE TWINE PROTOTYPE OF *UNDER THE ROCK*

This chapter will focus on the methodology used in the design and development of the Twine product created for this dissertation. Twine is an open-source product that enables users to create interactive novels that can be hosted online. These interactive novels are often based on requiring users to move forward in the narrative by selecting between two choices that will then take the user onward into the narrative, functioning as a “choose your own adventure” structure. Creating this product meant first determining the research questions, becoming aware of the pre-existing interactive novels and games, building a series of autoethnographic journal entries about the researcher’s experiences with hearing loss, translating those journal entries into a Twine narrative, and finally combining the narrative with the Twine engine itself. Each of these factors works together to take an initial idea of creating an informal learning experience that will provide users with a deeper insight into the impact of hearing loss on everyday life. The next section will discuss the research questions and their relation to the development of *Under the Rock*.

Research Questions

Before building this product prototype, it was important to determine what would be the primary focus of this project. The highest priority was to create a digital experience that would provide insight into how an invisible disability such as hearing loss impacts a person’s daily life in multiple ways that go unnoticed by those without the invisible disability. In deciding on the research questions for this project, two main research questions (with corresponding secondary questions) became clear:

1. How does an interactive narrative structure help in teaching users about invisible disabilities?
 - a. How does an interactive narrative help users gain an understanding of another's experience that differs from their own daily experiences?
 - b. How can the reflections and insights gained through autoethnography be translated into a game narrative?
2. How can an interactive narrative created in Twine be used to improve a user's understanding of hearing loss's effect on daily life?

At the core of these research questions is a goal of determining how successful using an autoethnographic methodology to translate twenty years of living with hearing loss into an interactive digital experience that will be used to informally educate users on the numerous ways hearing loss impacts one's daily life. The next section reviews the environmental scan that was conducted to find an available niche within the game design world.

Environmental Scan

To design a more effective product, the researcher needed to conduct an environmental survey to learn what other approaches have already been attempted. With this in mind, the researcher looked at previous research in Deaf Culture (previously discussed in the literature review), audiology, and game designers to see what types of products have already been created.

Audiologists and other medical professionals have developed several products focused on helping patients adjust to their hearing loss, adjust to their hearing aids, or to help their loved ones understand what hearing loss is like. There are apps such as Games 4 Hearoes_(2020), Auditory Workout (2012), AB Listening Adventures, VocAB Scenes, Hear Coach_(2016), and

Auditory Training that are meant to help children and adults with hearing loss to improve their ability to distinguish and understand different environmental sounds. Some companies such as Starkey have developed a hearing loss simulation program users can access online to gain an idea of how mild, moderate, and severe hearing loss impacts someone in a variety of situations. Separate from these products, the researcher's Twine experience places users in an interactive story in which they follow the main character through daily life situations that are affected by hearing loss.

In reviewing existing games addressing invisible disabilities, the researcher found several listed on itch.io through the website's search function using keywords such as 'hearing loss' and 'invisible disabilities'. Search results for various invisible disabilities included games for hearing loss, anxiety, depression, ADHD, and fibromyalgia. The games about hearing loss were the most difficult to find as the game creators had used more abstract titles for their games while the developers for the other categories of invisible disabilities were more likely to use 'anxiety,' 'depression,' or 'ADHD' in the game titles. These results revealed that other game developers were certainly interested in educating others about their journey with mental health, and there was still plenty of room to create something new. The next section will discuss the autoethnography production journal that was kept as part of this prototype's development.

Autoethnography Production Journal

To create the interactive narrative of the Twine game, first the researcher had to draft the collection of autoethnographic journal entries that would highlight the variety of experiences the researcher has had through the past twenty years of living with hearing loss. These journal entries were drafted throughout the summer months of 2021 (June-July), shortly after this the initial story map was drafted (see figure 1 below).

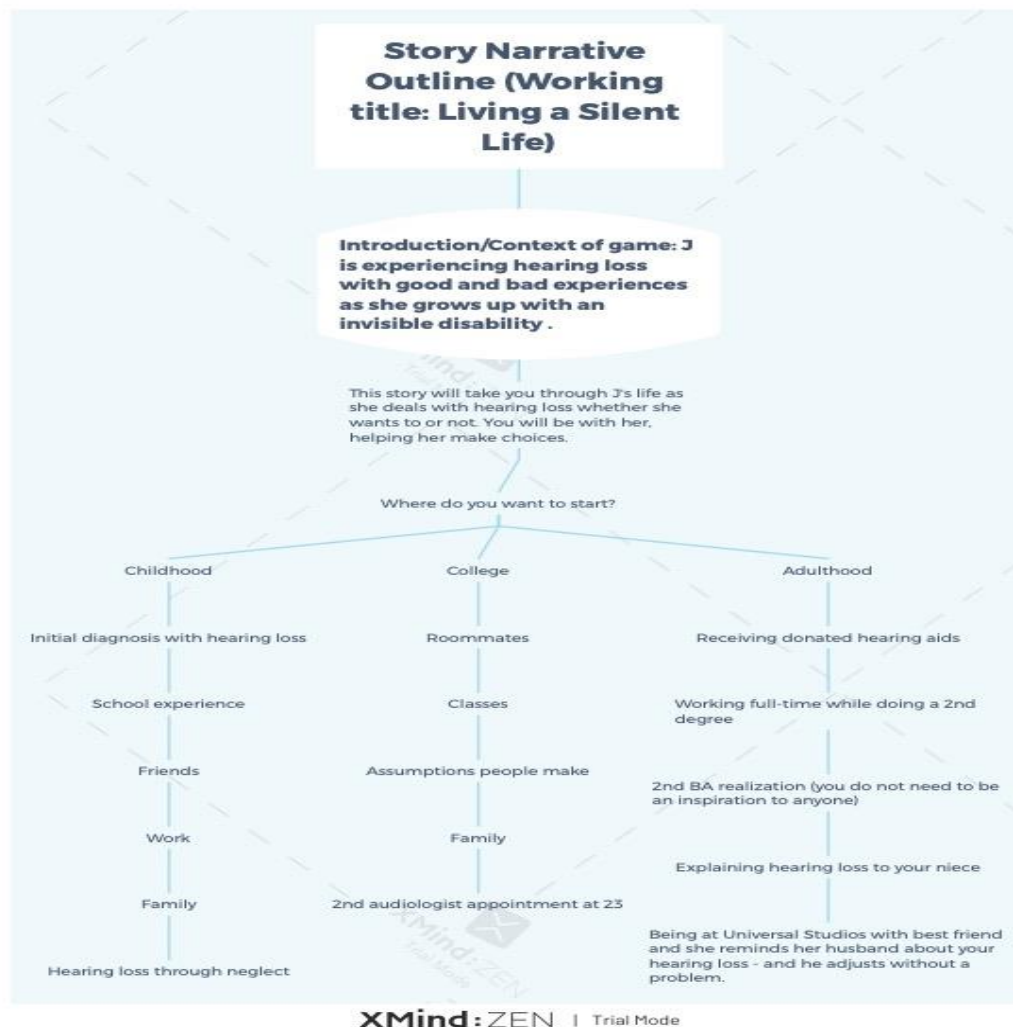


Figure 1. Initial Story Narrative Outline

This initial story map helped the researcher to categorize the variety of experiences documented into a comprehensible story. Instead of being the patchwork of difficult and confusing memories that the researcher had been working to understand for several years, it could now be seen as a progression of experiences that could be translated into a game.

It should be noted that drafting these journal entries was not an easy task to accomplish, largely because of the emotional and mental impact. Initially, the researcher had thought it would be a matter of setting aside time for a few weeks to write, and that would be the end of it. The entry about the initial diagnosis of hearing loss is the only entry the researcher handwrote (as she had planned to write all of the journal entries). As time was dwindling, she tried using the dictate function in Word instead and used this to document the remaining journal entries. An additional challenge the researcher encountered was focusing on the memories she needed for these journal entries caused a series of migraines as some of these were moments that had become associated with trauma. It was after the third migraine in three days that the researcher chose to document her remaining journal entries by dictating in Microsoft Word. The next section discusses the development of the Twine narrative for the prototype of *Under the Rock*.

Twine Narrative

After completing the autoethnography journal entries, the next step was to translate those entries into a narrative that would be compatible with Twine's interactive structure. Even though the journal entries were completed using an autoethnographic methodology (Chemi 2020, Tosca 2020, Frank 2017), initially it was challenging to translate the entries into an interactive narrative written from a first-person perspective. As a result of the initial difficulties of drafting the journal entries from dredging up difficult memories, it was challenging to write the first draft of the

Twine narrative. To work around this initial difficulty, the researcher created the main character (named “Isana”) and wrote the first draft in the 3rd person perspective to walk myself and the user through the interactive narrative. After completing this 3rd-person narrative, she was able to convert the narrative to 1st person as experienced by Isana.

While the purpose of the journal entries was to document the variety of experiences, the researcher had living with hearing loss and document the numerous ways hearing loss has had an impact on various parts of her life, the Twine narrative has a different purpose. The Twine narrative is meant to be an informal learning experience (Hainey et al. 2016, Schaller 2015) between the user and Isana as the user helps Isana to choose how to react to different situations as she goes through childhood and adulthood. As it is an interactive experience, the user does not know how the story ends or how their choices impact the narrative, this step in the prototype creation required being able to let go of the memories the researcher had used for the narrative so others could interact with them. A challenge for utilizing this methodology to document someone’s experiences living with and adapting to an invisible disability is quite often those memories are surrounded with frustration. It is not uncommon for someone living with an invisible disability to be ignored when they try to explain to others what they are experiencing, or the potential help they need (Meador & Zazove 2005). As a result, crafting a narrative based on someone’s experience with an invisible disability can be challenging if they have become jaded and no longer believe a “normal” person may want to understand what they are dealing with.

Through a round of beta testing in November 2021, it became clear the Twine narrative would be more effective and impactful written in first person. Drafting the updated narrative to be in first person was an easier exercise for two reasons: it required revising the narrative rather

than drafting the initial version of the interactive narrative and telling the story through Isana's lens. Through making this perspective adjustment, the narrative became more immersive and interesting for the reader. Rather than being told what had happened in the situation described, the reader is now reading about Isana's initial thoughts as she experiences each situation and processing the information provided as Isana is also learning to cope with the impact of her hearing loss has on her daily life.

Beta testing also revealed the initial Twine prototype contained too much text on each screen, causing users to scroll and spend too much time on each screen, resulting in a loss of interest in the experience. To improve the effectiveness of this prototype, the narrative's Twine layout was broken into chunks that fit on the screen without the user needing to scroll. The next section will discuss the design elements of the Twine prototype.

Product Design/Layout

In this section, the researcher will review the main design components of the Twine prototype's layout including the story map, characters, levels, styling, and assets. The technical design of the Twine prototype was arguably just as important as the written narrative. While the design is as visually advanced or as immersive as other types of media (e.g., virtual reality, 3D graphics, or augmented reality) the design did need to be unified to avoid the user becoming distracted from the intended message of the prototype. This section provides an overview of several key elements to this prototype's design, and a full design document can be found in Appendix B.

Story Map

The story map is the path the user takes through the interactive narrative through the choices made in each scenario. In general, users follow a similar path: all users start in Level 1: Childhood and progress through most of the same scenarios until they complete Level 3: Adulthood. There are a few side quests users can discover along the way that will provide additional information and potential insight into the main character's experiences. The next section discusses the character creation for the prototype.

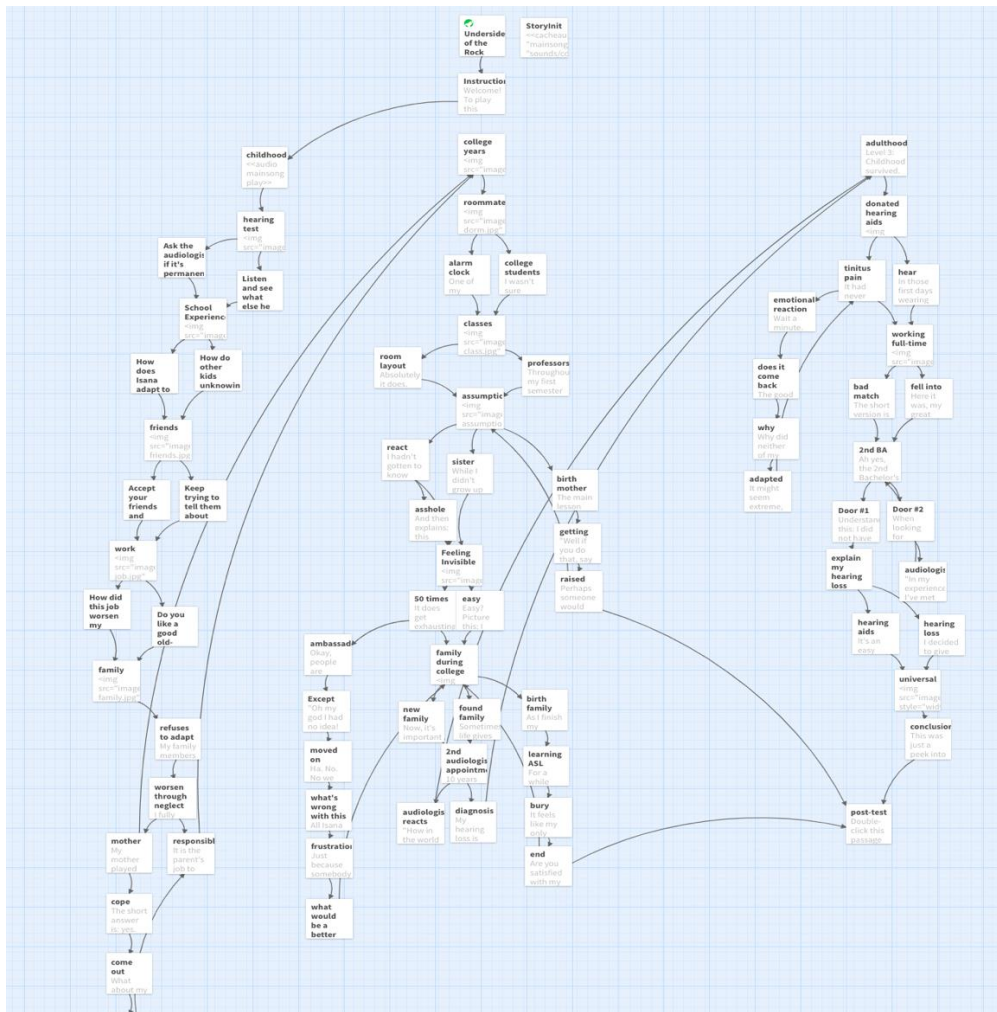


Figure 2. Overview of the story structure

Character(s)

The primary characters of this Twine prototype are the main character, Isana, and the user. Isana is introduced in the 2nd screen when an introduction to the game is provided: here the context of the story is provided, and Isana asks the user to help her decide what to do throughout the game. As a character, the user maintains their identity throughout the game experience. The purpose of having the user be a character in the game is to make the user feel like an active participant in the experience and ideally increase the user's level of learning through their influence on the narrative. The full description of Isana's character, taken from the design document (available in Appendix B), is:

“Main Character: Isana

Back story:

Isana's back story is based on my experiences living with hearing loss. I chose to give this character a different name instead of using my name because it was easier to write her narrative if she had a different name, and it made it easier to imagine the alternate choices she could potentially make if she were slightly separated from myself. Her childhood was difficult after she was diagnosed with hearing loss because her family then ignored it and acted as though she should understand how to handle it and overcome it. They made her feel like she was continually failing and had to hide her hearing loss because it was an excuse if she did try to talk about it. Because nobody talked about it or treated it like it was real, she didn't know how things would change in college. It wasn't until she got older and entered adulthood (college and her adult years) that she met people who were understanding and were curious about her hearing loss instead of treating her as though it was a problem she needed to deal with alone.

Personality:

Isana is a shy but determined person. She doesn't want to cause problems or be a problem to others. Her main goal in life is to understand how she can fit into the world, see more of the world, and be happy. Because of her early life experiences, she's also standoffish and distrusting of people, but she will warm up to people as she gets to know them. When she is making choices in this game she must ask herself “how important is it that I push my stance on this?”

Is it worth it to be aggressive or will things work out if I'm passive in this situation?" Because of her severe hearing loss she has a louder voice than most people and is also not very skilled as subtlety, and as a result, can be perceived as being aggressive when she tries to stand up for herself when she just wants to be listened to.

Relationship to other characters:

Isana is the main character in this story, there are brief mentions of people she meets throughout her story, but they do not become active characters in the game. She does have interactions with each NPC (non-player characters) (described in Section I, NPC's) to show the difference their reactions to her hearing loss makes in her daily life. Each of the experiences she has with them became moments that inspired her to feel hopeful about her life with hearing loss." (Appendix B)

There are also a few non-player characters (NPCs) that make brief appearances in the Twine prototype. While none of these characters are mentioned more than once or twice throughout the Twine narrative, they are briefly described in the design document. Each of the NPCs is based on a person from the experiences documented in the autoethnographic journal entries (the autoethnographic journal can be found in the design document in Appendix B). These NPCs could become more active in the experience in future prototypes, but this prototype focuses exclusively on the user's interactions with Isana. The next section reviews the levels the narrative for *Under the Rock* is divided into.

Levels/Scenarios

Under the Rock is comprised of a series of 3 levels with plot points within each level. These plot choice points were inspired by the autoethnography journal entries that were written as part of the game's development process. The levels, and a brief explanation of each plot choice point's intended purpose, are as follows:

- Level 1: Childhood

This level begins the user's journey with Isana as she receives her initial hearing loss diagnosis. Both Isana and the user have no understanding yet of how hearing loss can impact one's life.

- Plot Choice Point: Initial diagnosis with hearing loss

This point shows an example of how a child's hearing loss diagnosis has been handled, specifically focusing on the child's perspective as she is ignored by the audiologist.

- Plot Choice Point: School experience

At this point, users are shown how Isana's school experience has started to shift as she acclimates to her hearing loss. Her daily life begins to be impacted by her diagnosis being ignored by her family (as her school also doesn't know about it).

- Plot Choice Point: Friends

Isana's friends don't see her hearing loss as an actual problem, and she must decide if she should try to make new friends or if she should accept her friends' opinions.

- Plot Choice Point: Work

This point shows how Isana starts learning about getting a job, and how the two jobs she has have their effects on her life. One job highlights how her hearing loss makes her less aware of her surroundings, and the other job may damage her hearing.

- Plot Choice Point: Family

With this plot point, Isana talks about the rough treatment she gets from her family members, especially her mother. This is meant to impress upon the user that Isana's

hearing loss is now a point of anger by her family that she has no control over – even though they are acting as if she does control it.

- Plot Choice Point: Hearing loss through neglect

This plot point steps away from having the user help decide how Isana should react to a situation, and instead directly educate the user on how the parent of a child with hearing loss does carry responsibility for maintaining the child’s health.

- Side-quest with the mother’s responsibility

This supports the plot point “Hearing loss through neglect” to discuss how Isana’s mother impacted her daughter’s worsening hearing loss.

- Level 2: College

At this level, Isana is getting to explore life away from home. The plot choice points in this level largely show the user how her hearing loss impacts situations throughout her college years.

- Plot Choice Point: Roommates

This is a minor plot point, largely meant to serve as an example of how hearing loss impacted a situation at a more minimal level while still causing frustration.

- Plot Choice Point: Classes

Differing from Isana’s classroom experiences, the classrooms in her college are far different and create new obstacles due to hearing loss. Now the user must help her maneuver through them.

- Plot Choice Point: Assumption’s people make

There are several common assumptions people tend to make when a person with hearing loss doesn't react to them. Here the user is faced with this information as well as the different ways some people react to people with hearing loss.

- Side-quest: exploring the impact of the assumptions made by Isana's birth mother

As Isana has met more people in college, she starts to think maybe her mother's way of dealing with her hearing loss was wrong.

- Plot Choice: Feeling Invisible

This plot point addresses the frustrations Isana feels as she continually works to adapt to her hearing loss and function as normally as possible without inconveniencing others.

- Side-quest: Being an ambassador to the Deaf experience

Isana explains to the user that, just because she lives with hearing loss, it does not mean she also has to serve as everyone else's ambassador to the Deaf experience.

- Plot Choice Point: Family

Isana has learned that, as an adult, she is able to choose whom she wants to be in her family. If she wants to, she can form a new family.

- Side-quest: attempting to maintain a relationship with the birth family

This offers users to learn what would likely happen if Isana made the choice to continue having a relationship with her birth family.

- Plot Choice Point: 2nd audiologist appointment at age 23

This plot point takes Isana through her 2nd time visiting an audiologist and the diagnosis she is given, as well as the questions she finally has answered.

- Level 3: Adulthood

This level shows how Isana continues to adapt to her hearing loss after college.

- Plot Choice Point: Receiving donated hearing aids

Isana is offered a pair of donated hearing aids by her audiologist and is finally able to learn about the sounds she has been missing.

- Side-quest: the emotional realization that the years of tinnitus pain could have been avoided if her parents had not neglected her

In this plot point, Isana faces the anger she feels upon realizing how much harder living with hearing loss has been for no reason.

- Side-quest: Learning about assistive technology

This plot point presents an introduction to four types of assistive technology that can be used to help someone adapt to hearing loss.

- Plot Choice Point: Working full-time while doing a 2nd BA degree

Here Isana is trying to figure out what she should do for a career and follows someone's advice to complete a degree in speech-language pathology.

- Plot Choice Point: 2nd BA realization

This plot point is one of Isana's first times having to confront ableist-inspired advice. She learns that she does not need to overcome her hearing loss.

- Plot Choice Point: Explaining hearing loss to your nieces

Within this plot point, Isana answers her niece's questions when she sees Isana's hearing aids for the first time.

- Plot Choice Point: Universal Studios with friends

This plot point highlights the positive experience Isana has when her best friend takes action to remind her husband about Isana's hearing loss.

- Plot Choice Point: Conclusion

This final screen concludes Isana's story up to this point in her life.

Because this prototype is designed in Twine, users can restart the experience and play as many times as they would like to if the user wants to replay the experience to try different choices.

This ability can make it easy for users to complete all potential choices and see the maximum number of screens if they decide to play through *Under the Rock* multiple times. The next section will review the styling that was used for augmenting the visual appearance of *Under the Rock*.

Styling

The styling of the Twine prototype was done using a Cascading Style Sheet (CSS). The researcher found the "Simple Centered" example stylesheet meant for Twine on the Glorious Trainwrecks website (<https://www.glorioustrainwrecks.com/node/5163>). This CSS example is an uncomplicated design with a fading blue background and centered text (the full stylesheet can be found in the design document in Appendix B). The researcher wanted a simple styling for this prototype that would differentiate it from a blank web screen but did not detract from the text of the narrative. The CSS styling also ensures the entire game has a consistent design style and avoids causing the user confusion as they are processing the information in the interactive narrative portion of *Under the Rock*. Next, the assets that were used in the prototype are discussed.

Assets (Sound & Images)

While the text of the narrative is the most important part of the Twine prototype, sound files and images were added throughout the prototype to make it more engaging for users. Different sound files were used in several scenes to provide a better understanding for users about the confusion people with hearing loss can experience in different settings. In general, the sounds are meant to simulate the disorientation that can be felt in noisy environments or any environment where someone is trying to understand multiple audio stimuli – something that can be particularly challenging with hearing loss. For example, the initial audiologist appointment in Level 1 incorporates a sound file that is terribly similar to what one hears when in a sound booth during a hearing test. Depending on how quickly the user clicks through this scenario and proceeds to the next scene, the user may experience overlapping sounds (such as having the audiologist sound overlap with the classroom sound).

The researcher used a header image at the beginning of each scenario to try to create a feeling of visual interest and something for the user to connect with visually as they continue into each scenario. For this prototype, she found stock images with a creative commons license that were in a similar image style and applied a black and white visual filter in Photoshop to further unify them. The next section will summarize the key ideas that were discussed throughout this chapter.

Conclusion

Throughout this chapter the researcher has summarized several of the main elements that went into the design methodology for the Twine prototype. From the product research that took place before drafting the Twine prototype, drafting the autoethnographic journal entries, translating the journal entries into an interactive narrative, and styling the Twine interface, the researcher has provided an overview of the different types of work that went into building this Twine prototype. This design resulted in an interactive narrative that would allow users to make their own decisions of how to react to each given scenario. In the next chapter, the researcher will discuss the development of the survey study that was run to test the initial effectiveness of this prototype in answering the overarching research questions outlined in the Introduction.

CHAPTER 3 METHODOLOGY OF THE SURVEY STUDY

This chapter will review the creation and design of the survey study that was used to test the initial effectiveness of the Twine prototype. The purpose of this survey study is meant to determine where the prototype is successful in showing users the impact hearing loss has on a variety of situations in everyday life throughout each stage of someone's life from childhood through adulthood. This survey is comprised of a pre-test and post-test to measure any changes in user response as well as gather feedback about the technical design of the Twine prototype. Within this chapter, several factors that influenced the study's design will be reviewed including research questions, the survey's design, the virtual design of the study, and the Institutional Review Board (IRB) process. After this chapter, the factors that influenced the survey study's design and the intended goals of the study should be clear.

This study was run throughout January-February 2022 and had a total of 97 participants in the pre-survey and 71 participants in the post-survey. These survey participants were asked to complete 3 steps: complete a pre-survey, play the Twine game prototype, and complete a post-survey. All elements of this study were entirely online, and participants were able to complete the survey remotely to maintain their safety during the ongoing COVID-19 pandemic. The full reports for the pre-test and post-test generated by Qualtrics can be found in Appendices E and F, respectively. Throughout this chapter, the researcher will provide the survey data results for the pre-survey and post-survey responses and provide an analysis of this data. The next section will discuss the main research questions of this dissertation in relation to the survey study.

Research Questions

In looking specifically at this survey study, the questions the researcher is focusing on are:

1. How does an interactive narrative structure help in teaching users about invisible disabilities?
 - a. How does an interactive narrative help users gain an understanding of another's experience that differs from their own daily experiences?

These research questions will be answered by the survey study by making it possible to measure how survey participants' answers in the pre-survey compare with the post-survey after completing the Twine game. While the other main research questions the researcher have are related to the design of the Twine game and how an autoethnographic methodology can be utilized to translate one's personal experiences into an interactive narrative, this main research question and sub-question focus on measuring the game's impact after they have completed playing through the Twine game.

The results of this survey study will provide the initial indicators of how effective this prototype is in conveying the information the researcher has set out to informally teach. She will discuss the individual questions later in this chapter, but in general, users will be exposed to a variety of situations that are impacted by hearing loss and the survey questions ask participants to rate their knowledge in a variety of deafness-related categories, as well as feedback about the Twine game's design. The next section will discuss the survey study's design.

Survey Design

The main goal in designing this survey study was to gather data that would allow the researcher to measure if the Twine game can change a user's awareness levels of hearing loss as something that impacts a person in ways that are unnoticeable by someone without this invisible disability.

When designing the pre-survey and post-survey for this study, the main items the researcher focused on first were the areas of knowledge she thought were most important about the hearing loss experience that she hoped were impactful in the Twine game prototype. It was important to consider the themes the researcher focused upon from her experiences living with hearing loss that was communicated in the narrative of the game. Otherwise, it would have been too easy to create survey questions that called upon information and themes from Deaf culture that were not relevant in the autoethnography experiences.

To adapt this study to the COVID-19 pandemic, it was designed to be executed entirely online. The pre-survey and post-surveys were created using Qualtrics and can be sent online for survey participants to complete. The Twine game was publicly hosted online on the website itch.io for participants to access. While in different circumstances it may have been possible to have additional testing parameters for this study, the researcher focused on the pre-survey and post-survey and made everything available online to make the process accessible for study participants while maintaining their safety during the COVID-19 pandemic. The next section will discuss the survey parameters for potential participants.

Survey Parameters

To best determine the target population of this survey study, a series of parameters needed to be outlined. Participants had to be 18 years old or older and not have reported hearing loss. First, participants would complete the pre-survey first, which should take approximately 10 minutes to finish. Next, participants would play through *Under the Rock*, spending approximately 15-20 minutes playing. Last, participants would complete a post-survey, which should take approximately 10-15 minutes to finish. Utilizing these design parameters helped to maintain the focus of this study on measuring any changes in the study participants' answers in the pre-survey and post-survey. Any changes noted between these surveys would indicate how effective this Twine game's narrative is as an informal learning tool to educate users about the impact of an invisible disability on daily life activities. The next section summarizes the survey questions used in the pre-test and post-test.

Survey Questions

The pre-survey questions focused entirely on measuring the participant's initial perceptions and opinions about hearing loss, with the questions of this section being framed to the participant as "please answer these questions as though you have sustained severe hearing loss." Questions in this section are made up of statements and ask participants to rate their level of agreement or familiarity depending on the statement. The full list of pre-survey questions in this section is as follows can be found in Appendix C.

The post-survey includes this Part I section from the pre-survey, while also having a Part II (Feedback on the Interactive Experience) and Part III (Background Information). Part II will

gather user feedback about the Twine game through a series of questions and statements about the Twine game that will help to improve the design of future iterations as the game is developed. The post-survey questions can be found in Appendix D. The goal with the questions in Part II of the post-survey, as it can be seen from the questions outlined above, is to gather participant feedback regarding the design of the Twine game: which scenarios were potentially the most impactful, which scenarios were least impactful, and how easy the game itself was for participants to use.

Part III of the post-survey is meant to gather basic demographic information such as age, gender, and if the participants personally know someone with hearing loss. The goal with this section is to have the demographic data at hand in case there are any noted correlations between specific demographic points and any potential shifts between the pre-survey and post-survey results. The questions for Part III can be found in Appendix D. These demographic questions were placed at the end of the post-survey to avoid potentially influencing the participants' responses to Parts I and II of the post-survey. In initial drafts of the demographic questions, participants were asked to select from provided options. However, after consultation with CASTLE Labs at the University of Central Florida, the demographic questions asking for age and gender were changed to free-response questions. These questions were modified to free-response to provide a more accurate understanding of participants.

Participants

Survey participants are a key part of this study, and the study has been designed to be easy to complete and maintain their safety during the pandemic. For this study, the researcher specifically sought out participants that were 18 years old or older, and preferably those with

minimal experience with hearing loss. The Twine game is best experienced by adults because it covers stages in life that people who are 18 or older can comprehend realistically rather than it being a concept that does not yet make sense. After all, it has not yet been experienced by the participants (e.g., Childhood, College, and Adulthood).

The study was promoted through social media channels to find those individuals who would potentially be most interested in testing *Under the Rock*. This consisted of Facebook groups that were related to hearing loss (Hearing Loss Community – HLC and Living with Hearing Loss Group), graduate school (PhDivas, Working Folks’ Guide to a PhD/EdD, UCF Texts & Technology Graduate Student Organization, and Research Scholar group), user experience research-related groups (Student Volunteers | SIGGRAPH 2019, Women in UX and User Research Collective), and technical communication (Florida Chapter of STC, and Technical Communication and Rhetoric Scholars). In addition to this, the researcher also shared the study information on her LinkedIn profile.

The recruitment information used in these social media posts outlined the qualifying factors for potential participants. These factors included age (participants needed to be 18 years old or older), a lack of hearing loss (participants without hearing loss), and minimal levels of awareness related to hearing loss. In order to complete the study, participants were asked to complete three steps: the pre-survey, play through *Under the Rock*, and the post-survey. The time commitment was estimated to take a maximum of 45 minutes to complete the entire study.

Information for the study was promoted in social media groups throughout the month of January 2022. As a minimum recruitment goal, the researcher aimed to have 30 participants complete the study, and in total 71 participants completed the entire study (meaning these participants completed the pre-test, played through *Under the Rock*, and completed the post-test).

When this study was launched in January 2022, online recruitment began in full force. In addition to recruiting online, the researcher emailed numerous professional contacts with the study information. The researcher also reached out to the University of Central Florida's School of Communication Sciences to ask if any professors thought the study would be a good fit for their students. One professor responded that the study would be a good introduction to research for her students and offered it as an extra credit activity in one of her courses.

These recruitment efforts resulted in 71 individuals completing the entire study. Of these participants, 51 provided responses in the demographics question asking for their age range. These responses broke down as follows: 37 participants reported an age range between 20-30, 13 participants reported an age range between 30-40, 6 participants reported an age range between 40-50, and 1 participant reported an age range between 60-70. The second demographics question asked participants to indicate their gender, and 59 participants provided an answer to this question. The responses to this question broke down as follows: 8 participants reported as "male", 49 participants reported as "female", 1 participant reported as "non-binary", and 1 participant reported as "agender." The next section will briefly discuss the virtual nature of this survey study.

Virtual Study

When this study was initially discussed in Summer 2020, adapting the study design for the COVID-19 pandemic was unavoidable. While there are several potential methodologies to utilize when designing a qualitative study, the researcher focused on designing a survey that included Likert scale questions and free response questions to gather as much information as possible through the survey study. These surveys were then formatted into Qualtrics to be

distributed online. The survey instruments were then submitted to the IRB, which granted its approval on January 11, 2022.

Conclusion

Throughout this chapter, the researcher have focused on reviewing the design of the survey study and the motivations behind those design choices. From addressing the research questions related to this survey, the survey design, the survey questions, the virtual nature of the study's design, and the IRB process, this chapter has addressed each element of the survey's creation. In the next chapter, the researcher will report the results of this survey study.

CHAPTER 4: DATA FROM THE SURVEY STUDY

In this chapter, the data gathered through the survey study are reviewed. As was discussed in Chapter 3, this survey study was designed to gather user feedback on the Twine game prototype. Throughout this chapter, the researcher will provide the survey data results for the pre-survey and post-survey responses and provide an analysis of this data. The next section will review the pre-test results.

Survey Data Results

Pre-test results: Setting a baseline

The purpose of the pre-test was to set an initial baseline of participants' knowledge related to hearing loss information. In this section, the researcher will provide an overview of each of these pre-survey questions and the most dominant response for each question. Overall, participants had anticipated emotional reactions in considering the possibility of having to experience hearing loss. Additionally, most participants reported strong agreement that they would be treated differently by friends, family, and coworkers if they had to adapt to a new hearing loss diagnosis. Finally, while most participants claimed to be moderately familiar with hearing aids, they were unfamiliar with additional types of assistive technology. These pre-test results presented a survey population that has some awareness of hearing loss and the negative impact it could have on an individual's life. The pre-survey results are reviewed below with

graphs from the Qualtrics report to accompany them (the full pre-survey data report can be found in Appendix E).

Question 1: Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):

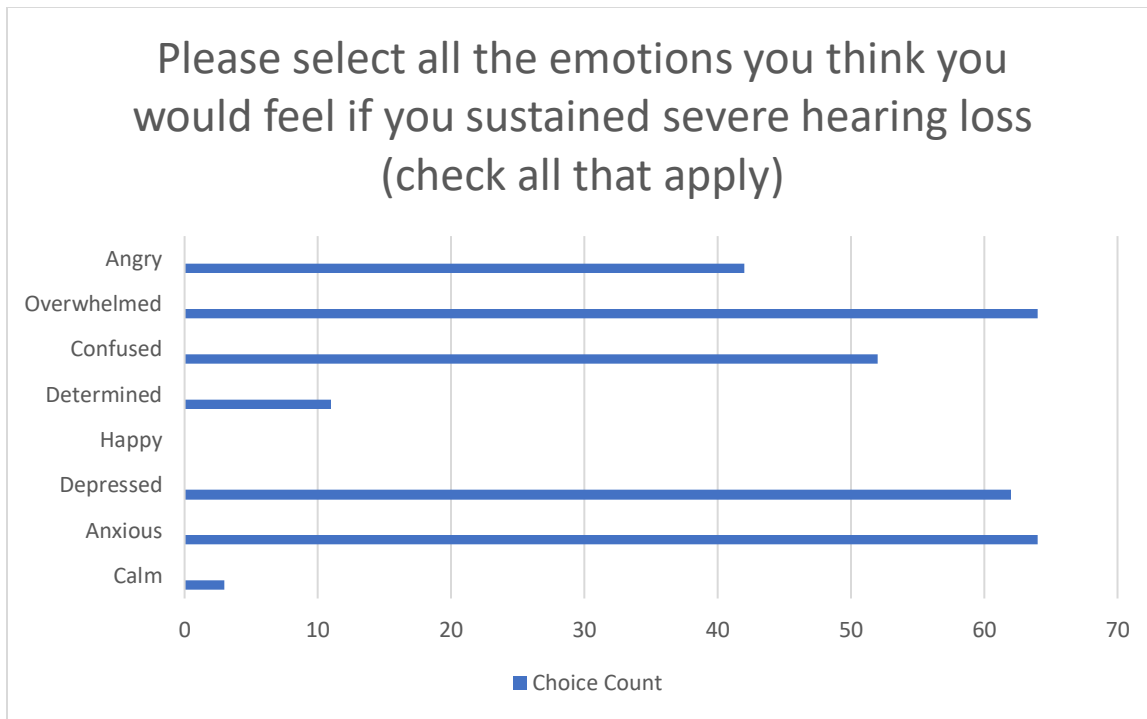


Figure 3. Bar graph of emotional reaction to hearing loss diagnosis (Question 1)

The above graph reflects participants' choice counts for the first question of the pre-survey. From the results of this question, the two most selected emotions for this question were anxious and overwhelmed, both were selected 64 times. The third most selected option (selected 62 times) was 'depressed'. In this pre-test question, 'happy' was selected 0 times, which was unsurprising since diagnosis with an invisible disability is not often cause for joy. These emotion selections begin to paint an image of a participant population that could be seen as unsure of how to handle a hearing loss diagnosis. Three participants did select 'calm' as one of their emotions,

which may be from a few participants that were from the UCF School of Communications and Disorders. These participants likely have a higher-than-average exposure to hearing loss as a result of their coursework.

Questions 2-9: Please rank the following statements depending on if you ‘strongly agree,’ ‘agree,’ ‘neither agree nor disagree,’ ‘disagree,’ or ‘strongly disagree.’

Table 1 Pre-Test Questions 2-9 Results

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
I think hearing loss would impact my daily life.	72	6	0	0	0	78
I think my friends would view me differently if I sustained significant hearing loss.	20	32	13	12	1	78
I think my family would view me differently if I sustained significant hearing loss.	22	28	9	13	6	78
I think my work associates would view me differently if I sustained significant hearing loss.	32	30	8	7	1	78

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.	22	23	13	16	4	78
If I had severe hearing loss, I would consider wearing hearing aids.	59	13	5	1	0	78
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language)	63	10	4	1	0	78
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	38	32	5	1	1	77

This set of statements focused on gauging the participants' assumptions of how people in their lives would react to a hearing loss diagnosis. Building upon the initial question, which asked participants to choose the emotions they would feel if diagnosed with hearing loss, this series of statements cause participants to consider what may change in their lives after a hearing loss diagnosis. As is seen in the charts above, the participants' responses can be summarized as:

participants know hearing loss would impact their life and it is likely several people in their lives may view them differently if they were diagnosed with hearing loss. Gauging participants' initial views regarding these statements was an important baseline to have in this study because these assumptions would influence how they would react to the scenarios in *Under the Rock*. For example, participants that are entirely unaware of the changes hearing loss can have on one's life would be taken aback by the situations they are exposed to in the game's narrative. Contrary to this, participants with some minor exposure to hearing loss and as a result have some basic understanding of this diagnosis would experience less shock at some of the more intense scenes in *Under the Rock's* narrative. These answers are indeed very personal, as every person is different, and this is seen the most in the answers for the statement "If I had severe hearing loss, I would be comfortable explaining my hearing loss to others." The 78 responses to this statement were the most spread out across the Likert scale, showing greater amounts of uncertainty in the participants. It is quite possible that when faced with this statement, participants had diverse opinions about how the people in their lives would react. While a majority of respondents were in agreement that they would be comfortable explaining their hearing loss, this question had a higher-than-average amount of neutrality or disagreement.

Questions 10-13: Please rate your current knowledge of the following types of assistive technology from 'minimal,' 'moderate,' or 'advanced'

Table 2 Pre-test results for questions 10-13

	Minimal	Moderate	Advanced	Total
Hearing aids	18	49	11	78
Cellphone haptics (vibration)	49	24	5	78
Screen readers	45	28	5	78
Transcription devices	34	34	10	78

These statements about assistive technology were added to the study to add additional educational content to the narrative. After one is diagnosed with hearing loss, a subsequent experience is to learn about multiple types of assistive technology for hearing loss (Chisolm, Noe., McArdle, & Abrams, 2007). In rating participants' awareness of four types of assistive technology, the responses regarding cellphone haptics need to be noted. This result may be the result of the researcher using misleading terminology as "cellphone haptics" refers to the vibration feature available in a majority of cellphones. If the researcher had used the term "cellphone vibration" the results may have been vastly different in this question.

After participants completed the pre-survey portion of the study, they were provided a link to the Twine game, *Under the Rock*, and asked to play through the game. Participants were given a general time estimate in their initial recruitment into the study (to plan for 45 minutes

maximum to complete the game) and told the link to the post-survey would be found at the end of the game. The next section will review the results of the post-test portion of the study.

Post-test results

The post-survey was used to measure any changes participants had in their thoughts and opinions related to hearing loss after playing *Under the Rock*, as well as gather design feedback about each level. This section reviews the post-survey questions and their most common responses. It is important to note that, unlike the pre-survey, the post-survey is made up of three sections. Section One is identical to the pre-survey questions, Section Two questions ask for feedback regarding the game's design, and Section Three is made up of demographic information. The next section will review the post-test compared with the pre-test results.

Section One: Baseline Questions – What changed?

Question 1: Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):

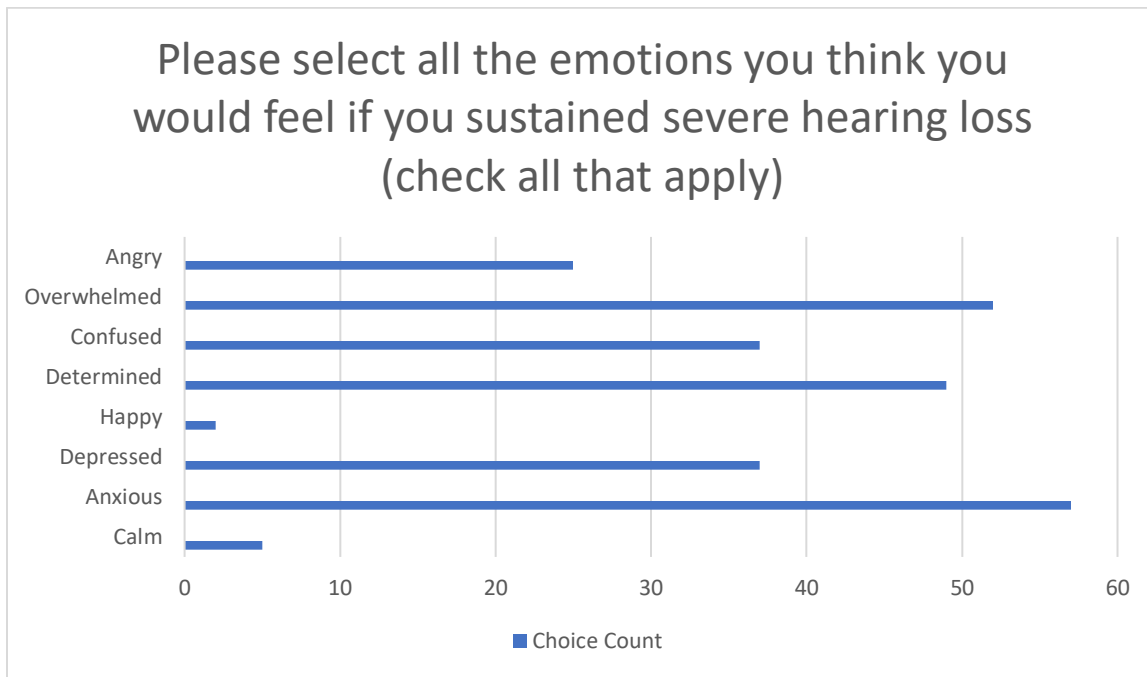


Figure 4 Post-test emotional responses to being diagnosed with hearing

Contrasting with the responses in the pre-survey, 3 participants did select “happy” as one of their emotional responses to receiving a hearing loss diagnosis. While this was an unexpected shift in responses, it may indicate that after playing *Under the Rock*, participants felt more prepared for handling a hearing loss diagnosis. This question also saw a rise in “determined” responses, which may also reflect participants’ feeling better prepared for handling this diagnosis. In comparing these results with the pre-test results, after playing through *Under the Rock*, a significantly higher number of participants now report feelings of determination. It is possible that participants’ experiences in guiding Isana through *Under the Rock* left them feeling a greater sense of preparedness if they were diagnosed with hearing loss.

Questions 2-9: Please rank the following statements depending on if you 'strongly agree,' 'agree,' 'neither agree nor disagree,' 'disagree,' or 'strongly disagree.'

Table 3 Post-test results for questions 2-9

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
I think hearing loss would impact my daily life.	52	14	0	0	0	66
I think my friends would view me differently if I sustained significant hearing loss.	20	25	7	9	5	66
I think my family would view me differently if I sustained significant hearing loss.	19	25	7	9	5	65
I think my work associates would view me differently if I sustained significant hearing loss.	22	29	6	7	2	66
If I had severe hearing loss, I	23	28	5	9	1	66

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
would be comfortable explaining my hearing loss to others.						
If I had severe hearing loss, I would consider wearing hearing aids.	53	8	4	1	0	66
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language)	58	4	1	1	1	65
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	28	28	6	4	0	66

The responses for these statements did not shift greatly from the pre-test responses, leading the researcher to conclude that *Under the Rock* reinforced participants' assumptions regarding these statements. Recall that the narrative moments used in *Under the Rock* were largely focused on the less seen, and often more challenging, moments one could experience with hearing loss. With this in mind, it is a reasonable conclusion that participants left the study with strong convictions that their personal lives would shift if they ever received this diagnosis even though the results for this set of questions did not shift greatly between the pre-test and the post-test. By combining these responses with the changes in the first question (regarding emotional response), one could interpret these results as an increase in being prepared to handle these potential situations.

Please rate your current knowledge of the following types of assistive technology from 'minimal,' 'moderate,' or 'advanced'

Table 4 Post-test results for questions 10-13

	Minimal	Moderate	Advanced	Total
Hearing aids	9	46	11	66
Cellphone haptics (vibration)	35	23	7	65
Screen readers	32	26	8	66
Transcription devices	28	28	19	66

This portion of *Under the Rock*'s narrative was not as impactful based upon these post-survey results. There were slight shifts from the pre-test results, but these were quite minor. The side quest in Level 3 that focused on assistive technology was quite short and optional with only minimal information about each type of assistive technology, and only provided a brief introduction to this information. This portion of the post-survey results indicates that in future iterations this portion of the interactive narrative would need to either be expanded upon or removed. The next section of the post-survey results will review the participant feedback on the design of *Under the Rock*. The next section will discuss the results of the second section of the post-test, which focused on experience design feedback.

Section Two: Experience Design Feedback

This portion of the post-test results reviews participants' feedback regarding different portions of *Under the Rock*. These questions asked for feedback regarding the game's ease of use, favorite and least favorite scenarios within each level, and general user feedback regarding the game's design. The results of the questions in this section of the post-survey feedback will be highly useful in developing future iterations of *Under the Rock*.

Please rate your ease in using this experience: (10 = difficult to use, 100 = very easy to use)

Table 5 Post-test Section 2, Question 1 results

	Min	Max	Mean
Ease of using the experience	43	100	90

These responses indicated the user interface for *Under the Rock* did not present any large challenges to the participants, and the choice structure was easy for participants to adapt to. The responses to this section lead the researcher to conclude the choice-based structure used in *Under the Rock* was a cohesive choice with the interactive narrative nature of this game.

Please select all of the experiences you completed

Table 6 Post-test Section 2, Question 2 responses

Scenario:	Choice count
Level 1: Initial diagnosis	63
Level 1: School experience	62
Level 1: Friends	60
Level 1: Work experience	56
Level 1: Family experience	56
Level 1: Hearing loss through neglect	45
Level 2: Roommates	53
Level 2: Classes	52
Level 2: Assumptions made by others in college	44
Level 2: Family experience during college	44

Level 2: 2 nd audiologist appointment at 23 years old	52
Level 3: Receiving donated hearing aids	48
Level 3: Working full-time while completing a 2 nd BA	47
Level 3: Realizing the 2 nd BA was a bad fit for your hearing loss	49
Level 3: Explaining hearing loss to your niece	52
Level 3: Going to Universal Studios with friends	54

One of the concerns in developing *Under the Rock* was making sure users would complete most (if not all) of the experience. Earlier iterations of the story structure offered options for leaving the story at the end of each level or starting at a different age group than childhood if a user wanted a specific experience, and this was eventually changed to give users a more thorough experience. The side-quests were the least-selected scenarios within the game, likely indicating that users did not see every possible option within the side-quests. For example, participants may have only completed one possibility in the assistive technology side-quest. This might help explain the lack of change in the pre-test and post-test question regarding participants' knowledge of assistive technology.

Which experience in Level 1 was your favorite:

Table 7 Post-test Section 2, Question 3 responses

Scenario:	Choice Count:
Level 1: Initial diagnosis	9
Level 1: School experience	13

Level 1: Friends	22
Level 1: Work experience	4
Level 1: Family experience	9
Level 1: Hearing loss through neglect	6

In the free-response question, participants stated numerous reasons for why they had selected their favorite scenario. These reasons included: “I never thought about a family having this kind of negative look at their child who has hearing loss. This was the most eye-opening and interesting experience from level one”; “I chose friends because I feel like my social life would be impacted greatly if I had hearing loss”; and “It was interesting to learn that young kids thought it wasn't a big deal, though it is to the person with hearing loss.” While these are only three of the free responses, they do indicate that participants had been actively participating with the narrative of *Under the Rock*. Participants were able to understand the narrative and connect with it throughout Level 1.

There were some outliers in the free responses that did not coincide with the researcher’s intentions in the narrative such as: “Her friends were trying to help as much as they can.” This strongly contrasts with the researcher’s intentions behind the Friends plot point within Level 1. Perhaps this is because the Friends plot point seemed the least abrasive, the participant felt this was the least offensive choice.

Which experience in Level 1 was your least favorite:

Table 8 Post-test Section 2, Question 5 responses

Scenario:	Choice Count:
Level 1: Initial diagnosis	8
Level 1: School experience	4
Level 1: Friends	7
Level 1: Work experience	2
Level 1: Family experience	31
Level 1: Hearing loss through neglect	11

The free responses for the least favorite portion of Level 1 largely reflected the participants' disgust towards Isana's family. One participant, that stated in an earlier question that they live with a different type of disability than hearing loss, stated, "Family experience was my least favorite because it reminds me of my own when it comes to others with other disabilities. Family should have been her biggest support." This participant's ability to connect her own experiences with Isana's can indicate the expansion of her network towards better understanding hearing loss (Latour 2007). Several responses discussed the portions of their chosen experience that felt morally wrong, with fewer specifically mentioning design choices. One response that did mention a flaw in the narrative structure stated "I felt like there were unexplored possibilities. I wanted to take a middle road--accept and appreciate that my friends didn't feel like there was a problem (even if they weren't the most receptive) while also pursuing more understanding relationships." Feedback such as this one will help to guide the development in future iterations of *Under the Rock*.

Which experience in Level 2 was your favorite:

Table 9 Post-test Section 2, Question 7 responses

Scenario:	Choice count:
Level 2: Roommates	8
Level 2: Classes	10
Level 2: Assumptions made by others in college	9
Level 2: Family experience during college	10
Level 2: 2 nd audiologist appointment at 23-years old	26

The favorite scenario within Level 2 was Isana’s second audiologist appointment. This plot point brought out the participants’ relief that she had finally gotten another diagnosis. In reviewing the free-response feedback participants went into greater detail with statements including: “The relief she felt when the audiologist confirmed details about her hearing loss made me happy”; “This felt somewhat triumphant, the narrator was getting the help she needed”; and “I was happy to see she went back to the audiologist again after a horrible first experience. It was refreshing to see one bad experience with a health care professional doesn’t mean all are that way.” Based on this feedback, participants were able to enjoy the growth Isana had undergone in seeking out another audiologist appointment as an adult.

Which experience in Level 2 was your least favorite:

Table 10 Post-test Section 2, Question 9 responses

Scenario:	Choice count:
Level 2: Roommates	14
Level 2: Classes	10
Level 2: Assumptions made by others in college	21
Level 2: Family experience during college	14
Level 2: 2 nd audiologist appointment at 23-years old	4

The participant feedback gathered for the least favorite portion of Level 2 was quite insightful. One response that stood out the most to the researcher was “This one was mildly humiliating because I can put myself in the position of making those assumptions.” This free response, more than any others, confirmed for the researcher that the interactive narrative had truly been effective in providing insight to participants about hearing loss. Through the researcher’s process of documenting their autoethnography entries, a moment they wanted to change was the “Assumptions made by others in college.” Perhaps by experiencing the outcome of jumping to these assumptions in an interactive narrative such as *Under the Rock* individuals would learn to consider other possibilities before jumping to a negative assumption.

Which experience in Level 3 was your favorite:

Table 11 Post-test Section 2, Question 11 responses

Scenario:	Choice count:
Level 3: Receiving donated hearing aids	20
Level 3: Working full-time while completing a 2 nd BA	4
Level 3: Realizing the 2 nd BA was a bad fit for you with your hearing loss	4
Level 3: Explaining hearing loss to your nieces	11
Level 3: Going to Universal Studios with friends	20

The results for this question asked participants to select a favorite experience in Level 3, it was a tie: participants felt a connection to both the moment when Isana received donated hearing aids and when she went to Universal Studios with friends. While reading the reasons participants gave for selecting the donated hearing aids plot point, participants showed their understanding of the vast expense hearing aids can be: “This was so enlightening. I didn't even know people donated hearing aids they had”; “This is a huge step. Hearing aids are very expensive”; and “Money is a huge issue for a lot of people, glad she could get the hearing aids regardless of money.” These responses reflected the participants’ understanding of how important this moment was for Isana, and their growing understanding of how impactful moments such as this one can be for someone with hearing loss.

When reviewing the reasons participants gave for choosing the Universal Studios experience, participants listed “I thought it was interesting to read about how her friend made sure she was included when her husband was telling a story. She told her husband to look at her while he spoke.”; “A nice conclusion, going on vacation with nieces and a best friend who understands your situation, as well as her husband who accepted it”; and “The example of gently

reminding the boyfriend to simply face the narrator to help with her understanding and how kindly it was received—displayed how a small change can make things much better for someone.” This conclusion of the story provided the participants with a moment of hope for Isana, and the participants recognized that. Their free responses recognized the importance a small moment like the one shown in Isana’s experience in Universal Studios.

Which experience in Level 3 was your least favorite:

Table 12 Post-test Section 2, Question 13 responses

Scenario:	Choice count:
Level 3: Receiving donated hearing aids	4
Level 3: Working full-time while completing a 2 nd BA	15
Level 3: Realizing the 2 nd BA was a bad fit for you with your hearing loss	29
Level 3: Explaining hearing loss to your nieces	6
Level 3: Going to Universal Studios with friends	5

Regarding this question, participants reacted the most strongly to the scenario “Realizing the 2nd BA was a bad fit for you with your hearing loss.” In many ways, this question reflects the expertise of the participants from UCF’s School of Communication Disorders. Participant feedback included “I did not enjoy that she was recommended to go to school for SLP. Hearing is huge for this track”; “Being a full-time student and a full-time worker is already stressful enough. On top of that, Isana had to put in extra effort paying attention in class. It must have been extremely draining”; and “It is unfortunate that someone in the program or profession didn’t tell her that this program would not be a good fit for her.” These pieces of feedback reflect the

combination of their understanding of the student experience, as well as the impact hearing loss, has on Isana’s experience.

Throughout each of these questions, the researcher has been able to review the feedback provided by the participant population on their favorite and least favorite scenarios in each level. These scenarios were based upon the autoethnographic entries generated in the game development process, and the scenarios chosen for both favorite and least favorite overall do indicate that users do resonate and connect with the researcher’s (or developer’s) emotional connection with the content. Asking participants to identify their favorite and least favorite scenarios within each level allowed the researcher to see which portions of the narrative were the most memorable for both positive and negative reasons. Each of these questions was followed with a free-response question asking participants to explain why they chose each scenario. The full responses gathered in the post-test can be found in Appendix F.

Please rate the following statement based on your experiences playing Under the Rock:

Table 13 Post-test Section 2, Questions 15-18 responses

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Total
This interactive fiction experience was useful to me for learning about hearing loss	37	23	1	2	1	64
I would recommend this experience to others that want to learn more about hearing loss	40	21	2	1	0	64

The scenarios within this experience were helpful for learning about hearing loss	40	18	3	1	1	63
There were too many scenarios	5	15	22	13	9	64

This series of questions provided the final feedback regarding the design portion of *Under the Rock*. These results indicate this prototype was an effective resource in helping participants learn about hearing loss, the content was effective in communicating information to the participants, and most indicated they would recommend it to others. One item to consider in developing future iterations of *Under the Rock* is the number of scenarios. This question received almost neutral results, indicating this could be improved, tightening the number of scenarios in each level to focus on key plot moments. The next section will review the demographic information gathered in the post-test.

Section 3: Demographics: Who made up the participant population?

This final section of the post-test was used to gather demographic information from the participant population. Most of these questions were free responses at the suggestion of CASTLE Labs to increase the number of potential responses participants could give.

Do you personally know someone that has hearing loss?

Table 14 Post-test Section 3, Question 3 responses

Do you personally know someone that has hearing loss?	Choice Count
Yes	45
No	12
I'm not sure	6

The responses to this question does reflect a large number of participants knowing of at least one person in their life with hearing loss. This may reflect the students in the University of Central Florida School of Communication Disorders that have likely been introduced to individuals with hearing loss as a result of their coursework.

Please rate your knowledge related to hearing loss:

Table 15 Post-test Section 3, Question 4 responses

Please rate your knowledge related to hearing loss:	Choice count:
Limited	15
Moderate	41
Advanced	7

The responses to this final question may also reflect the percentage of participants that were recruited from the University of Central Florida's School of Communication Disorders. Or it may reflect the participants' overall learning experience with *Under the Rock*. The full post-test results can be found in Appendix F. The report generated by Qualtrics includes bar graphs

for each question, thus providing an opportunity for a more rapid visual analysis of the pre-survey and post-survey results. The final section of this chapter will summarize the contents of this chapter.

Conclusion

The survey data will be analyzed in greater depth in Chapter 5, though reviewing the responses laid out in this chapter shows promising feedback. In understanding the overall purpose of the survey study had been to test the effectiveness of *Under the Rock* in giving users insight into the impact hearing loss has on daily life, the survey results show positive results. In the next chapter, the data provided by these survey responses and their potential implications will be reviewed with a specific focus on how the survey results influence the overarching research questions of this dissertation.

CHAPTER 5: DISCUSSION

In this chapter, the researcher will discuss the results of the survey study. As was discussed in the previous chapter, 70 participants completed both the pre-survey and post-survey in early 2022. While the purpose of Chapter 4 was to outline the highlights of the survey results, this chapter focuses on how those results can be interpreted and their potential implications. The comparative nature of the pre-/post-survey structure of this study allows one to see where opinions shifted throughout the process. Even if opinions did not shift largely for every question, in some cases even slight shifts in answers indicated the initial effectiveness of *Under the Rock*. The next section will discuss the researcher's interpretation of the survey study's results, beginning with the pre-test.

Interpreting the Survey results:

Pre-test

The purpose of the pre-survey was to set the baseline of the user's knowledge regarding hearing loss (the full pre-survey report can be found in Appendix E). Several of the statements asked in the pre-survey and section I of the post-survey (i.e., "I think my family would view me differently if I sustained significant hearing loss") are obstacles that are often faced by individuals after being diagnosed with hearing loss, especially if one must consider learning to use a new form of communication such as American Sign Language, lipreading, or cochlear implants (Tucker 1998, Padden 2009, Boothroyd 2010). Based on the survey responses, participants had anticipated responses: some were aware of adaptive technology and most

respondents were unsure of how they would be treated by friends, family, and coworkers if they were diagnosed with hearing loss. The first question of the pre-survey and section I of the post-survey asked participants to indicate the emotions they expected to feel with a hearing loss diagnosis. The dominant emotional responses to being diagnosed with severe hearing loss were anxious, depressed, confused, overwhelmed, and angry – all emotions one would expect upon receiving this type of diagnosis.

When asked to rate statements about hearing loss, most participants strongly agreed that hearing loss would impact their daily life, they would be interested in getting hearing aids and would consider learning American Sign Language. What is interesting to note in the rest of these statements (most of these statements focus on how they assume different people would react to their hearing loss) had more varied results. Instead of having 50 or more responses in one category, these results were dispersed between Strongly Agree to Disagree. This dispersion shows that participants are confident in how they would respond to a hearing loss diagnosis and much less certain of how others would react to them. The responses to the statements regarding how family and friends would react to a hearing loss diagnosis are based on how participants hope these people would react to them. It also could indicate that the participants were influenced by how they had previously seen deaf and hard-of-hearing individuals depicted in popular media.

Depending on the media in question, each show decides to either depict deaf characters as having their primary language as part of a minority group that is a part of American culture or as individuals whose entire identity centers around being deaf (Golos 2010, Valentine 2001, Foss 2014). These pre-survey results altogether present a population with common opinions one would expect to find when asked about hearing loss: in its abstract form, a majority of people

assume they would adapt to hearing loss and hope their loved ones would also adapt with them. However, there is still a level of anticipated concern that a lot of participants experienced in considering if their families did not accept their diagnosis or began excluding them from activities (Foss 2014). The next section will move on to discuss the post-test results.

Post-test

In reviewing the post-survey results, and comparing the responses with the pre-survey, the results did shift. Most interesting to note is those who selected ‘anxious’ went down from 64 to 57, ‘depressed’ dropped significantly from 62 to 37, ‘happy’ went from 0 to 2, ‘determined’ went from 11 to 49, ‘confused’ dropped from 52 to 37, ‘angry’ lowered from 42 to 25. These shifts in emotional responses show the author that *Under the Rock* did its job in providing users with information about a hearing loss diagnosis and the potential impact it could have on one’s life. It can be inferred that these participants’ increase in ‘determined’ has resulted from their experiences playing *Under the Rock*. By navigating the main character through the story, instead of passively watching how others react to hearing loss, they instead had to face each situation themselves. Participants experienced a variety of ways hearing loss continually impacts a person’s life, as well as the positive and negative ways others react to a person with hearing loss – and this resulted in newly formed determination in being able to handle a hearing loss diagnosis.

In the next set of statements, participants were asked to rate statements regarding how they would deal with hearing loss. When reviewing how these answers shifted between the pre-test and post-test, in general, the results stayed roughly the same. The exact numbers indeed did shift between the pre-test and post-test; however, the numbers did not shift widely from one end

of the scale to the other. If one accounts for the number of participants that completed the pre-survey (97) and the amount that completed the post-test (70) then the varying numbers may only reflect the lower number of participants completing the post-test. It may be a similar case with the final question block that is in both the pre-test and post-test (rate your knowledge of the following kinds of assistive technology). While the numbers did shift between both the pre-test and post-test, the overall conclusion did not. Overall, most participants felt they had either a minimal or moderate understanding of assistive technology. It should be acknowledged that participants may have been confused by the names of the assistive technology. For example, the term ‘cellphone haptics’ is used in the pre-survey and post-survey and might have made participants confused as to if there were different forms of cellphone vibrations rather than the vibration capabilities that are commonly available with cellphones (Mayisela 2013).

Based on the survey results, it can be hypothesized that this participant population is unfamiliar with assistive technology. *Under the Rock* only briefly touched on other forms of assistive technology (aside from hearing aids) in Level 3, this could be an area that could be expanded on in future iterations of the prototype. With this understanding of the participants’ attitudes in hand, the next section will discuss the design feedback gathered in the second section of the post-test.

Design Feedback on *Under the Rock*

The post-test ventured beyond the set of questions asked in the pre-test to gather feedback about the technical and narrative design of *Under the Rock*. As this game is meant to function as an advanced prototype to test the interactive narrative’s effectiveness, it was important to gain feedback on *Under the Rock*’s effectiveness as a digital media product. The interactive narrative

developed and tested in this study provided a new way for users to learn about an invisible disability that differed from the narratives seen in traditional media (Louchart & Aylett 2004). By creating a narrative that situated the user within an environment in which the user had to face the impact of hearing loss firsthand and choose how to react in each given situation adds weight to the decisions made (Vicary & Fraley 2007). This experience contrasts with the passive viewer experience when watching a movie or television show featuring a deaf or hard-of-hearing character navigating their way through mainstream society (Gilroy, Porteous, Charles, & Cavazza 2012).

Overall, the feedback regarding the product's design was encouraging as participants reported completing most of the scenarios listed in the survey questions, alleviating an early concern that participants either may not recall all of the scenarios they completed or may find a way to skip ahead and avoid too many of the scenarios for it to be an impactful experience. Contrasting with this early design concern, over 60 of the participants provided feedback regarding why the scenes they chose throughout each level were their favorite and least favorite. This section of the post-survey also asked participants to choose their favorite and least favorite scenario from Level 1, Level 2, and Level 3. Each of these questions was followed by being asked to explain why the scenario chosen was the participant's favorite or least favorite. These free-response questions allowed the researcher to learn why they reacted to the scenarios they had chosen. While it was helpful to see which specific scenarios stuck out most to participants, it was even more informative to read the participant's written explanations of why their chosen scenarios stood out for them.

The reasons varied from emotional impact, insight gained from the information provided in a scenario, or citing potential design flaws that caused users to disconnect with the story.

Amongst these reasons the strongest (and more detailed) emotional free-response questions often revolved around participants' reactions being brought about by moments of participants feeling a connection to an element of the narrative personally or were feeling a strong emotion for the main character's experiences. These were the types of reactions the researcher had hoped to elicit from participants when testing *Under the Rock*. The story content for *Under the Rock* was comprised of several uncomfortable and demanding situations: family trauma, negligence, difficulties in social situations. In reviewing the post-survey feedback regarding why selected scenarios were either the participants' favorite or least favorite, in Level 1 the family experiences were most often selected as the least favorite. When asked why responses often mentioned that it was wrong of the parents to neglect their child, it reminded them of their own experiences, or it elicited feelings of sadness. This feedback confirmed that the narrative for *Under the Rock* had accomplished the intended goals: making participants confront inconvenient situations and decide how to react. While their choices could not change how the narrative turned out, the purpose of having participants choose how they would react in each scenario caused them to consider the emotional and mental impact of each scenario.

These answers indicated that participants were quite open in discussing the portions of the experience that made them uncomfortable including portions of the narrative and audio files. This is one of the largest indicators of success in testing this prototype of *Under the Rock* because one of the main intentions of this interactive narrative was to expose users to new ways of thinking and new information, which may make participants feel uncomfortable (Riedl & Bultiko 2013). This feeling of being uncomfortable would have led to growth as one needs to feel uncomfortable to expand their understanding of another's perspective (Bollmer 2017). The written feedback in the post-survey for each participant's least favorite scenario reflects those

moments of being made to feel uncomfortable either from the sound used in a level or (most often) the story content of the specified scenario.

A game can be designed to communicate a variety of messages. In prototyping *Under the Rock*, a large goal was to help to spark better-informed conversations about hearing loss. As someone who has lived with hearing loss for over 20 years, the researcher has had countless conversations trying to explain what hearing loss means with varying results, often having the same conversations multiple times until the information begins to sink in. Interactive narratives such as *Under the Rock* could help to accelerate these conversations by providing a resource that can interactively answer several frequent questions. In viewing the game as an informal learning resource, this prototype shows promise as a new way of teaching users about invisible disabilities, potentially leading to less stigma around these conditions in the future (Kattari, Olzman, & Hanna 2018; Flink 2017). The next section will review the feedback focused on the interactive narrative portion of the experience.

Interactive Narrative Feedback:

As was discussed in Chapter 2, the interactive narrative for *Under the Rock* was based on the researcher's personal experiences living with hearing loss since the researcher was a child. These experiences were documented using an autoethnographic methodology that made it possible to make a mess of emotions, trauma, and experiences and map them into a path users could take in a game. This map was then furnished with several scenarios to show users multiple ways hearing loss impacts daily life.

When reviewing the post-survey feedback about the three levels within *Under the Rock*, a majority of respondents commented on feeling an emotional connection to moments within each

level for either personal reasons or because they felt a moment of enlightenment and understanding about the subject matter. It has often been the researcher's experience when attempting to explain the implications of having hearing loss to another person that the information is often forgotten unless the individual has a deeper connection to the information (rather than only being abstract information they were told once or twice). These post-survey results show that an interactive narrative can be an effective tool in informally educating users about hearing loss. The next section will review the research questions that guided this dissertation research and the outcomes of those research questions.

Research Questions

The research questions proposed in earlier chapters sought to understand how an interactive narrative could be used to informally teach users about invisible disabilities, and if using this interactive narrative in Twine could be used to improve a user's understanding of hearing loss in daily life. The survey study results helped to provide the answers to these questions and will be discussed below.

How does an interactive narrative structure help in teaching users about invisible disabilities?

As has been discussed in earlier sections of this chapter, the pre-test/post-test structure of this study allowed the researcher to compare participants' attitudes towards being diagnosed with hearing loss. As was discussed in earlier sections in this chapter, in reviewing the written feedback in section II of the post-test, participants were able to explain why they chose different scenarios in each level as their favorite and least favorite. Reviewing this feedback showed that

participants often focused on the scenarios that were the most emotionally intense for the researcher to draft. Participant feedback showed that quite often these scenarios made an impact for users to learn from as they often reacted to the personal nature of the scenarios. This feedback reflected the effectiveness of the autoethnography methodology used in drafting the interactive narrative of *Under the Rock* in translating personal experiences into a navigable story map (Markham 2020, Thorndahl & Frandsen 2020, Chemi 2020).

Two sub-questions accompanied this first research question: “How does an interactive narrative help users gain an understanding of another's experience that differs from their own daily experiences?” and “How can the reflections and insights gained through autoethnography be translated into a game narrative?” In reflecting on these questions, the survey presented mixed results. Regarding the first question, the survey study provided mixed results. As it was to be expected, some participants were able to draw connections to their own life experiences and draw parallels to their own experiences which may have either helped or hindered their ability to keep the experiences in the interactive narrative separate from their own life. The true extent of this would warrant further investigation in future research.

In analyzing the second sub-question, *Under the Rock* does serve as an example of how autoethnographic entries can be converted into a game narrative. To create the game narrative of *Under the Rock*, an autoethnographic journal was first created as part of the production process. Drafting these entries allowed the researcher to process through the emotional impact of the memories associated with the journal entries, as well as allowing the researcher to analyze the journal entries to be organized into a story map. In drafting the narrative for *Under the Rock*, after analyzing the autoethnographic entries the three different age categories became the most logical levels for the interactive narrative. While there was considerable emotional difficulty in

drafting this interactive narrative, this methodology was an effective system for creating an interactive narrative that other users could learn from (Tosca 2020).

How can an interactive narrative created in Twine be used to improve a user's understanding of hearing loss's effect on daily life?

The post-test results of this study indicated that participants completed most of the scenarios within each level, and a majority of these participants also provided feedback regarding why they selected a scenario as their favorite or least favorite (the full post-test results can be found in Appendix F). Referring to the discussion of ANT in chapter 1, the survey results do indicate that participants did improve their knowledge base of hearing loss in daily life (Latour 2007, Law 2009), leading to potential new connections being made in their networks through this digital interactive experience. *Under the Rock* did utilize the main character, Isana, that users were asked to assist in navigating each scenario. Connections created to their network about hearing loss may be associated with this fictional character rather than only having a general understanding of hearing loss. In the future, if they are faced with situations or questions about hearing loss they may first think of Isana and their experience helping this fictional character rather than thinking of their knowledge of hearing loss in general terms. The final section of this chapter summarizes the main data interpretations the researcher discussed in this chapter.

Conclusion

Throughout this chapter, the researcher have reviewed the results of the pre-survey and post-survey and discussed how these results could be interpreted. In general, the results showed that this prototype of *Under the Rock* was effective in the goals of the project: providing users with deeper insight into hearing loss and its impact on daily life. While this was only a prototype of *Under the Rock* and future iterations would be influenced based on the survey responses, the results of this study do indicate the design methodology used in developing the interactive narrative was successful. The specific research questions outlined in earlier chapters are also discussed, and the implications the survey results showed regarding these overarching research questions. In the concluding chapter, the researcher will review the design processes that were used in designing *Under the Rock*, testing it and its potential future applications.

CHAPTER 6: CONCLUSION

Throughout this work, the high-level prototype of *Under the Rock* and its initial test has been outlined and discussed. *Under the Rock* was created to explore a new potential way of providing insight into the impact the invisible disability of hearing loss has on a person's daily life. While popular media such as books, movies, and television shows have been infused with examples of individuals with hearing loss, the majority (if not all) of these have focused on showing how a person living with hearing loss has either attempted to find a place within mainstream society or has been successful in being accepted into mainstream society. With this research in developing *Under the Rock*, the focus was instead on encouraging members of mainstream society (i.e., individuals without hearing loss) to explore information about the hearing loss experience that otherwise goes unnoticed.

The interactive narrative for *Under the Rock* was developed using an autoethnographic methodology. By documenting several of the personal experiences, the researcher has had from her initial hearing loss diagnosis with partial deafness at age 11 through a trip with the family to Universal Studios at age 27, an autoethnography methodology proved effective in thoroughly documenting these experiences. It should be noted that this methodology was effective, though the nature of the memories should be respected as the potentially painful nature of the memories can be a challenge in completing the needed autoethnographic entries. This can be accomplished by utilizing a patient approach and allotting an ample amount of time for documenting the entries.

Once the entries were documented, an initial story outline that included the majority of the autoethnographic entries came forward. While reviewing personal memories can be akin to

looking at a tangled web, the autoethnographic methodology creates the ability to review and analyze the memories. During this analysis, it became clear the memories fell into three main categories (Childhood, College, and Adulthood) with several scenarios and side quests organized within each level. Each of these scenarios offers the user two choices of how to proceed, and after making a decision the user sees how their choice impacted the main character. Once this prototype of *Under the Rock* was built, a survey study was conducted to test its effectiveness in informally educating users about the impact hearing loss has on someone's daily life. The next section reviews the data that was gathered in the survey study.

Review data collected in a survey study

To test the initial effectiveness of *Under the Rock* as an informal learning tool, a survey study was run in early 2022. In this study, participants were asked to complete three steps: complete a pre-test, play through *Under the Rock*, and complete a post-test. The participant population was recruited through posting on social media channels and offering participation to students in the University of Central Florida's School of Communication Sciences and Disorders. In reviewing the results of the pre-test, the results showed that participants overall had a minimal to middling knowledge related to hearing loss's impact on daily life. The pre-test also asked participants to indicate the emotions they would feel if they were diagnosed with hearing loss, and as one might expect, participants reported an elevated level of anxiety, being overwhelmed, depression, and anger. Overall, these initial results presented a group of participants that do not have a lot of first-hand personal experience with hearing loss and would not know how to handle it if they were suddenly diagnosed.

The first section of the post-test was identical to the pre-test, though the answers shifted slightly through the questions. The first question, which asked participants to indicate the emotions they would feel if diagnosed with hearing loss, anxiety, and overwhelmed were still top choices, except now determined was the third most common answer. This shift in answers indicates that the participants felt better informed of how a hearing loss would potentially impact their lives if they were to be diagnosed.

The second section of the post-test gathered feedback regarding the technical design and user experience of *Under the Rock*. Responses from this section included feedback regarding which scenario within each level was each participant's favorite and least favorite and why, which scenarios the participants can recall completing and responding to a series of statements regarding the game experience. These responses indicate that most participants found the experience helpful in educating them about hearing loss and would recommend the experience to others. The responses also indicated that future iterations of *Under the Rock* would be better received if the number of scenarios were potentially lessened to make the narrative experience focus on the most impactful parts of the narrative. The next section discusses the potential future applications of this research.

Future uses of this research

This use of interactive narratives can be expanded to teach users about additional invisible disabilities including anxiety, depression, fibromyalgia, and diabetes. Through combining the research areas of autoethnography, actor network theory, and user experience design future creators can utilize these theories to create interactive digital experiences that could help provide insight and understanding towards a lesser-seen experience. *Under the Rock*

provides an example of how personal experience with an invisible disability can be translated into an interactive experience. This type of digital product could be useful for medical students in learning to understand patient experience, helping family members to understand an individual's recent diagnosis, or used in human resources departments to better understand how employees with an invisible disability may adapt to a job.

Future iterations of *Under the Rock* could be branched out into a series of experiences that delve deeper into the experiences individuals with hearing loss have at specific ages and provide more thorough scenarios that reflect what individuals experience as they grow up with a hearing loss. This prototype for *Under the Rock* provided general overviews of experiences had throughout childhood to adulthood, if future iterations were able to focus on specific scenarios or age ranges these would be able to provide more detailed narrative experiences. Potential future interactive narratives could also be combined with other forms of interactive media such as a virtual reality video game that could create a more sensorial immersive experience to educate users about hearing loss and other invisible disabilities. Utilizing the combination of interactive narrative design with autoethnographic work regarding personal experiences individuals have with invisible disabilities can lead towards impactful learning and better-informed populations.

APPENDIX A
IRB APPROVAL LETTER



UNIVERSITY OF CENTRAL FLORIDA

Institutional Review Board
FWA00000351
IRB00001138, IRB00012110
Office of Research
12201 Research Parkway
Orlando, FL 32826-3246

EXEMPTION DETERMINATION

January 11, 2022

Dear Jesslyn Parrish:

On 1/11/2022, the IRB determined the following submission to be human subjects research that is exempt from regulation:

Type of Review:	Modification / Update
Title:	Investigating the Efficacy of Interactive Fiction in Communicating the Impact of Hearing Loss on Daily Life
Investigator:	Jesslyn Parrish
IRB ID:	MOD00002515
Funding:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"> • Explanation of Research (HRP-254), Category: Consent Form; • Protocol, Category: IRB Protocol; • Recruitment Email, Category: Recruitment Materials; • Social Media recruitment script, Category: Recruitment Materials;

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made, and there are questions about whether these changes affect the exempt status of the human research, please submit a modification request to the IRB. Guidance on submitting Modifications and Administrative Check-in are detailed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system. When you have completed your research, please submit a Study Closure request so that IRB records will be accurate.

If you have any questions, please contact the UCF IRB at 407-823-2901 or irb@ucf.edu. Please include your project title and IRB number in all correspondence with this office.

Sincerely,

Karilla C. Birkbeck

Kamille Birkbeck
Designated Reviewer

APPENDIX B
GAME DESIGN DOCUMENT

Under the Rock

An informal learning experience showing users how hearing loss impacts daily life.

Copyright: None at this moment.

Version number: 6.0

Author: Jesslyn Parrish

Date: January 11, 2022

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Design History

1. September 8, 2021: Design Document is drafted in this template.
2. September 16, 2021: Updates throughout the document were made.
3. October 20, 2021: Updates to the explanation of choices and story elements were updated.
4. January 11, 2022: Updates were made throughout the document to reflect feedback from beta testing and final updates. This included minor edits through sections to clarify information, adding information about the side quests, correcting the list of plot points to include all plot points, and finally adding sound and image information.

Section I - Game Overview

Game Concept

An informal learning experience built in Twine that gives users insight into how an invisible disability (hearing loss in this experience) impacts someone's daily life. This will be an interactive fiction piece following a structure similar to a 'choose your own adventure' game to allow users to make decisions that will provide insight into the impact hearing loss has on daily life. The experience is meant to make users more aware of what people with an invisible disability experience even if people aren't aware of it.

Feature Set

To enhance the interactive story, audio files are being added to the scenes within the narrative to help users feel more immersed and connected to the narrative. As this project focuses on teaching users about hearing loss, it is important to give users an idea of how sounds are perceived differently in various environments because of hearing loss as well as the potential difficulty and distraction sounds cause in some situations. Visually, the narrative is styled with a blue background to unify the entire experience with images inserted as needed to provide more context, engagement, and connection to the user.

Genre

Interactive Fiction / Choose-Your-Own Adventure

This experience is an interactive fiction piece and is serving as a high-quality prototype of a future video game. Using an autoethnography methodology, it provides the framework for translating my personal experiences growing up with hearing loss from childhood through adulthood into a story narrative that will informally educate users by allowing them to navigate through my life experiences while making their own choices about how to react to each scenario.

Target Audience

- Adults (18 years and older) with minimal exposure or understanding of hearing loss
- Family members of someone recently diagnosed with hearing loss
- Friends of someone diagnosed with hearing loss
- Employers/Human Resources departments expanding their training regarding inclusivity and accessibility

Game Flow Summary

In playing the game, the general flow users will experience is as follows:

- Read the instructions screen
- Begin playing in Level 1: Childhood
- The user will then begin playing the experience in the first experience within Childhood. For example, in the childhood scenarios the user will play through scenarios about initial diagnosis with hearing loss, school, friends, and family. In each of these scenarios there will be two choices in how the user wants to proceed, users will select one of these choices, read the result of that decision, then continue to the next scenario.
- After users complete all the scenarios in Level 1: Childhood, they will continue through Level 2: College and Level 3: Adulthood in order to complete the game.

- Throughout the 3 levels there will also be a total of 6 side-quests/tangents that will show users how the main character's experience may change depending on their choices.
- Once the user has completed the experience, they will have the option to play again if they want to play through and find out about the information in the options they did not select previously.

Look and Feel

This experience will have a simple appearance: a blue background with images and audio files that enhance the written narrative. The purpose of the simplified appearance of the experience is to avoid distracting users from the narrative itself – a busier background design could disrupt the storyline, making it harder to comprehend the intended learning experience.

Playing the experience should feel as though users are being guided honestly through different stages of life with accurate depictions of hearing loss in those stages. The game should make users react with feelings of, “I never would have thought of that before.”

Project Scope

This project has been designed using Twine, an open-source program used to create interactive fiction games. It is important to remember this is being viewed as an advanced prototype of the story and its potential as an interactive experience and could be expanded into a more immersive game experience in the future. For this iteration, users are largely interacting with a text-based story.

Number of locations

There are 3 main locations (Levels) within this experience: Childhood, College, and Adulthood. Childhood is comprised of scenarios that happen until the main character is 18 years old. College contains scenarios that are likely to happen from the ages of 18-24. Adulthood is made up of scenarios that happen after college as the main character is working to continue in their life after completing college.

Number of levels

This experience is made up of 3 total levels with a series of plot decision points within each level:

- Level 1: Childhood
 - Plot Choice Point: Initial diagnosis with hearing loss
 - Plot Choice Point: School experience
 - Plot Choice Point: Friends
 - Plot Choice Point: Work
 - Plot Choice Point: Family
 - Plot Choice Point: Hearing loss through neglect
 - Side quest with the mother's responsibility
- Level 2: College
 - Plot Choice Point: Roommates
 - Plot Choice Point: Classes
 - Plot Choice Point: Assumptions people make

- Side quest: exploring the impact of the assumptions made by Isana's birth mother
 - Plot Choice: Feeling Invisible
 - Side quest: Being an ambassador to the Deaf experience
 - Plot Choice Point: Family
 - Side quest: attempting to maintain relationship with birth family
 - Plot Choice Point: 2nd audiologist appointment at age 23
- Level 3: Adulthood
 - Plot Choice Point: Receiving donated hearing aids
 - Side quest: emotional realization that the years of tinnitus pain could have been avoided if her parents hadn't neglected her
 - Side quest: The realization of living with tinnitus pain since childhood
 - Plot Choice Point: Working full-time while doing a 2nd BA degree
 - Plot Choice Point: 2nd BA realization
 - Plot Choice Point: Explaining hearing loss to your nieces
 - Plot Choice Point: Universal Studios with friends
 - Plot Choice Point: Conclusion

Number of NPCs

There are 3 NPCs throughout the narrative that are mentioned once or twice in the story's narrative. NPCs in the narrative include:

- Joanne: Isana's adopted sister
 - She is two years younger than Isana, and she met Isana while studying anthropology in undergrad. While she tends to be pretty quiet and shy towards anyone other than her close friends, she is entirely the type to jump forward to defend her friends if someone threatens them. She also can't resist correcting someone when she hears incorrect information.
- Rowena: Isana's best friend
 - Rowena and Isana met in their master's program in Ireland and became very close and remain close still. Rowena is filled with sci-fi knowledge and works as an English language teacher. She has a sharp memory for both her work and what her friends and family like and are comfortable with.
- Tashi: Rowena's husband
 - Tashi has been married to Rowena for 10 years and is passionate about cooking and anything to do with creating exciting and delicious food. He and Isana became friends due to their respective connection to Rowena and follow Rowena's lead in regard to how to approach each other when a conflict arises.

Section II - Gameplay and Mechanics

Gameplay

The gameplay of this project will feel similar to building a story by making choices in each level and feel similar to an interactive website as the experience is hosted online rather than in a game engine.

Game Progression

The game progresses through the user selecting an option in each level, then they progress forward by clicking the link they select on the screen. An example of the links they will see onscreen is below. This screenshot shows a drafted page of the narrative experience, specifically when Isana is taken for her initial audiologist appointment. In this portion of the narrative, she is faced with deciding if she should directly ask the audiologist questions or if it would be better to wait and listen to what he is telling her mother – bearing in mind that she is only 11 years old at the time and scared. The two choices underlined in the image below show the first of many choice points throughout the narrative that users will navigate through as they decide how they would react in this reality. Their decisions in each choice point will influence how the narrative is shaped going forward, and the experiences Isana will have.

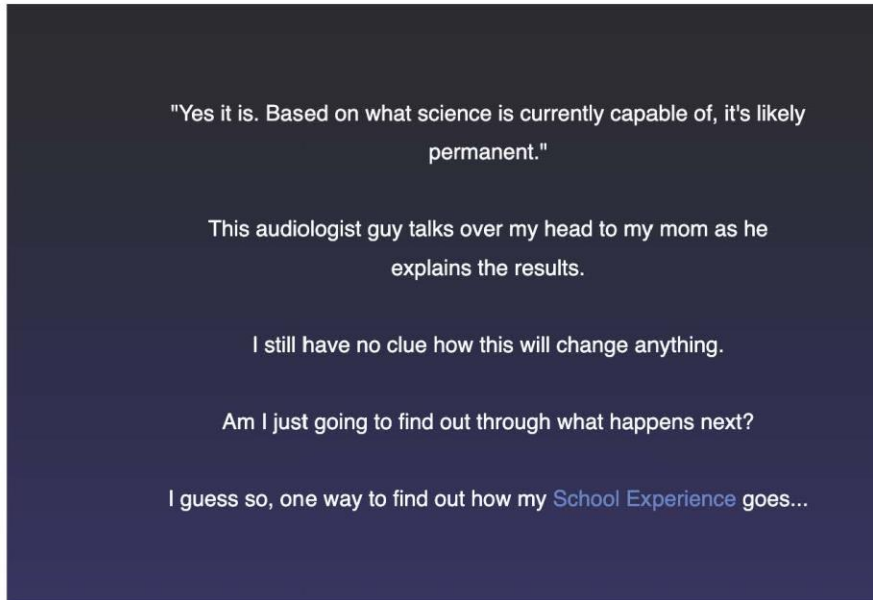


Figure 1. Example of a Game Screen in Level 1

Mission/challenge Structure

Each level will follow the same structure:

- Reading the text on the screen (with this text providing the context for the level's scenario).
- Reading the choices at the bottom of the screen, and selecting (clicking) one choice of how to proceed.
- Once an option has been clicked, the user will be taken to the next screen. This screen will contain the explanation of how the choice made will impact the main character's experience.

- After reading the explanation of their choice's impact, users can then click on an option at the bottom of the screen to continue to the next scenario.

Choice Structure

The choice structure of this game is based on the user making a choice of how to react to coping with hearing loss in each scenario without being given a lot of contexts before deciding. After making a decision, users are then provided with the context of how their choice impacts the main character's experience with hearing loss in that situation.

Objectives

There is one main objective throughout the entire game: to learn about hearing loss in daily situations. There are no wrong choices in this game, but each choice made does impact the information/context the player and Isana (the main character) will receive throughout the story. For example, in the first plot choice point in which Isana is receiving her initial hearing loss diagnosis, she can decide to actively try to ask the audiologist questions or instead listen to what the audiologist is telling Isana's mother about the diagnosis. This may seem like an easy choice to make as an adult, but Isana is a child at the point in the narrative, and some choices are unrealistic to ask a child to make. This plot choice point is meant to show users how important a child's family is in helping them learn about their diagnosis, especially their parents.

Throughout each additional plot choice point, users are meant to select an option in each level to expand their knowledge base about hearing loss and better understand the context in which users learn about hearing loss.

Play Flow



Figure 2. Play Flow Summary

Mechanics

Actions

Actions in this game are very basic: the only action users need to make in the game is to select options throughout each level of how to proceed or react to the information given in the story.

Switches and Buttons

- Choosing a hyperlinked section in each level (there are usually 2 choices shown as hyperlinked text in each level, though some screens only have 1 choice at the end of the screen to minimize how much text is provided on some screens. This is to avoid overwhelming users with too much text at any one point.)

- Users will either use their computer mouse to select an option, or their finger if they are playing on a touchscreen device

Screen Flow

Screen Flow Chart



Figure 3. Screen Flow Chart

Screen Descriptions

Main Menu Screen

The main menu screen in this game will provide the introduction to the story's narrative, and instructions for the user on how to play through the narrative and make choices to interact with the story.

The current text in the main menu screen is as follows:

Welcome to "Under the Rock"

How does hearing loss impact someone's day to day life?

What goes unseen by those who have normal hearing?

This story will help show the moments that are rarely seen without experiencing hearing loss firsthand.

<u>I strongly recommend playing in full-screen and sound turned on!</u>

[[Instructions]]

Instructions Screen

Following the main menu will be an instructions screen. This screen will present users with brief instructions on how to navigate through the game's narrative. Instructions have been split into two screens to minimize the amount of text on one screen at a time and to make the experience more engaging. The current text on these two screens is as follows:

"Welcome!

To play this experience you will follow me, Isana, as I'm diagnosed with hearing loss, and help me make choices of how to handle each situation I find myself in. I have no idea how to handle any of this, and would really like some help.

[[next screen]]

At the end of each screen, there will be 1 or more options (these will be linked text). Choose the option you think you would be more likely to pick if you had to handle these situations.

Throughout your experience, you may find yourself on side quests that will provide additional insight into daily life with hearing loss. At the end of each, there will be an option to return to the scene before the side quest began.

To begin your experience, continue to Level 1: [[childhood]]”

Game Options

The only action, or decision, made in the game is to choose between the options in each level. Users are provided with minimal amounts of information at each level until they make a decision, then additional information is provided as the game explains what would happen in the outcome of their decisions.

Replaying and Saving

Because this game is built in Twine, it follows the structure of Twine games, meaning this game can be saved and does allow for the game to be restarted so users can play again from the beginning. As an interactive narrative product (that can be made into a

game or other form of interactive experience), the main purpose is to take users through a story that they can participate in.

Section III – Story, Setting, and Character

Story and Narrative

Back story

The backstory of this game is based on my 20 years of experience growing up and living with hearing loss. I have documented several of my memories since my diagnosis with hearing loss using an autoethnography methodology and then translating those entries into a narrative featuring a fictional character going through those experiences. In this game, the user has been invited in by the main character because she has asked for help in deciding how to react to life after she was diagnosed with hearing loss.

Themes

The main themes of the narrative are as follows:

- Hearing loss impacts daily life in ways you wouldn't expect if you haven't lived with it.
 - This is experienced through the plot points that describe work and school in the childhood and adulthood levels to provide examples of how hearing loss can influence these areas.
- Living with hearing loss is a continual process of learning and adapting.

- I am highlighting this by dividing the game levels into childhood, college, and adulthood. I hope that by doing so it will show users that hearing loss isn't something someone learns to overcome and never has to adjust to again – it's a lifelong process.
- The people you interact with (when you have hearing loss) and their actions are just as important to your own. If they aren't open to learning about what you need and how they can help, it will make things unnecessarily difficult.
 - By including plot choice points focused on family, friends, and classmates I am showing how the people in someone's life can influence their daily experiences in ways they may not realize but are still important. In this instance, I am focusing specifically on how the way people react to someone's hearing loss impacts that person's experience.

Game Progression

The game progresses by repeating the following steps until the narrative is complete:

- Enter a new level
- Read the information presented in that new level
- Choose between the 2 presented options in that level
 - Click on that choice
- Read the context provided after making a choice
- Continue to the next level
- Repeat these steps until the narrative is complete

License Considerations

I have not considered licensing this product yet.

Game World

General look and feel of the world

This game is entirely text-based, and I have purposely left the descriptions of the physical locations fairly general throughout the game to allow users to picture related environments they have experienced. For example, rather than describing the school or classrooms in detail, users can picture their schools and classrooms when reading about Isana's experiences. This may help them connect her experiences to reality.

While I want users to connect with the main character, I want them to pull on their own experiences and memories from their families, friends, work, and college as they consider how they would react in each scenario. The interface has a simple design with a deep blue background and an easy-to-read font, with pictures inserted throughout the experience to better help users feel connected to the game's world while encouraging their imagination to explore their own thoughts of what these places would look like (or did look like when they were in similar age groups). Sound files will also be playing throughout the levels to provide users with an idea of how disconcerting and unintelligible sounds are in some situations when you deal with severe hearing loss.

Characters

Main Character: Isana

Back story

Isana's back story is based on my experiences living with hearing loss. I chose to give this character a different name instead of using my name because it was easier to write her narrative if she had a different name. It made it easier to imagine the alternate choices she could potentially make if she was slightly separated from myself. Her childhood was difficult after she was diagnosed with hearing loss because her family then ignored it and acted as though she should understand how to handle it and overcome it. They made her feel like she was continually failing and had to hide her hearing loss because it was an excuse if she did try to talk about it. Because nobody talked about it or treated it like it was real, she didn't know how things would change in college. It wasn't until she got older and entered adulthood (college and her adult years) that she met people who were understanding and were curious about her hearing loss instead of treating her as though it was a problem she needed to deal with alone.

Personality

Isana is a shy but determined person. She doesn't want to cause problems or be a problem to others. Her main goal in life is to understand how she can fit into the world, see more of the world, and be happy. Because of her early life experiences, she's also standoffish and distrusting of people, but she will warm up to people as she gets to know them. When she is making choices in this game she must ask herself "how important is it that I push my stance on this? Is it worth it to be aggressive or will things work out if I'm passive in

this situation?” Because of her severe hearing loss, she has a louder voice than most people and is also not very skilled as subtlety, and as a result, can be perceived as being aggressive when she tries to stand up for herself when she really just wants to be listened to.

Relationship to other characters

Isana is the main character in this story, there are brief mentions of people she meets throughout her story, but they do not become active characters in the game. She does have interactions with each NPC (described in Section I, NPC’s) to show the difference their reactions to her hearing loss make in her daily life. Each of the experiences she has with them became moments that inspire her to feel hopeful about her life with hearing loss.

Section IV – Levels

Level 1: Childhood

Plot Choice Point #1: Hearing Test

Synopsis

Isana is taken to a school-mandated hearing test by her mother after repeatedly failing the hearing tests conducted in school.

Objectives

The user will learn about the hearing test process and must decide how to react to the audiologist since the audiologist is ignoring Isana and talking directly to her mother instead.

Does the user choose to ask the audiologist questions, or choose to listen to what the audiologist is telling Isana's mother and see what they learn from that?

Plot Choice Point #2: School Experience

Synopsis

Isana is learning how to adapt to school as she accepts her hearing loss but isn't sure if she should talk about her hearing loss or not.

Objectives

Should the user decide to learn more about how Isana is adapting to her hearing loss? Or do they want to learn more about how Isana's classmates are unknowingly reacting to her hearing loss?

Plot Choice Point #3: Friends

Synopsis

Isana tells some of her close friends about her hearing loss, and they don't care or think it's real.

Objectives

Do you think Isana should accept her friends' reactions and move on? Or should she keep telling them about what she's dealing with?

Plot Choice Point #4: Work

Synopsis

As she enters her teenage years, Isana starts working. When she does, she learns how each job could either impact her hearing loss or be impacted by her hearing loss.

Objectives

Do you choose to learn more about how one job might have worsened her hearing loss? Or do you want to learn about one of the challenges of being a sales associate when you can't hear people walking up behind you?

Plot Choice Point #5: Family

Synopsis

Learn more about how Isana's family treats her after her hearing loss diagnosis.

Objectives

Do you choose to learn about other examples of families with a deaf/hard-of-hearing member? Or do you learn more about the difficulties of when a family refuses to adapt to someone's hearing loss?

Plot Choice Point #6: Hearing Loss Worsening Through Neglect

Synopsis

Isana can only do so much on her own (as a child) to adapt to her hearing loss and try to prevent further hearing loss...except what about her parents' responsibility?

Objectives

Do you face the blunt truth of how Isana's mother neglected her daughter? Or read a blunt message of the parents' responsibilities of raising a child with hearing loss?

Side-Quest Point #1: The Mother's Responsibility

Synopsis

Explores the impact a specific parent has on Isana's experiences and shapes her view of herself with hearing loss

Level 2: College Years

Plot Choice Point #7: Roommates

Synopsis

Isana starts adjusting to her first year in college and has to adjust to living with roommates.

Objectives

Do you choose to learn about Isana's problem with her roommates? Or do you learn about how her friends in college reacted when she told them about her hearing loss?

Plot Choice Point #8: Classes

Synopsis

Isana adjusts to her college courses, with all of them being discussion-based.

Objectives

Do you want to learn about the room layout in her courses? Or do you want to learn about how her professors react when she tells them about her hearing loss?

Plot Choice Point #9: Assumptions

Synopsis

Isana learns more about the assumptions people have made about her because of her hearing loss.

Objectives

Do you learn about how her classmates react when they find out she has hearing loss? Or do you find out how her found sister handled it when she heard classmates talking about Isana?

Side-Quest Point #2: Impact of the Birth Mother

Synopsis

Users can explore the impact of Isana's birth mother's choice to push Isana down mentally with assumptions about hearing loss.

Plot Choice Point #10: Feeling Invisible

Synopsis

The emotional impact of living with an invisible disability that many people don't understand.

Objectives

Learn about the mental impact hearing loss has on Isana as she gets older.

Side-Quest Point #3: Being an ambassador to the Deaf experience

Synopsis

Users can explore the impact of Isana's birth mother's choice to push Isana down mentally with assumptions about hearing loss.

Plot Choice Point #11: Family During College

Synopsis

Isana finds her new family during college.

Objectives

Do you want to find out about why Isana found a new family? Or do you want to learn about Isana's found family?

Side-Quest Point #4: Maintain a relationship with birth family

Synopsis

The player can explore what could potentially happen to Isana if she chose to remain with her birth family rather than forging a new family.

Plot Choice Point #12: 2nd Audiologist Appointment

Synopsis

Isana goes to her first audiologist appointment in ten years.

Objectives

Do you want to know how the audiologist reacts when she learns Isana hasn't been to an audiologist in 10 years? Or do you want to know what Isana's diagnosis is?

Level 3

Plot Choice Point #13: Donated Hearing Aids

Synopsis

Isana's audiologist reaches out and tells her she has a pair of donated hearing aids she can give her.

Objectives

Do you want to know what it was like for Isana to suddenly not have tinnitus pain anymore? Or do you want to know what she is now able to hear?

Side-Quest Point #5: Tinnitus pain realization

Synopsis

What emotional reaction does Isana have when she realizes the severe tinnitus pain she's experienced for ten years was actually an option rather than a requirement for her life.

Side-Quest Point #6: Assistive technology

Synopsis

Isana learns about the different types of assistive technology that could help her be aware of her surroundings.

Plot Choice Point #14: Working While Doing a 2nd BA

Synopsis

Isana struggles to balance working full-time while completing a 2nd BA in Speech

Pathology.

Objectives

Do you want to know why this program was a bad match for her? Or do you want to talk about the potential backlash with falling into a choice when someone else talks you into it?

Plot Choice Point #15: 2nd Bachelor's Degree

Synopsis

Isana has a realization while finishing her 2nd BA.

Objectives

No matter what option you pick for this level, you get the same message: that Isana did not have anything to overcome.

Plot Choice Point #16: Explaining Hearing Loss to Her Nieces

Synopsis

Isana's niece asks her one day what is in her ears, so she must explain what hearing aids are.

Objectives

Do you merely explain what hearing aids are to Isana's niece? Or do you start by explaining what hearing loss is?

Plot Choice Point #17: Universal Studios

Synopsis

Isana is on vacation with her best friend and her family. What happens when she has trouble understanding her best friend's husband while they're all in line for a ride?

Objectives

This level does not have any options: Isana's best friend reminds him that Isana is hard-of-hearing, and he adjusts easily and they have a lovely day.

Plot Point #18: Conclusion

Synopsis

A brief conclusion to the story, reminding users that this was only based on 1 person's experiences.

Section V - Interface

Visual System

The visual system for this game will be very similar to what one would see on a webpage: making choices throughout the game made by clicking on hyperlinked text, and the game is styled using a cascading stylesheet (CSS).

Menus

There will be a sidebar menu on the screen to allow users to restart the game and to save one's rounds in the game. The sidebar menu can also be collapsed if users want to keep it out of sight while playing the game.

Rendering System

This game does not use a rendering system.

Control System

The control system for this game is the user's computer mouse. Or, if they are using a touchscreen device to play the game, their hand will act as the control system as they select options by touching their desired option on the screen.

Audio

Audio files are to be inserted into the different levels to enhance the idea that sound becomes a different experience for someone when they experience hearing loss. Instead of choosing audio that is relaxing, I am aiming for audio files that stand in for incomprehensible loud conversations. This will hopefully provide a deeper idea of the type of frustration that accompanies hearing loss.

One example of how I will be using an audio file to enhance the narrative experience will be in the Level 1 plot choice point for friends. I will be using an audio file of loud chatter to give an idea of how overwhelming it can be for someone with severe hearing loss when they are trying to understand friends talking in a loud hallway at school.

List of audio files used in this game:

- Universal.mp3
- Adult.mp3
- Gossip.mp3
- Alarm.mp3
- Hearingtest.mp3
- Family.mp3
- Work.mp3
- Friends.mp3
- Work.mp3
- Friends.mp3

- Classroom.mp3
- Coffeeshop.mp3

Music

I am not using music in this game. I am focusing entirely on the audio files I described in the previous heading.

Help System

This game does not have a help system aside from the instructions given at the beginning of the game.

Section VI – Technical

Target Hardware

The target hardware for this game is to be played on a user's computer (it should work on any web browser). This game should also work on mobile as long as the media file formats are coded to be compliant with mobile devices.

Development hardware and software

The game is being developed in Twinery. More information about Twinery can be found [here](#).

Development procedures and standards

The general procedure for building this game in Twine is as follows:

- Map out the potential paths users will follow
- Fill in the storyline in each block
- Modify the CSS to make the experience more engaging than a blank white screen
- Add audio and image files to screens.

Below is a screenshot of the story map layout in Twine:

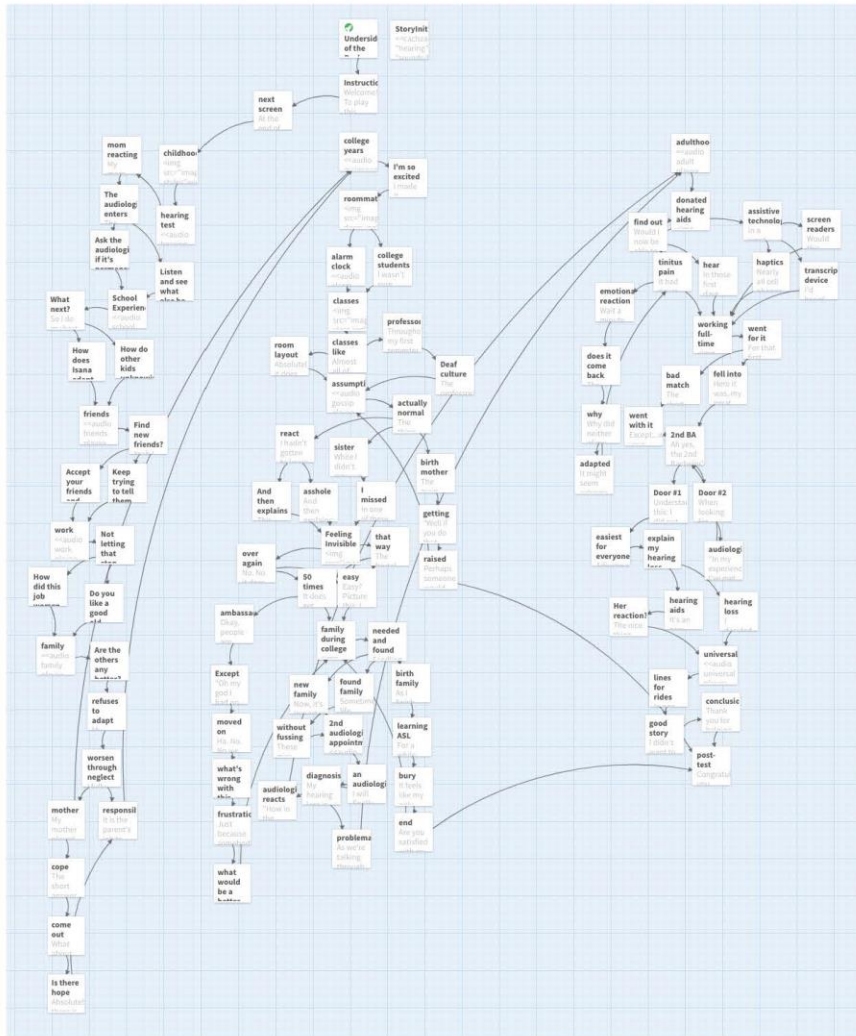


Figure 4. Storyline Map

Scripting Language

Twinery uses HTML, CSS, and JavaScript. Developers can augment the CSS and JavaScript to modify their game experience.

Section VII – Game Art

Concept Art

This game does not have any concept art because this version is entirely text-based. Images were found on unsplash.com and were modified in Photoshop to add a black and white filter to each image in order to provide a unified visual theme to all images.

In total fifteen images were used in this game, one of the images is inserted below to provide an example of the visual theme used in the game.



Figure 5. 'Invisible' image from the game

List of images used in this game:

- Childhood-class.jpg
- Childhood-family.jpg
- Childhood-friends.jpg
- Childhood.jpg
- College-class.jpg
- College-dorm.jpg
- College.jpg
- Family-college.jpg
- Gossip-assumptions.jpg
- Hearing-aids.jpg
- Hearing-test.jpg
- Invisible.jpg
- Teenagers-job.jpg
- Universal.jpg
- Work-adulthood.jpg

Style Guides

The game design can be modified using CSS. The current stylesheet being used can be found in the Appendices.

Section VIII - Management

Detailed Schedule

The remaining development schedule is as follows:

- September 14, 2021:
 - Deadline to complete adding in audio and image files
 - Publish the game to the web and send the link to Dr. Underberg-Goode
- October 2021:
 - Begin user testing through the survey study portion of the dissertation
 - Gather feedback through surveys on what is effective and needs to be improved
- December 2021:
 - Complete revisions to the Twine story, and add sound files to the levels
 - Beta test with Dissertation committee members
- January-February 2022:
 - Gather initial feedback about the game prototype through a survey study

Budget

There is no budget for this game and has been developed for free.

Risk Analysis

This game is low risk to play. It does not feature violence. Users might be concerned about the mention of childhood neglect.

Localization Plan

The game will be launched online (on itch.io), so users will be able to access it anywhere they have internet connection.

Test Plan

This game will be tested through a survey study as part of my dissertation research.

Further details can be found in my prospectus document, but a brief overview of the test plan is I am going to conduct a survey study (with a minimum of 30 users) in which each participant will take a pre-test to establish their starting opinions about hearing loss, then complete a post-test after finishing playing the game to establish any changes in their opinions about hearing loss. The post-test will also collect some general feedback about the experience design.

Appendices

Asset List

Art

The full CSS Stylesheet for this game is:

```
html {  
    width: 100%;  
  
    /* Vertical colour gradient */  
    background-image: linear-gradient(to bottom, black, midnightblue);  
    background-image: -webkit-linear-gradient(top, black, midnightblue);  
    background-attachment: fixed;  
  
    /* Fallback colour */  
    background-color: midnightblue;  
  
    /* Vertical centering */  
    height: 100%;  
    display: table;  
}  
body {  
    /* Remove default styles */
```

```
font-size: 100%;  
background-color: transparent;  
margin: 0;  
  
/* Vertical centering */  
height: 100%;  
display: table-cell;  
vertical-align: middle;  
}  
#passages {  
border-left: 0px;  
margin: 0;  
/* Keep a gap at the top and bottom of the page,  
   when the text is longer than the window's height. */  
padding: 5% 0;  
}  
  
.passage {  
/* Passage width */  
width: 60%;  
/* Horizontal centering */  
margin: 0 auto;
```

```
/* Text formatting */  
  
color: white;  
  
font-size: 100%;  
  
text-align:center;  
  
}  
  
/* No sidebar */  
  
#sidebar {  
  
    display:none;  
  
}  
  
/* Links */  
  
a.internalLink, a.externalLink {  
  
    color: cornflowerblue;  
  
}  
  
a.internalLink:hover, a.externalLink:hover {  
  
    color: lightskyblue;  
  
    text-decoration: none;  
  
}  
  
/* Shrink the page when viewed on devices with a low screen width */  
  
@media screen and (max-width: 960px) {  
  
    .passage { font-size: 90%; width: 70%; }  
  
}
```

```
}  
  
@media screen and (max-width: 840px) {  
  .passage { font-size: 87.5%; width: 80%; }  
}  
  
@media screen and (max-width: 720px) {  
  .passage { font-size: 75%; width: 90%; }  
}
```

Autoethnography Journal

Disclaimer before reading: These entries were documented through using the dictate option in Word, you'll notice the diction may seem a bit choppy. Originally, I was going to edit it to be more polished, but once I read through it I really thought it communicated the emotion and stuttering, and difficulty in thinking about it.

Attending School (K12) with hearing loss:

School with hearing loss. So I was diagnosed officially at about 11 and I went through the remainder of school without assistance and I have no idea if any of them actually ever knew I had hearing loss. And for the most part, I did fine in the sense that I had good grades. And it was, you know, I didn't cause trouble. And teachers in general were fine with me in their class because I was fairly quiet. Little did they know that part of it was being quiet to try to not miss things that people were saying. But it was also very regular for. The thing is, I cannot hear if someone is calling me. When they're standing behind me, I don't know. And when you're a kid, you can't explain this to people because they're not going to take you seriously. And they're just going to tell you to pay attention. And I have vivid memories of being in class and suddenly having one of the popular girls in my class suddenly in front of me in my face going just and suddenly you know, yelling at me almost saying, you know the teacher is calling you why aren't you paying attention are you deaf or something? And it turns out, yes, the teacher was calling me. And I had no idea. Which I remember that one specific instance really clearly but I don't remember a lot of other ones. I think that one just stood out the most so other than that, it was. There, the truth is, no one cared, no one cared. No one cared at home. No one cared in school.

I'd mention to the students I did say I have I'm partly deaf and just. In one ear, out the other, pardon the pun. Because it didn't matter, it was. It was just it was what it was. They didn't care. I didn't wear hearing aids or have any extra assistance in class, so. It was a thing that it wasn't worth noticing. And something that not everybody I don't think knows about hearing loss is that or when one of your senses are dulled is that your other senses they do become more important to you and they also can become strained overtime. It's not very uncommon for someone with hearing loss to also be wearing glasses because you're you depend on your site and your site. King become strained overtime because you're focusing on it so much you're very visually oriented and suddenly here you are with this issue. So Yep, I depend heavily on my glasses. To this day I can see alright, but in front of me but I can't see far away and I'm not good seeing the board in school. That's not to say that no one ever noticed or took advantage of my hearing loss, that's for sure. If sometimes it what it was. You have a friend that. Yeah, takes great delight in sneaking up on you at your locker. Which she got she got in a great habit of doing that. Until it I got overwhelmed and just had enough and yelled at her for sneaking up on me. Because it was irritating having people take care of take advantage of. An invisible disability is not fun. And they always think in when you finally have had enough and you get mad at them that you're oversensitive. And you're just blowing things out of proportion. Without fail, all that happens is you get tagged as someone with a temper.

Family ignoring my hearing loss:

You would think that. My family, or at least my parents would have been very aware of my hearing loss diagnosis. That would be a good assumption. Only it would be incorrect.

In my case. This is a good time to note. That I was adopted as an adult. So mentions of my parents here are my biological parents not my adoptive mom. My mom noticed my hearing loss only so far as she was required to take me to a doctor because the school mandated it and I'm sure there was a form that had to be turned in. Once my diagnosis was official and we left the doctors office. It was like she thought it was her. It was not her problem anymore. You know it was hard. The audiologist had told her. That she was that she should bring me back if I had pain in my ears. And in it she took it as I have need to tell her if I have to go back to an audiologist I was 11. And the only thing I knew was at that age was an audiologist cost money and we didn't have health insurance, so it was causing a financial strain if I had to go to a doctor. And that I would also be in trouble for talking if I made her take me to a doctor and there was nothing wrong. So I never I never thought about it. I did not go to an audiologist again until I was 23. Do and found an audiologist through my undergraduate research. My siblings I grew up with two brothers. They ignored it. As far as I can remember it. I remember at times they would yell at me for having a TV turned up too high in a room they weren't even in an I barely I could barely hear it. So I just got in the habit of not having the TV turned on loud enough for me to hear it. If anyone was anywhere near me. If anyone was in adjoining room or something, if I was the only person in the house I would have the TV turned up loud enough for me to hear it, but other than that I just got used to not being able to understand all the dialogue. And I didn't even notice that it became a habit till I went to college and. Friends were telling me, you know, can you turn it up? I can't. I can't even hear it. I can't understand it. How can you understand it? And I told her no, I can't. I just said never play it very loud. And it didn't seem like a big deal to me until people told me that was not

fair. And you know it. I get yelled at for not. Suddenly hearing everything my mother would say to me at 5 minutes after I woke up in the morning and I asked her, I would ask her to repeat it and she would suddenly yell at me going. You know, your hearing would be better if you didn't listen to so much music. When we don't know what caused my hearing loss and it was never just OK that i was a teenager and i had just woke and somehow this all became an idea. That when I just had to overcome my hearing loss. Because if I didn't, then people would think I was stuck up and it wouldn't. Matter if I told them I was hard of hearing. Or partly deaf and. That it was just I had to learn how to just seem like I didn't have a problem. And even my father he never. Tried I remember being in New York City with him when I was 20. And telling him at one point because he kept. Starting to talk to me and turn away mid-sentence to start walking and he would not maintain eye contact with me. I can't understand people if they turn away mid-sentence. I will not be able to understand that second half of the sentence. I need that visual to understand. At it it was so frustrating. But he would not. Listen, when I told him I need this one thing I need you to look at me when you're speaking and he wouldn't do it. He just kept doing however he wanted to do it and it was so frustrating. Especially when you factor in NYC is loud. I could barely understand him when he was looking at me, but at least I had enough of a visual that, through reading his lips and the sound or just this combination of sound and visual. I could eventually understand him. But he never. He didn't care. He didn't care either. And. I hate them both so much. I hate them so much. It was not my fault that I had a hearing loss and it did not have to be so hard, but they made it hard.

Adoptive Family and my hearing loss

Now let's talk about how my adoptive family reacted to my hearing loss. Well, they knew about it right from the start. Charlotte, my sister, she actually noticed, I think within a month of US meeting in college she I told her partway through the fall semester, he said, Oh yeah, I notice that's fine. I'm trying to make sure I look at you when I when I'm speaking so you can hear me. Anne. Our mom, she didn't blink. She tries her best to remember to look at me when she's speaking and to be in the same room and. It's, you know, we've we both know it's a moving target where the line of my hearing is an. The point is. That it's it acknowledged and it's not an awkward thing. And we all just work around it and it doesn't have to be a problem. When Charlotte and I were in college, it became quite fun because. We were in a lot of classes together as archaeology and cultural anthropology majors, and she. She knew I couldn't hear her if she whispered to me, and oftentimes in class, students would whisper snarky comments to each other based on the readings and whatnot. So what Charlotte did instead was she would write and pass me notes and we would do that if she had something that amused her that she wanted to talk about and whatnot, and our instructor actually asked her to one point. Apparently during office hours. Just yeah, I know you always. Write notes to Jesse why? Why do you do that? And Charlotte looked at at him and said, well, she can't hear me. So why shouldn't she get to have the fun of snarky conversation? Like everyone else can. And he never questioned it again.

New College Undergraduate Dissertation:

So to graduate from New College of Florida, you have to complete. A research dissertation. And everyone comes up with their research focus and their area of concentration. And initially when I transferred to new college, I thought I would pursue some aspect of Mayan culture because we had several Mayan archaeologists at the college, so we so I went for Spanish immersion for three weeks. And in the first week, everyone when would ask me about well, how. What is American culture like? What is this like? If you're here learning about our culture an I could not answer their questions because I've never thought about it before. And it got me thinking. So I came back from Guatemala. And asked my professors if I could do my thesis on deaf culture. And their first response was yes, you can quickly followed by how did you get there? Didn't you just go to Guatemala for Spanish immersion? How are you now on deaf culture? And that was the first time I told them that I had a hearing loss and they were shocked they'd never saw that coming. And they could not understand why I had never mentioned it. They were astounded that I just thought I shouldn't talk about it. And so we worked through it. From there, you know, none of them knew American Sign Language or deaf culture. It hadn't been studied at new college yet, so we fit. We learned about it together. And that was fine. I went to Gallaudet University for two weeks of sign language immersion. And it was a crash course of certain, for sure is about 5 hours a day in the classroom practicing American Sign Language. And it was mentally exhausting more than anything else. And so. I came back and you know it's I worked on this thesis for the next two years. And. Everyone was really interested in it. It was I. And that was the way that people found out about my hearing loss, because the question always was what is your thesis on? Because all of us had to write a thesis. And then when I told them it would be. How did you get

there? And I told them well I'm I'm partly deaf and suddenly there were a lot of shocked responses and people saying Oh my God, I am such an asshole. To which I would then say, oh, why is that? And I would find out how frustrated everyone had been over the past year when I didn't respond to something they said. Without fail. And now they knew why. The biggest thing? That influenced me towards doing this dissertation topic and what really was the start of the various research I've done into deaf culture & languages. Is just that. I wanted to understand this thing that had influenced my life since I was like 10 years old. And I'd never gotten to look into it or see what it was or how people coped with it. Aside from the massively stupid. Suggestion of. Just try to act like it doesn't exist because that is a Thomas thing anyone ever told me or taught me, however intentionally it was.

Audiology appointment at 23 years old

While doing my new college thesis I had to do field work because I was in cultural anthropology. So it's one of my. Contacts I was interviewing him because he worked at a hearing loss group. Office and I wanted to learn about how his take on the deaf community and Sarasota. And so we're we met at a cafe and had a great time learning about his experience with the growing up deaf in Europe and how different it was handled there. And I also got the name of his audiologist because I knew I needed to get a hearing screening. And I hadn't had one in over 10 years and I had no idea where my hearing was that and not knowing was incredibly stressful and scary. And. So I reached out to Doctor Nalu and we thought an appointment time gave an so I came in for hearing

screening and when I first went into her office we started chatting so she could get to know who I was. And as soon as I told her while I was diagnosed at 11 and I haven't had a hearing screening since she looked at me and went. Then how the hell can you speak so clearly now? And I didn't know what to tell her because the answer was just I've had just learned how to and. I tried to make a strong effort to speak as clearly as I could. And so she was dumbfounded by that, and we did the hearing screening and she showed it to me. She's explaining the chart to me, and it was clear that I had massive hearing loss, especially in high pitch sounds, which is where most of human speech especially. English, as well as probably many others. Happens deeper pitches are much easier for me to understand, but once you get into high pitch. Sounds where a lot of consonants happen. Apparently. I can't distinguish them from each other. It's mostly through context that I know what's happening. And that was news to me. So. I I asked her after she explained the test to me said OK so could I then accurately say that I am hard of hearing because I don't really know what term I should actually be telling people. I just don't think partly deaf for years because that's what they said when I was 11. And my ideologists then emphatically said, Oh no, you are severely hard of hearing. That is not a lie. And that was the news that was illuminating. For sure.

Getting Hearing aids in 2013:

And during that audiology appointment, hearing AIDS did come up because she said no, you really, you would benefit a lot from hearing aids. You really need them. I don't know how you're getting by without them, but they would help. And I knew I couldn't afford them. I didn't have insurance and hearing aids easily cost an average of two to \$3000 if

not more. And so I left her office thinking OK? Well, thank you so much and think about it. Try to come up with a way to make it happen. And I was still. In touch with my biological mother, I hadn't been adopted yet, so I called her to tell her about my audiology appointment and that, yeah, I apparently really need to think about finding a way to get hearing aids. And the first thing she said was, well, if you start wearing hearing aids, say goodbye to talking on the phone because you can't talk on the phone while wearing hearing aids. Which is wrong. It may have been true in very early models of hearing aids, but they've come a long way. They don't interfere with this talking on her phone. I know I do it regularly. So anyway. Fast forward a few months and I was dealing with. Other really traumatic events in my life. And struggling very heavily. I was having a massive swings of depression and just I had been assaulted. And I was not. Handling things well, it was. It was a very dark time in my life and I was trying to think what OK I need to find a way to I can't cope with my life as it is anymore. Let me talk to Doctor Nalu about the hearing aids, so I emailed her in December of 2013 and she said to ask her about is there a payment plan we could talk about or something? Maybe a way to? Make it a little easier to pay off. And she responded, saying, I was just about to email you because one of my patients donated his hearing aids and I thought they would be a very good fit for you. So she gave me a free pair of hearing aids. Because this patient donated his. So I now have his hearing aids and so I came to her office. I think a couple weeks after that and. She set them when you. She said them with an initial level because your brain needs time to adjust to the new input. She explained to me that she would set them to this the initial level and I could come back in a couple weeks and she would turn them up the rest of the way that I needed. And that. Was to give me time to adjust because it

can be very painful when you get hearing aids because you have all this input coming in. And so I put the hearing aids on. We went through care and maintenance and the battery types that I would need to use for them. And, I was walking back to the bus bus station 'cause I didn't have a car at the time. And I remember I went into Whole Foods to pick up a snack, and when I walked back out I heard something fall on the ground behind me and it was my ID badge for new college. And somehow I heard this tiny little square of plastic fall on the ground. That was one of my first moments of going holy crap. I heard that that never happens. And then that evening at home, charlotte and our roommates and I were. Trying to figure out wait, what else makes a noise that I don't know about. So I found out my keyboard was far noisier than I ever knew about. I found out the toaster oven, handed an alarm and at the laundry the washing machine also had an alarm that I had no idea happened.

Karolina casually remembering my hearing loss:

Karolina is my best friend in the entire world. we met in our masters program. And we have been very close ever since Anne. Currently note, took it in stride. When I told her I was hard of hearing. I don't remember really any specifics of when I told her about my hearing loss. It probably came about when we talked about research areas since I was doing multiple sign language acquisition for my masters. And anyway it. I never thought much about it. Anne. Just I know she knew about it and that was fine. And but there are a couple of times when she specifically. I didn't even say anything. She just adjusted the situation 'cause she knew I couldn't handle it. Where we were a group of us were out in the city center one day we had her two kids and some friends and we were walking

through a construction area on when the sidewalks and Carolina started walking faster to get past it and her friend said, why are you speed walking? We're not in a hurry and she looked them and pointed at me and said I want us to get through this area so Jesse can hear what's happening. I know she can't hear anything right now. Angest and kept speed walking and she until we were in the quieter area again past the construction and. I never asked her to do that, but she just did it and just factored it into her life, Ann. A few years later we were. On we were at Universal Studios. It was her myself and her husband. And Ricardo was telling a story. And while the three of us waited in line for the Harry Potter ride, and you know Ricardo selling his story, and at one point he turned he was looking at the two of us and he turned while he was speaking to look at the rest of the park or get a better look at something. And you know, just like you would do. And she looked at me, saw the look of confusion. I think on my face. And tapped him on the shoulder, said no. You have to look look at Jesse while you're telling the story. She can't hear you, and Ricardo adjusts it said oh OK, fine yeah and went on his on his way telling the story and. I. Even now I want I just have this desire to cry as just casual, courtesy that she showed, and it didn't faze her, and it still doesn't. And I love her so much for it. And it never occurred to me that. That was something someone would do for me and she just. It's why she's my best friend. It's one of the reasons why.

Zofia asking about my hearing aids:

Anyone who has kids knows they notice everything and they will ask about everything. And so Carolina has two daughters. And one of them was. About 7-6 or seven. When I met her Zofia. So while I was living in Dublin, I went over for lunch with them one day

and me sitting down was about I was about as tall as Sophia was at that age, so. Zofia is standing next to me after we've finished eating lunch at the garden and she suddenly says and to Jesse. What is that in your ears? And I looked and you know it, I explained to her. Oh sweetie, I'm wearing hearing aids. And said, why wait why and explain to her? Well, I'm hard of hearing. I have some hearing loss so this makes it easier for me to understand what people are saying. And be aware of my situation or my surroundings. And she was fine with it. Just the beauty of explaining things to a child. Sometimes they just accepted an. It makes sense to her. And she was not fazed by said, OK, fine yeah that that makes sense cool. And versus when adults ask me questions sometimes because they don't get it. With adults like, well, what about in this situation? Or wait, you understood me here, but now you say you have trouble and. It's more complicated explaining to adults at times. Yes, I figured out what you were saying here. I never said it was easy, but I got it done. But with kids, especially with Sophia in that moment, she had a question and I answered it. And she knew I was telling her the truth. So she just factored it into her life and like oh OK moving on. Can we play with Barbies now?

Learning Mandarin during my AA degree and getting an A:

I have always been a language nerd. Without bail. The greatest wish I always had as a kid was I wanted to study languages. So when I was finishing my associates degree in 2010. There was an option to take a semester of Mandarin Chinese and it was the first time the course had ever been offered at the State College I was at. And so I signed up and I did know Mandarin uses a tonal system. And I knew it was gonna be hard. But I wanted to learn another language and spend time learning something aside from Spanish. Because I

had been taking Spanish classes since high school and I wanted something new so bad. So, and the instructor was great. She actually was my Spanish teacher my sophomore year of high school. So I took her class and. It always amazes people that someone with severe hearing loss willingly took Mandarin and they never. They always ask me how the hell did you ever do that? Anne. The best I could explain it was The thing is. It was a small class we focused on understanding the different tones and yes, they do sound the same. But if you look at the person speaking it, there are minute differences in how they look when they're saying the different tones. And there's also context context helps. But yes, the short, very short version is that I found a way to sort of lip read the different Mandarin tones. The more accurate version is. That there is different muscle memory and people look slightly different when they are saying different tones, and I memorized how it felt for me to pronounce different tones when that having that memory of this is how it should feel. In your face, in your throat, and just how that's experience, you should have one saying this tone versus the other tone or the other one or the other one. That is how I learned the tunnel system in Mandarin Chinese. Can I do it now, no? I have not studied Mandarin since 2010. But it was a very great experience and had that offered a bit more cultural awareness, which is what I wanted. And there's I, I am so into firmly believes you're never wasting time when you're learning something about another language.

Why my 2nd BA in Communication Sciences & Disorders (Speech Pathology) was a waste of time:

It was 2013. And I was trying to figure out what to do next and I had no clue. And. I had run into just this random person on new college campus one night and we got to talking

and she worked at University of South Florida and told me, oh, you should look at the communication sciences. Degree because you would be a really good speech pathologist. I hadn't really thought about it. I I'd never considered it before, but. Clearly it was advice I should look at. And I got my bought into it. She fed me align about are you would think of what a great inspiration you would be to show people that you can overcome your disability. And. I was 23 at the time and like many people I had a chip on my shoulder and I didn't like being underestimated. And so it made sense at the time. Here's what people don't always factor into these types of things. There is a reason if you do not have certain abilities you should not do certain jobs. i learned this during the coursework for this bachelors program because there was a phonology coursework you your grade depended on your ability to identify and transcribe found files that the professor would load onto the online coursework. And I was so bad at this. None of it made sense. It was. Really hard to ignore the. Truth after that course. I continued on though, because honestly I am someone that once I start a degree program I do not like to leave. I am going to finish it. The why did consider heavily leaving this program. Anne. Anyway. So partway through the program. I am. It was initially supposed to be a one year second bachelors full time, but I was also working full time so this was not possible so it ended up being a two year program so I had an audiology list appointment at one point and I asked her. If she had ever known anyone with severe hearing loss that worked as a speech pathologist and she said no. She knew people that were deaf or hard of hearing that worked is Audie Ologists. Because there's assistive equipment they can wear. And utilized that compensates and makes it possible for them to do the work. But to be a speech pathologist you have to be able to hear and distinguish individual sounds. As. I cannot do

that. I depend heavily on context. And so I thought about it more, and the more I thought about it, the clearer it became that this was a terrible idea. Because I do not possess those basic abilities because of my hearing loss and the more I thought about it, I also realized there were a lot of other things I could do with my life. And I continued thinking and. I eventually landed on a conclusion. That I do not need to overcome anything. If I did need to overcome something I already did it by finishing my first bachelors degree. And. The biggest thing I took away from this degree was I do not have anything to overcome or prove to anybody. And. If there is ever a degree I would erase from my life. It is this one. His. I I carry a lot of hatred towards this degree because. This. I was not doing well. When I was doing this degree. There are, there's a lot of trauma happening in my life at the time. That is. Painful to look back on. And it. Influenced. Nearly every element of my daily life, even more so in some ways than my hearing loss did because. When you're recovering from trauma, you functioning on a daily level. Just a basic level is your challenge and then add in. Also attending school and working full time, it just becomes harder and harder and harder. And the last thing that I needed was someone. Essentially, conning me as I viewed it later. Into thinking, oh, you're overcoming this disability. And you'll inspire people and no. People that cannot hear should not be working as speech pathologists. It's a stupid idea.

I speak clearly so is my hearing loss even real?

Yeah, it's true. I speak pretty clearly, especially when you factor in. The severe level of my hearing loss. And it is a. Concentrated effort. Learning other languages does help with this. It keeps parts of my pronunciation sharper, I think. Since it's a mental exercise

and also a physical one because my tongue and mouth all of those things. Get to RP their challenge to produce different sounds so that keeps things working. But yet I speak very clearly. I do not have a deaf accent. I tried to not slur my words together. And I try not to stutter. I did have a pretty decent stutter as a child. Because I was raised by abusive people that love to scare me. But I try not to set her at least one one as possible. But all of these things together means I am able to speak clearly. I do not try to whisper because I cannot easily understand whispering. And I tend to speak at a decent volume because of my hearing loss. So all of this results in someone who. Speaks loudly without meaning to. And. the irony of this is that i am such a severe introvert I would rather be hanging out in the background of social situations. But often end up. More involved than I would like to be. Because. I it just happens somehow. Not really sure how. But this does lull people into a false sense of security. It. A common excuse that I am given. Is well, they. They don't realize that your hearing loss is real Jesse because you speak so clearly there's no indication to them. Which I understand. Even though I would like to just slap people because of this because. Might like I said, my Speech is a concentrated skill. And. It would be so nice if when I explained to someone I am severely hard of hearing that they believe me and actually. Tried any of the things I ask them to do, which is usually just. Can you look at me when you are speaking?

Hearing loss's physical effects (the first time the tinnitus pain stopped):

So anyone who has experienced hearing loss will probably have experienced tinnitus. Which is a essentially it. It can be ringing in the ears and can also be pain in your ears. Because when something that happens with hearing loss, especially it's after you reach a

certain level of hearing loss. Is when you have. The brain expects to hear sound. It expects to get. Input. And in your inner ear, when it damaged and it's not receiving sound, you experience what it's called Phantom sounds, which unfortunately the brain translates into pain. No. One thing I did not know hearing aids would have an effect on because I'd never had them until I was 23. Was Terry this? So. About a few days after I got my hearing aids, even at their initial levels, I'm at work at a retail shop. And suddenly it was like. I relaxed for the first time in my life. And I was so confused and suddenly realized. My head does not hurt. For the first time, I am not in pain. And consequently not frustrated and irritated every time someone speaks to me or bothers me. Because I no longer feel like I'm getting stabbed in my ears all day long. So hearing aids. For me they do not fix everything. They do not make me not hard of hearing. But they do help with tinnitus and that makes them worth it. Even if I could not hear anyone any better. I can, which is great. But not having tonight is pain. Made my life so much more doable. And I. The only way I can explain the type of pain is if you imagined shoving a handful of needles into your ears off and on for about 12 hours a day. Every day. And at random intervals, because there's no telling how bad it's going to be on any given day, but you will be exhausted. And won't really know why. At least this is a good time to remember. That I am. Had that I had been diagnosed as a kid. And had never been educated about hearing loss, which is why I did my dissertation on hearing loss in undergrad. So a lot of the effects at hearing last takes on someone I didn't know what they were. As a child or young adult until I started researching deaf culture.

Disclaimer: This entry was actually written down in a notebook, so this is the transcription of that entry (I chose to do it this way to keep these entries together and to make sure the entry was legible rather than submitting a scan of my hand-written note)

Hearing loss through neglect:

My upbringing was not great, neglectful is the easiest summary. When I think back on my birth family it makes sense why my adoptive mom gets so rage-induced when we talk about it. My hearing loss started being noticed in elementary school. There were school-wide hearing and vision tests once or twice a year – the first time I failed the test I was sent to the doctor, who found some built up ear wax, removed it, and I was deemed back to normal afterwards. Damn removing that wax hurt and was terrifying. It was done at an air force base hospital and I remember the doctors only spoke to me to give me instructions.

In middle school my luck ran out. I failed another hearing test, and the follow up in the nurse's office a month or so later. Sometime later my mother was taking me to an audiologist at a local hospital and I had a hearing screening in one of their sound proof booths. I was about 11 or 12. The screening was okay, but then the audiologist gave his diagnosis: partial hearing loss in higher pitches that was likely permanent and no idea what caused it. He said I'd have problems with hearing whispering, and understanding people if they weren't looking at me.

Then out of nowhere he asked me to tell him about a movie I'd seen recently and I started rattling off details about Harry Potter and the Chamber of Secrets. Even thinking back on it I can picture Molly Weasley's entrance (which is the only reason I remember the

movie). I'd loved the movie and was getting excited about the movie when he stopped me mid-sentence. He went on to tell me and my mother that I would string my words together when I got excited because I can't hear myself so I would need to be aware of this. Even now it feels like a trap, this was used against me so much. He also said I should be brought in if I felt pain in my ears. Yeah. That didn't happen.

And just like that I was partly deaf.

And it was never acknowledged anywhere official again. (Until I had another hearing screening when I was 23).

APPENDIX C
PRE-SURVEY QUESTIONS

Pre-Survey:

Part I: Perceptions on Hearing Loss: For the following questions, please answer as though you had sustained severe hearing loss.

- 1) Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):
 - a. Calm
 - b. Anxious
 - c. Depressed
 - d. Happy
 - e. Determined
 - f. Confused
 - g. Overwhelmed
 - h. Angry
 - i. Other
 - i. Please explain:
- 2) I think hearing loss would impact my daily life.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 3) I think my friends would view me differently if I sustained significant hearing loss.
 - a. Strongly agree

- b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 4) I think my family would view me differently if I sustained significant hearing loss.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 5) I think my work associates would view me differently if I sustained significant hearing loss.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 6) If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree

- e. Strongly disagree
- 7) If I had severe hearing loss, I would consider wearing hearing aids.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 8) If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 9) Sustaining severe hearing loss would influence my comfort level in participating in social activities.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 10) Please rate your current knowledge of **hearing aids** as a type of assistive technology
- a. Minimal

- b. Moderate
- c. Advanced

11) Please rate your current knowledge of **cellphone haptics** as a form of assistive technology. Cellphone haptics means the vibrating features of a cellphone.

- a. Minimal
- b. Moderate
- c. Advanced

12) Please rate your current knowledge of **screen readers** as a form of assistive technology:

- a. Minimal
- b. Moderate
- c. Advanced

13) Please rate your current knowledge of **transcription devices** as a form of assistive technology:

- a. Minimal
- b. Moderate
- c. Advanced

APPENDIX D
POST-SURVEY QUESTIONS

Post Survey:

Part I: Perceptions on Hearing Loss: For the following questions, please answer as though you had sustained severe hearing loss.

- 1) Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):
 - a. Calm
 - b. Anxious
 - c. Depressed
 - d. Happy
 - e. Determined
 - f. Confused
 - g. Overwhelmed
 - h. Angry
 - i. Other
 - i. Please explain:
- 2) I think hearing loss would impact my daily life.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 3) I think my friends would view me differently if I sustained significant hearing loss.
 - a. Strongly agree
 - b. Somewhat agree

- c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 4) I think my family would view me differently if I sustained significant hearing loss.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 5) I think my work associates would view me differently if I sustained significant hearing loss.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 6) If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.
- a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree

- 7) If I had severe hearing loss, I would consider wearing hearing aids.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 8) If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 9) Sustaining severe hearing loss would influence my comfort level in participating in social activities.
 - a. Strongly agree
 - b. Somewhat agree
 - c. Neither agree nor disagree
 - d. Somewhat disagree
 - e. Strongly disagree
- 10) Please rate your current knowledge of **hearing aids** as a type of assistive technology
 - a. Minimal
 - b. Moderate

c. Advanced

11) Please rate your current knowledge of **cellphone haptics** as a form of assistive technology. Cellphone haptics means the vibrating features of a cellphone.

a. Minimal

b. Moderate

c. Advanced

12) Please rate your current knowledge of **screen readers** as a form of assistive technology:

a. Minimal

b. Moderate

c. Advanced

13) Please rate your current knowledge of **transcription devices** as a form of assistive technology:

a. Minimal

b. Moderate

c. Advanced

Part II: Feedback on the Interactive Fiction Experience

1. Please rate your ease in using the experience: (1 = difficult to use, 10 = very easy to use)

a. 1

b. 2

c. 3

d. 4

- e. 5
- f. 6
- g. 7
- h. 8
- i. 9
- j. 10

2. Please select all of the experiences you completed:

- a. Level 1: Initial diagnosis
- b. Level 1: school experience
- c. Level 1: friends
- d. Level 1: work experience
- e. Level 1: family experience
- f. Level 1: loss through neglect
- g. Level 2: roommates
- h. Level 2: classes
- i. Level 2: Assumptions made by others in college
- j. Level 2: Family experience during college
- k. Level 2: 2nd audiologist appointment at 23 years old
- l. Level 3: Receiving donated hearing aids
- m. Level 3: Working full-time while completing a 2nd BA
- n. Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss
- o. Level 3: Explaining hearing loss to your niece
- p. Level 3: Going to Universal Studios with friends

3. Which experience in Level 1 was your favorite:
 - a. Level 1: Initial diagnosis
 - b. Level 1: school experience
 - c. Level 1: friends
 - d. Level 1: work experience
 - e. Level 1: family experience
 - f. Level 1: hearing loss through neglect
4. Why was the experience you chose for Level 1 your favorite?
 - a. Free response question
5. Which experience in Level 1 was your **least** favorite:
 - a. Level 1: Initial diagnosis
 - b. Level 1: school experience
 - c. Level 1: friends
 - d. Level 1: work experience
 - e. Level 1: family experience
 - f. Level 1: hearing loss through neglect
6. Why was the experience you chose for Level 1 your **least** favorite?
 - a. Free response question
7. Which experience in Level 2 was your favorite:
 - a. Level 2: roommates
 - b. Level 2: classes
 - c. Level 2: Assumptions made by others in college
 - d. Level 2: Family experience during college

- e. Level 2: 2nd audiologist appointment at 23 years old
8. Why was the experience you chose for Level 2 your favorite?
- a. Free response question
9. Which experience in Level 2 was your **least** favorite:
- a. Level 2: roommates
 - b. Level 2: classes
 - c. Level 2: Assumptions made by others in college
 - d. Level 2: Family experience during college
 - e. Level 2: 2nd audiologist appointment at 23 years old
10. Why was the experience you chose for Level 2 your **least** favorite?
- a. Free response question
11. Which experience in Level 3 was your favorite:
- a. Level 3: Receiving donated hearing aids
 - b. Level 3: Working full-time while completing a 2nd BA
 - c. Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss
 - d. Level 3: Explaining hearing loss to your niece
 - e. Level 3: Going to Universal Studios with friends
12. Why was the experience you chose for Level 3 your favorite?
- a. Free response question
13. Which experience in Level 3 was your **least** favorite:
- a. Level 3: Receiving donated hearing aids
 - b. Level 3: Working full-time while completing a 2nd BA
 - c. Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss

- d. Level 3: Explaining hearing loss to your niece
 - e. Level 3: Going to Universal Studios with friends
14. Why was the experience you chose for Level 3 your **least** favorite?
- a. Free response question
15. Which of the following scenarios within the experience did you enjoy the most?
- a. Level 1: Initial diagnosis
 - b. Level 1: school experience
 - c. Level 1: friends
 - d. Level 1: work experience
 - e. Level 1: family experience
 - f. Level 1: hearing loss through neglect
 - g. Level 2: roommates
 - h. Level 2: classes
 - i. Level 2: Assumptions made by others in college
 - j. Level 2: Family experience during college
 - k. Level 2: 2nd audiologist appointment at 23 years old
 - l. Level 3: Receiving donated hearing aids
 - m. Level 3: Working full-time while completing a 2nd BA
 - n. Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss
 - o. Level 3: Explaining hearing loss to your niece
 - p. Level 3: Going to Universal Studios with friends
16. Which of the following scenarios within the experience did you enjoy the **least**?
- a. Level 1: Initial diagnosis

- b. Level 1: school experience
- c. Level 1: friends
- d. Level 1: work experience
- e. Level 1: family experience
- f. Level 1: hearing loss through neglect
- g. Level 2: roommates
- h. Level 2: classes
- i. Level 2: Assumptions made by others in college
- j. Level 2: Family experience during college
- k. Level 2: 2nd audiologist appointment at 23 years old
- l. Level 3: Receiving donated hearing aids
- m. Level 3: Working full-time while completing a 2nd BA
- n. Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss
- o. Level 3: Explaining hearing loss to your niece
- p. Level 3: Going to Universal Studios with friends

17. This interactive fiction experience was useful to me for learning about hearing loss.

- a. Strongly agree
- b. Somewhat agree
- c. Neither agree nor disagree
- d. Somewhat disagree
- e. Strongly disagree

18. I would recommend this experience to others that want to learn more about hearing loss.

- a. Strongly agree

- b. Somewhat agree
- c. Neither agree nor disagree
- d. Somewhat disagree
- e. Strongly disagree

19. The scenarios within this experience were helpful for learning about hearing loss.

- a. Strongly agree
- b. Somewhat agree
- c. Neither agree nor disagree
- d. Somewhat disagree
- e. Strongly disagree

20. There were too many scenarios.

- a. Strongly agree
- b. Somewhat agree
- c. Neither agree nor disagree
- d. Somewhat disagree
- e. Strongly disagree

Part III: Background/Experience

1. Please enter your age range:
 - a. Free response question
2. With what gender do you identify?
 - a. Free response question
3. Do you personally know someone that has hearing loss?

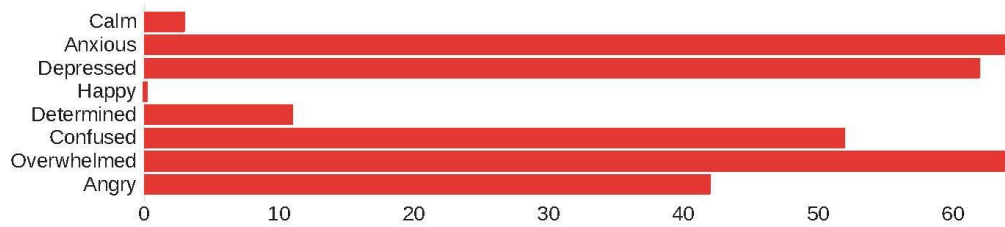
- a. Yes
- b. No
- c. Not sure

4. Please rate your knowledge related to hearing loss:

- a. Limited
- b. Moderate
- c. Advanced

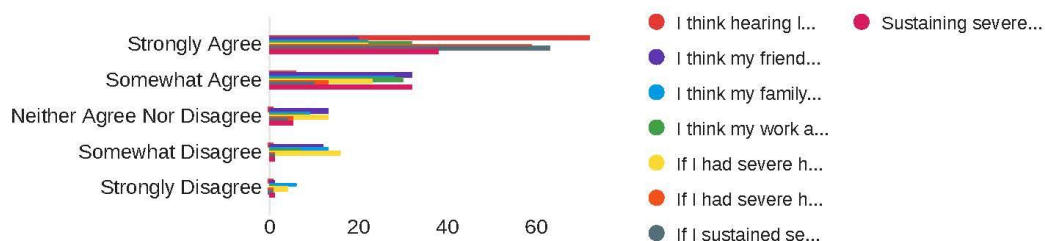
APPENDIX E
PRE-SURVEY REPORT

Q17 - Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):



Field	Choice Count
Calm	3
Anxious	64
Depressed	62
Happy	0
Determined	11
Confused	52
Overwhelmed	64
Angry	42
Total	298

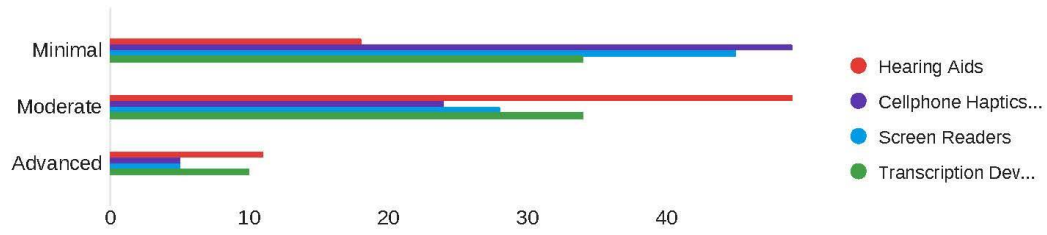
Q19 - Please rank the following statements from depending on if you 'strongly agree', 'agree', 'neither agree nor disagree', 'disagree', or 'strongly disagree'



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
I think hearing loss would impact my daily life.	1	2	1	0	0	78
I think my friends would view me differently if I sustained significant hearing loss.	1	5	2	1	1	78
I think my family would view me differently if I sustained significant hearing loss.	1	5	2	1	2	78
I think my work associates would view me differently if I sustained significant hearing loss.	1	5	2	1	1	78
If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.	1	5	2	1	2	78
If I had severe hearing loss, I would consider wearing hearing aids.	1	4	1	1	0	78
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):	1	4	1	1	0	78
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	1	5	2	1	1	77

Field	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree	Total
I think hearing loss would impact my daily life.	72	6	0	0	0	78
I think my friends would view me differently if I sustained significant hearing loss.	20	32	13	12	1	78
I think my family would view me differently if I sustained significant hearing loss.	22	28	9	13	6	78
I think my work associates would view me differently if I sustained significant hearing loss.	32	30	8	7	1	78
If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.	22	23	13	16	4	78
If I had severe hearing loss, I would consider wearing hearing aids.	59	13	5	1	0	78
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):	63	10	4	1	0	78
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	38	32	5	1	1	77

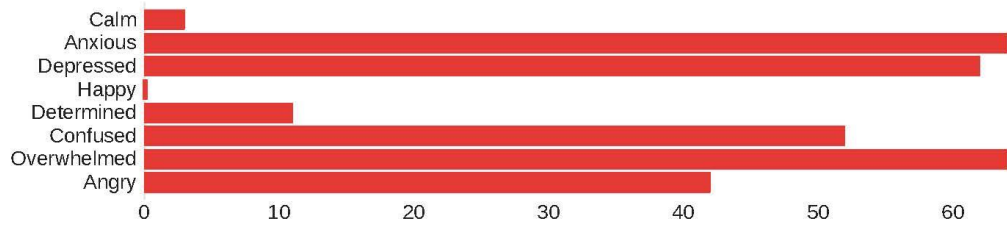
Q20 - Please rate your current knowledge of the following types of assistive technology from 'minimal', 'moderate', or 'advanced'



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Hearing Aids	1	3	2	1	0	78
Cellphone Haptics (vibration)	1	3	1	1	0	78
Screen Readers	1	3	1	1	0	78
Transcription Devices	1	3	2	1	0	78

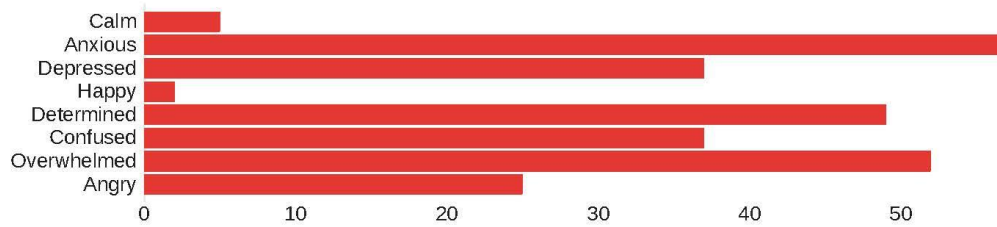
Field	Minimal	Moderate	Advanced	Total
Hearing Aids	18	49	11	78
Cellphone Haptics (vibration)	49	24	5	78
Screen Readers	45	28	5	78
Transcription Devices	34	34	10	78

New Custom Page



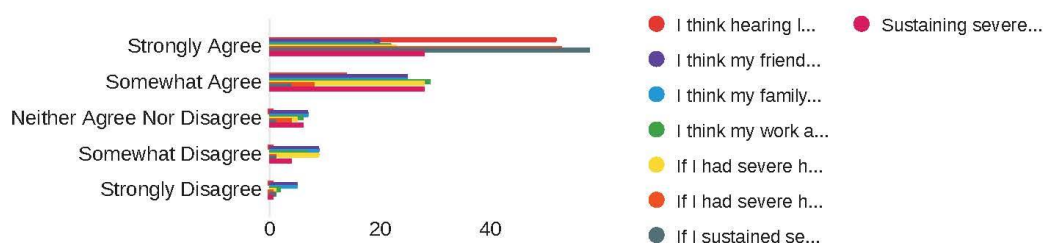
APPENDIX F
POST-SURVEY REPORT

Q17 - Please select all the emotions you think you would feel if you sustained severe hearing loss (check all that apply):



Field	Choice Count
Calm	5
Anxious	57
Depressed	37
Happy	2
Determined	49
Confused	37
Overwhelmed	52
Angry	25
Total	264

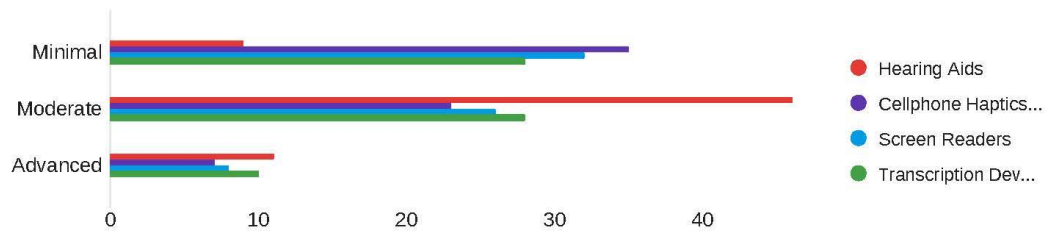
Q19 - Please answer the following statements depending on if you 'strongly agree', 'agree', 'neither agree nor disagree', 'disagree', or 'strongly disagree'



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
I think hearing loss would impact my daily life.	1	2	1	0	0	66
I think my friends would view me differently if I sustained significant hearing loss.	1	5	2	1	2	66
I think my family would view me differently if I sustained significant hearing loss.	1	5	2	1	2	65
I think my work associates would view me differently if I sustained significant hearing loss.	1	5	2	1	1	66
If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.	1	5	2	1	1	66
If I had severe hearing loss, I would consider wearing hearing aids.	1	4	1	1	0	66
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):	1	5	1	1	0	65
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	1	4	2	1	1	66

Field	Strongly Agree	Somewhat Agree	Neither Agree Nor Disagree	Somewhat Disagree	Strongly Disagree	Total
I think hearing loss would impact my daily life.	52	14	0	0	0	66
I think my friends would view me differently if I sustained significant hearing loss.	20	25	7	9	5	66
I think my family would view me differently if I sustained significant hearing loss.	19	25	7	9	5	65
I think my work associates would view me differently if I sustained significant hearing loss.	22	29	6	7	2	66
If I had severe hearing loss, I would be comfortable explaining my hearing loss to others.	23	28	5	9	1	66
If I had severe hearing loss, I would consider wearing hearing aids.	53	8	4	1	0	66
If I sustained severe hearing loss, I would be interested in expanding my communication abilities (i.e., lipreading, American Sign Language):	58	4	1	1	1	65
Sustaining severe hearing loss would influence my comfort level in participating in social activities.	28	28	6	4	0	66

Q20 - Please rate your current knowledge of the following types of assistive technology from 'minimal', 'moderate', or 'advanced'



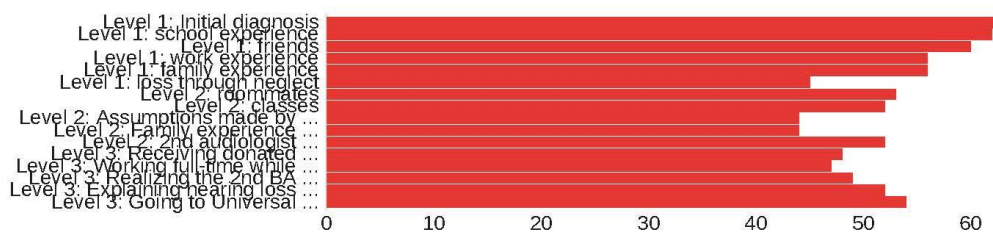
Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Hearing Aids	1	3	2	1	0	66
Cellphone Haptics (vibration)	1	3	2	1	0	65
Screen Readers	1	3	2	1	0	66
Transcription Devices	1	3	2	1	1	66

Field	Minimal	Moderate	Advanced	Total
Hearing Aids	9	46	11	66
Cellphone Haptics (vibration)	35	23	7	65
Screen Readers	32	26	8	66
Transcription Devices	28	28	10	66

Q21 - Please rate your ease in using the experience: (10 = difficult to use, 100 = very easy to use)

Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Ease of using the experience	43	100	90	14	192	55

Q22 - Please select all of the experiences you completed:



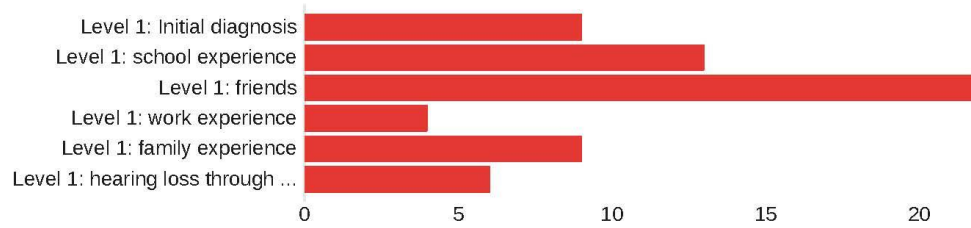
Field	Choice Count
Level 1: Initial diagnosis	63
Level 1: school experience	62
Level 1: friends	60
Level 1: work experience	56
Level 1: family experience	56
Level 1: loss through neglect	45
Level 2: roommates	53
Level 2: classes	52
Level 2: Assumptions made by others in college	44
Level 2: Family experience during college	44
Level 2: 2nd audiologist appointment at 23 years old	52
Level 3: Receiving donated hearing aids	48
Level 3: Working full-time while completing a 2nd BA	47
Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss	49
Level 3: Explaining hearing loss to your niece	52
Level 3: Going to Universal Studios with friends	54

7

Total

837

Q23 - Which experience in Level 1 was your favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which experience in Level 1 was your favorite:	1	6	3	1	2	63

Field	Choice Count
Level 1: Initial diagnosis	9
Level 1: school experience	13
Level 1: friends	22
Level 1: work experience	4
Level 1: family experience	9
Level 1: hearing loss through neglect	6
Total	63

Q24 - 4. Why was the experience you chose for Level 1 your favorite?

4. Why was the experience you chose for Level 1 your favorite?

N/A

Slightly more accepting?

I chose friends because she still communicated to her friends her hearing loss and found new friendships that took the time to understand her.

THE EXPERIENCE CHOSEN WAS MY FAVORITE DUE TO THE IMAGINED SCENARIOS THAT OCCUR IN SCHOOL, AND THE RELATABILITY AS WELL CONSIDERING THE EXPERIENCE PUTS YOU IN HER SHOES

best insight

I felt that it made me really aware of how big an impact family can have on a persons hearing loss.

N/A

It shows how if people want to be in your life they will adapt and adjust with you and your abilites to be with you.

N/A

Friends are a huge part of a childs life.

Allowed me to better understand the personal struggles of hearing loss.

It seems as though the friends handled it the best.

N/A

She learned to tell people

It was interesting to learn about how hearing loss impacted an experience within a school environment.

it put hearing loss in the workplace into perspective

The friends level gave great detail about how hearing loss impacts relationships.

School experience with hearing loss is very descriptive and an experience many people have.

It pointed out risks in the work environment I hadn't considered such as not fully recognizing the risks of noise from heavy machinery due to reduced hearing.

Isana could easily adapt to her school environment.

Compared to the other experiences, she at least had made some friends who she said were "amazing". Except for the situation where she would scare her.

N/A

N/A

I found it shocking, but I am sure it is more common than one would think.

Reminder that families can be extremely neglectful.

Interesting to see relationship between personality and hearing loss and their combined effect in school

It shed light on the honest truth a hearing impairment can have on social life growing up.

Helped me understand the loss the most

interesting to learn about this environment

I am interested in the effects that peers/teachers in a school setting have on children with hearing loss and how future educators can help guide these children.

It showed that if you do not take charge, you will often be ignored by the professional, which can be frustrating especially when you are old enough to understand what is going on.

I liked the diagnosis

It helped me better understand the difficulties faced by individuals with hearing loss in school settings.

I know they would be there for me.

It was very eye opening to hear about her experience with school during a time when she wasn't given any guidance with her hearing loss.

Having this knowledge was very enlightening when considering how the character viewed her hearing loss throughout her life.

I got to see how her family life impacted the way she viewed her hearing loss.

I never thought about a family having this kind of negative look at their child who has hearing loss. This was the most eye opening and interesting experience from level one.

Because it was interesting to see how the diagnosis impacted her school life.

cause it shows that your friends don't care if you can't hear they still want to be your friend even if you are different

I chose friends because I feel like my social life would be impacted greatly if I had hearing loss.

Family

It was well written and showed some pros alongside all the cons

It was interesting to hear someone's experience in a situation I've never heard before.

showed that there was initial concern

There could be empathy

Explaining that sometimes being passive can be the problem

N/A

N/A

N/A

How your environment impacts your health

It was interesting to learn how hearing loss could be diagnosed because that's something I don't really know about.

I have a different disability and family responses matter a lot!

It was my favorite because level 1 is terrible. Literally everything else is worse than finding out you have hearing loss.

Interesting and pivotal

N/A

N/A

Obviously, context matters and all family dynamics are different, but I could relate to not having a good relationship with people to whom I am genetically related, and not being believed by them (and then told it is your fault).

Because it showed how friends can be supportive and validate your needs.

There was possibility of acceptance.

It was interesting to learn that young kids thought it wasn't a big deal, though it is to the person with hearing loss.

Her friends were trying to help as much as they can.

N/A

This was a very impactful and emotional section for me that made me reflect on some personal experiences, as well as motivating me to consider how to navigate an experience like this as a parent.

I have experience with cardboard balers and identified with Isana as they are extremely loud.

N/A

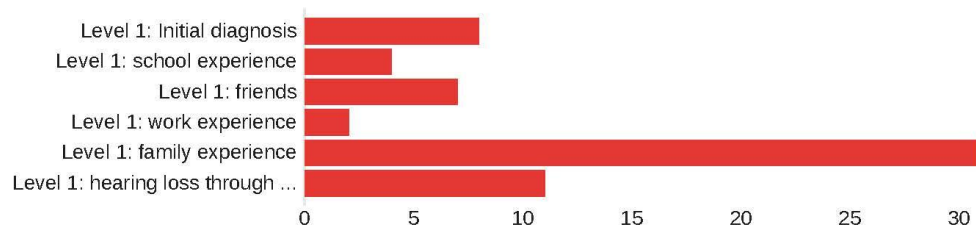
Family is the most important thing to a child. This is where the child learns what to think of their experiences.

it informs about the impact of parental decisions on child's wellbeing

The concept of school hearing tests suggests a level of healthcare that is better than what I experienced.

N/A

Q25 - Which experience in Level 1 was your least favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which experience in Level 1 was your least favorite:	1	6	4	2	3	63

Field	Choice Count
Level 1: Initial diagnosis	8
Level 1: school experience	4
Level 1: friends	7
Level 1: work experience	2
Level 1: family experience	31
Level 1: hearing loss through neglect	11
Total	63

Q26 - Why was the experience you chose for Level 1 your least favorite?

Why was the experience you chose for Level 1 your least favorite?

So many compounding issues

Family experience was my least favorite because it reminds me of my own when it comes to others with other disabilities. Family should have been her biggest support.

IT WAS MY LEAST FAVORITE DUE TO THE LACK OF SUPPORT THAT WAS SHOWN BY THE FAMILY; FAMILIAL SUPPORT IS ONE OF THE MOST IMPORTANT THINGS IN A SCENARIO SUCH AS HEARING LOSS

seemed random and out of place

I did not like the way the mother reacted to the situation, and barely made a comment on the situation.

Her family didn't put her needs first like parent should.

It was sad to hear her not being supported by her family.

It was disheartening to see how one could be treated.

Parents almost ignored it

Her family neglected her and did not help at all.

It made me sad how some of her friends treated her.

neglect is very unfortunate

I wish there was more detail about her experience in the school setting.

It is very sad to experience loss in this manner.

The quality was high, the material was emotionally challenging.

Her family was insensitive.

It was disappointing to see the way the family treated her and her hearing loss.

I thought it was incredibly sad that her family didn't care. It was a very crucial time for her hearing loss to not deteriorate, which it did.

Don't really have a least favorite.

The sound hurt my ears

Though this topic was important it made me feel extremely sad for the child's mental health and physical health being tossed to the side.

Mad me sad for her

a lot of information to consume

The family experience was my least favorite because it made me very sad to realize that not every family helps support their children with hearing losses. I think the audiologist from the initial diagnosis was unprofessional in the way he spoke about her hearing loss.

It's sad to know that there are families who won't understand or be supportive.

I didn't like neglect

I thought it was quite sad that one's family can ignore and even make fun of hearing loss.

I would feel overwhelmed and lost.

I didn't hate any of the experiences but this one was just the least interesting

Her families' attitude towards her was very sad and frustrating.

This was my least favorite because her hearing wasn't taken seriously by her family and they made her feel ashamed of it which was wrong

School is a hard time as it is and having a physical difference (especially one that is not visible) is hard.

The audiologist tricked her instead of just describing to her what she should do

It was my least favorite because when thinking about hearing loss, I would want my family experience to remain the same. This would be a hard change.

School

I felt like there were unexplored possibilities. I wanted to take a middle road--accept and appreciate that my friends didn't feel like there was a problem (even if they weren't the most receptive) while also pursuing more understanding relationships.

It was unfortunate to hear :(

sad to hear family did not seek further treatment or assistive technology

Because the family prefers to not accept the reality

I would have maybe preferred to hear a sound or have a description of the experience more than be told

Family pisses me off

It was sad how the family treated her.

More lead-up in how the main character's experiences were different might have illustrated the concepts more strongly

It is my least favorite because of all the ways the family made the situation dramatically worse.

Family should always be there if not there is the one you build. This reflected that.

I liked this one in terms of the story and the descriptions of the experience. The loud ringing on that one was not something I was ready for though.

As a parent, it was sad and frustrating to me that you didn't receive the support we as parents are literally 100% responsible for and that it caused you further damage.

The family depicted are complete jerks.

I was sad by the reactions of the family and how unsupportive they were.

It shows the family responsibility to care for their child. Maybe if they continue going to the doctor her hearing loss wouldn't have been so permanent. The family needed to empathize with her and understand her suffering. Maybe getting her hearing aids at younger age would have saved her many social problems.

I wanted to know the other options, what they led to

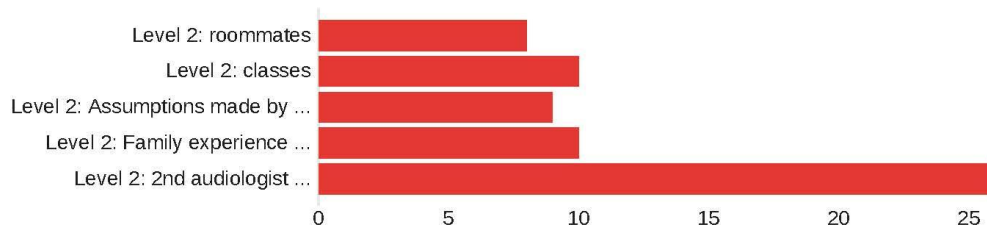
The "friends" seemed cruel

This part was the saddest because seeing a child neglected and mistreated makes me angry and sad.

the doctor was a complete jerk

Similar to aspects of my own traumatic childhood

Q27 - Which experience in Level 2 was your favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which experience in Level 2 was your favorite:	1	5	4	1	2	63

Field	Choice Count
Level 2: roommates	8
Level 2: classes	10
Level 2: Assumptions made by others in college	9
Level 2: Family experience during college	10
Level 2: 2nd audiologist appointment at 23 years old	26
Total	63

Q28 - Why was the experience you chose for Level 2 your favorite?

Why was the experience you chose for Level 2 your favorite?

Support!

Roommates was my favorite because they displayed their dedication in learning how to work with her hearing loss and accepted her 100%

THIS WAS MY FAVORITE DUE TO THE UNEXPECTED SUPPORT FROM OTHERS AROUND HER, SINCE SHE NEVER EXPERIENCED THAT FROM HER OWN FAMILY.

She finally experiences relief

I was happy when she decided to go to another audiologist appointment to see how bad her hearing has gotten.

She proved to someone she can do things on her own and be strong.

She found her chosen family.

Showed patients acceptance

More answers

The audiologist was impressed by how well she could speak

The relief she felt when the audiologist confirmed details about her hearing loss made me happy.

the audiologist appointment at 23 years old brought hope to finding new treatment

I found it very interesting to see how her classmates reacted once the woman felt comfortable sharing her hearing loss.

I think this is a huge external factor

This felt somewhat triumphant, the narrator was getting the help she needed.

Isana got a proper diagnosis for her condition.

Although the audiologist was in shock that she had gone so long and is speaking clearly, I think it was a good experience.

Her roommate was a great friend to have.

Really excited that she go to go to the audiologist.

Great to hear how accommodating the teacher was

I was happy to see she went back to the audiologist again after a horrible first experience. It was refreshing to see one bad experience with a health care professional doesn't mean all are that way.

happy she went back

showed different challenges in this area

The experience with the second audiologist was my favorite because I feel like she finally got a better understanding of her hearing loss from someone who was very educational and professional.

Isana showed amazing growth in working with her hearing loss even though it worsened drastically since she was age 11.

I liked learning about the family experiences

It was relieving to actually have a diagnosis.

They would always have my back.

I was so intrigued to see how her hearing loss would have progressed and how the audiologist was going to react

I enjoyed experiencing the professors reception of her hearing loss. I have seen many of my professors be extremely mindful to make accommodations for people who need them, and it made me happy that their reaction gave the character some confidence and empowerment.

She finally took matters into her own hands and went to see a audiologist after not seeing one for year which was very incredible

I think that it was great how well she had adapted without even knowing. The fact that the audiologist was so impressed by the way she was speaking so clearly is incredible.

People in college didnt care and teachers were happy to help

because classes may have to change.

Roommates

It was interesting to think about how the structure of a class(room) affects ability to learn.

Interesting unique experience that gave me new perspective.

seemed like roommates were excepting except for th eloud alarm clock

Helpful to know how people make assumptions about something (thinking someone is a "bitch" when they... just can't hear you)

Shows understanding

I think that ended up being a positive experience overall.

Validation! Meaningful help and advice!

I am specifically referring to found family, which is an important experience for everyone.

Again the found family is great.

Again, I recognize that the dynamics are always specific and contextual, but I could relate to most of the ones about people to whom one is genetically related.

I learned something. It made me recognize areas that I just take for granted and that I should pay more attention to those around me.

Finding a family that accepts you is a dream come true for many.

It is good to know that sharing the information is what friends/classmates want. It sounds like it make her realize that she should speak up for herself.

She got hearing aids.

This was another section that made me think a lot about other folks experiences, as well as my own

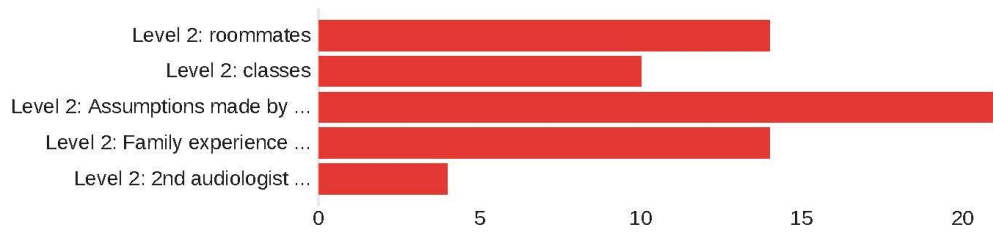
it gave me a bit more perspective on hearing loss in a familiar setting

This experience was the most hopeful and positive moment, because it led to a positive change.

students were clearly more mature than youngsters and when faced with explanation regarding Isana's ignoring them they seemed to understand it a bit better

They were accepted by teachers rather than judged and discriminated against, and they learned about the Deaf communities and culture

Q29 - Which experience in Level 2 was your least favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which experience in Level 2 was your least favorite:	1	5	3	1	1	63

Field	Choice Count
Level 2: roommates	14
Level 2: classes	10
Level 2: Assumptions made by others in college	21
Level 2: Family experience during college	14
Level 2: 2nd audiologist appointment at 23 years old	4
Total	63

Q30 - Why was the experience you chose for Level 2 your least favorite?

Why was the experience you chose for Level 2 your least favorite?

Struggling to find a way

I feel like the family again was not supportive for her as much as they should have.

THE CONTINUED LACK OF SUPPORT, AND THE MOTHER SAYING SHE WONT BE ABLE TO TALK ON THE PHONE JUST BECAUSE SHE HAS HEARING AIDS.

People can be so Judging

I did not go into the part about her birth family, but there was a little information about the found family and that was it.

they weren't understanding

It would be really tough to learn with a severe hearing loss.

Family remained unsupportive so this was saddening

Hard to live w/ different set ups and alarms

People said she was rude and ignored them

It was hard to hear about the struggles of trying to participate in a college classroom setting when you have hearing loss.

it is sad that others make assumptions instead of asking what is truly going on

It was similar to her classmates reaction but was still very interesting to read.

This is a sad reality and assumptions are hard to avoid

This one was mildly humiliating because I can put myself in the position of making those assumptions.

All I saw was that the alarm clock was a hot button topic.

The family was not supportive and chose to ignore the hearing loss rather than look for ways to

The shock of course was unbelievable to the audiologist. Wish they could of understood her background more.

No real least favorite.

Again, the sound hurt my ears

Unfortunate that her roommates were not more receptive to her needs.

It's hard to learn how to live with people

type of content discussed

This experience was my least favorite just because I can only imagine the struggle she felt as others assumed she was ignoring them and how that also occurs on a daily basis with others in different settings.

Frustrating that Isana would not mention to her professors her hearing loss until the end of the semester.

I hated the assumptions that were made

It was sad to see that others make assumptions before actually understanding the situation.

It is something rude to do.

i dont even remember what this one was about besides an alarm clock

It is sad that we never know what may be going on with someone just because it is not something we can visually "see."

This was my least favorite because it showed how people just assumed things about her and stopped talking to her than find out why she did listen/ hear what they said.

I think it's sad that her peers just assumed she was rude because she didn't respond to them. They just jumped to conclusions rather quickly. I feel like I would have inquired a little bit more or paid attention to her interactions with others in order to gain more information.

Her half sister was like mean

this must be hard to cope with.

Classes

It was nice, but I also felt like there were other solutions. For example, I have an alarm on my watch which vibrates to wake me up instead of making noise.

Again, unfortunate to hear that school and education is something that others take for granted- something that I even took for granted.

still family not on board with accepting hearing loss

Static would have been a good audio choice for this part to help understanding

b

While that was interesting to learn, it sounded like a stressful situation for her to be in and deal with every day. I mean, you wake up in the morning and they are already annoyed? That's not her fault and it seemed stressful to me.

I'm glad this story had others realizing their mistakes, apologizing, and doing better...it just was different from my experience with my disabilities

Since the focus of college is class, the maladaptive nature of this focal point frustrated me the most.

This can be bad because it also impacts the way you feel about your intelligence.

I have had roommates, but I avoided them, so roommate dynamics are harder to wrap my head around, I think.

It reaffirmed your parent's neglect.

Humans are stupid.

It's a reminder how hard it is for students to succeed in a traditional classroom setting.

She didn't get enough support

This section kind of made me feel stuck, with no options. But I guess that really makes sense, too

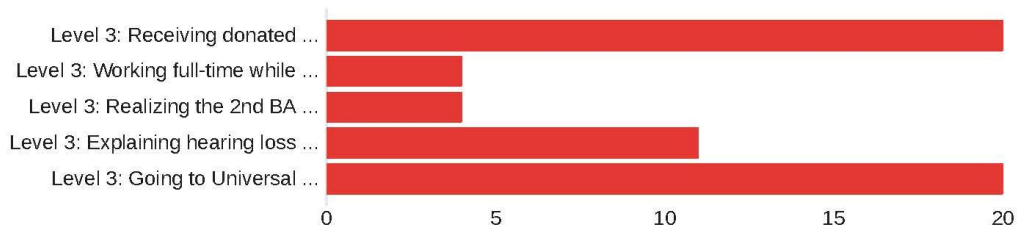
I just don't like traditional alarm clocks

I found this part to be sad, because once again, Isana was mistreated.

very frustrating, compromising on class participation and how much you can get from classes and lectures

Had the least information in it

Q31 - Which experience in Level 3 was your favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses	
Which experience in Level 3 was your favorite:	1	5	3		2	3	59

Field	Choice Count
Level 3: Receiving donated hearing aids	20
Level 3: Working full-time while completing a 2nd BA	4
Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss	4
Level 3: Explaining hearing loss to your niece	11
Level 3: Going to Universal Studios with friends	20
Total	59

Q32 - 12. Why was the experience you chose for Level 3 your favorite?

12. Why was the experience you chose for Level 3 your favorite?

Communal support

Because children are so open and accepting in an innocent and sincere way to others. Kids are real when it comes to other's differences and they will tell you how they feel. In this case it was a positive way of telling their aunt how they feel.

She got the help she was looking for

I thought that was a really great development in the story line.

It important to educate others. Kids are so observant.

Doing fun things with good friends.

Was an interesting decision; did not see this happening while other struggles persisted

still can have fun at a park

That had the biggest impact on her life and was so kind

Sometimes little kids have the best responses. It was nice to see how her niece reacted compared to other people mentioned.

this was great news for them and it gives hope that others can experience this if they cannot afford hearing aids.

I thought it was interesting to read about how her friend made sure she was included when her husband was telling a story. She told her husband to look at her while he spoke.

This is a huge step. Hearing aids are very expensive

The narrator has achieved acceptance. Life is not completely devoid of irritants but she is surrounded by people who are aware and care.

Isana's friend and her husband are really nice.

Very nice of the audiologist to give her donated hearing aids, considering they are very

Money is a huge issue for alot of people, glad she could get the hearing aids regardless of money.

Excited she got hearing aids.

Because her friend did the right thing

This was so enlightening. I didn't even know people donated hearing aides they had.

How incredible for her!

learning about new goal

This experience was cute, I have heard of hearing family members who had similar conversations with my younger cousins and I think it is really great for normal hearing children to understand hearing loss so they can effectively communicate with hard of hearing or Deaf individuals.

A nice conclusion, going on vacation with nieces and a best friend who understands your situation, as well as her husband who accepted it.

It was nice to see others being sensitive to an individual's hearing loss.

I would feel super grateful.

It was sweet to hear this interaction

Over the years I have had many people try to tell me how to live my life, and at the end of the day those people do not necessarily know what is best for me, so I found this relatable.

She was able to hear better and help some of her hearing loss problems

So exciting that she was offered the opportunity for hearing aids. They can be expensive as she stated so it's nice that it wasn't an expense she had to put out on her own while in school.

It shows that they understand that she can't hear and it's different for her

This would be very sad especially if it was a dream job.

Universal

Kindness is such a happiness booster.

I was excited for you!

she had someone recognize her hearing loss and help try to offer solution

The example of gently reminding the boyfriend to simply face the narrator to help with her understanding and how kindly it was received—displayed how a small change can make things much better for someone

I thought it was cool how she just accepted it and it didn't seem to negatively impact their relationship.

The simple fix of the boyfriend's behavior; he apologizes, doesn't make it a big deal, and makes the necessary changes!

Familial acceptance sounds really sweet at the end of this story.

I was a great thing that happened.

I think I enjoyed this one the most because it surprised me; I had not thought about this experience, so thank you for sharing it.

Again, it shows how those around you can be supportive and open and that it takes very little to accommodate your needs in order for you to hear.

Finding acceptance.

I was so happy when she was able to experience the new sounds!

Educating kids about these issues and how they deal with them helps raise awareness among the new generation.

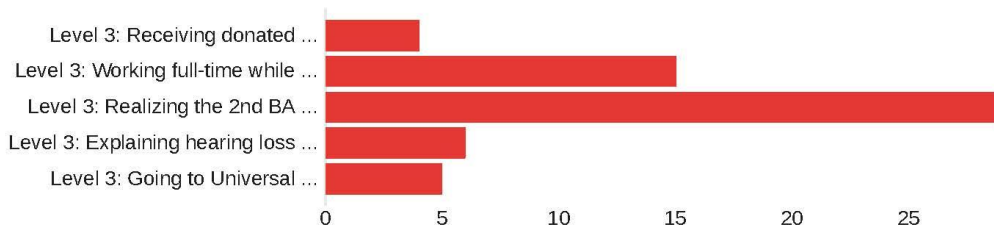
This experience was relatable, simple, and reassuring

it was good to see someone else finally advocate for Isana and correct other's behaviors

This experience was a demonstration of how to interact positively with Isana, and she got to hear the good story.

kids are very mouldable - they don't add their own perception they simply take on information which then becomes a part of universal truth for them

Q33 - 13. Which experience in Level 3 was your least favorite:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
13. Which experience in Level 3 was your least favorite:	1	5	3	1	1	59

Field	Choice Count
Level 3: Receiving donated hearing aids	4
Level 3: Working full-time while completing a 2nd BA	15
Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss	29
Level 3: Explaining hearing loss to your niece	6
Level 3: Going to Universal Studios with friends	5
Total	59

Q34 - 14. Why was the experience you chose for Level 3 your least favorite?

14. Why was the experience you chose for Level 3 your least favorite?

So much effort

Her friend's husband should have known and have the courtesy to keep the logical idea of looking at her face when talking to her in a group or at least in her direction. His wife shouldn't have to be calling him out like that, but it's understandable that people can "forget".

It stinks to realize something you put work into isn't going to work out

I felt that this did not add much to the story for the character.

It overwhelming to work somewhere that is loud and people aren't considerate

It would have been tough to make that choice.

Felt as though this person was constantly overcoming a new struggle because of hearing loss

bad fits are never fun

She went through my realized it wasn't good after spending. Lot of time doing it

Its hard working full time while completing a 2nd BA

hearing loss can be affected by many other factors other than just everyday life. jobs and school can truly affect hearing loss as well.

I thought it was interesting to see how the woman handled sharing her hearing loss and how her niece was accepting and ready to go play again. However, this story did not go into detail and describe her conversation with her neice.

It is hard to explain hearing loss to others, especially younger family members, but it is really important to educate them

This didn't seem very memorable and I can't recall if it moved the narrative forward significantly.

I felt anxious choosing a door.

I did not enjoy that she was recommended to go to school for SLP. Hearing is huge for this track.

No real least favorite.

Expensive mistake

I didn't feel it was necessary for her to continue school, if she was feeling isolated during studies previously from teasing to hearing issues in classes.

Sad

seeing the struggles of fulfilling this goal

This experience was a bit overwhelming, even for someone with normal hearing. I can only imagine the anxiety and stress in this situation with a hearing loss is even greater.

Being a full-time student and a full-time worker is already stressful enough. On top of that, Isana had to put in extra effort paying attention in class. It must have been extremely draining.

It would be a stressful situation.

I dont remember a lot about this one

It was disheartening that her college did not have a good career placement program so she felt the need to then go back to school again.

She ended up seeing that it was a good idea to do that. In my opinion, wasted money and time.

I currently work retail now while completing my first BA and it is no joke. It is a very difficult time with covid to be working retail so I don't know how I would do it with hearing loss as well.

You are failing and failing is never fun

Would be hard to hear in louder environments a lot of noise

Explaining hear loss

I couldn't really connect with the experience. A whole BA is a big commitment of both time and money. If money was scarce, jumping into a 2nd BA without considering its fit with you as an individual seemed like a path I did not want to follow Isana down. I would have rather gone into debt on the hearing aids (luckily she didn't end up having to) than for a potentially wasteful degree.

Can totally relate to most of this situation and the difficulty associated.

sad she missed the funny story because friend did not face her when talking

I think there should maybe be more explanation about how expensive hearing aids are or how they work—I know there was some mention of insurance not covering some things, but I never got a sense of how expensive these things are or how inaccessible they are.

That part of the story really didn't stand out to me

Losing a dream, especially one you've invested in and worked for so hard, is difficult

It is frustrating to have that much time and effort go into an unclear transition.

The process of going through this education with no real prospects is frustrating at best.

I cannot say that I disliked this one; it was just my least favorite by comparison.

While this is awesome, it's also ridiculous that hearing aids are so expensive and that donated hearing aids are even a thing!

The counselor was an idiot.

It is unfortunate that someone in the program or profession didn't tell her that this program would not be a good fit for her.

It was hard for her

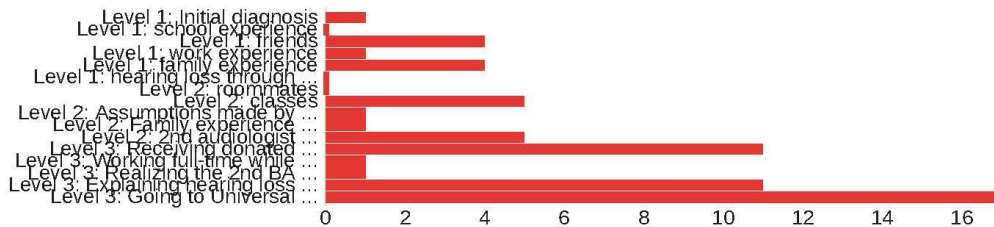
The idea of finding work within skillsets

I'm not very comfortable around kids

Isana worked so hard to acquire a degree that was ultimately of little use to her.

the concept of overcoming a hearing loss is idiotic, as well as being being a speech pathologist with hearing loss - whoever came up with that is a real "genius"

Q35 - Which of the following scenarios within the experience did you enjoy the most overall?

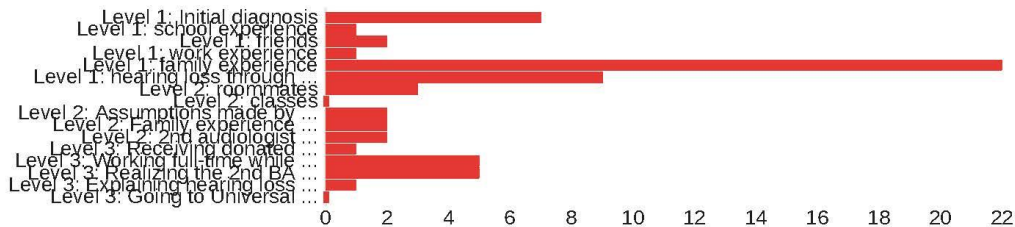


Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which of the following scenarios within the experience did you enjoy the most overall?	1	16	12	4	19	63

Field	Choice Count
Level 1: Initial diagnosis	1
Level 1: school experience	0
Level 1: friends	4
Level 1: work experience	1
Level 1: family experience	4
Level 1: hearing loss through neglect	0
Level 2: roommates	0
Level 2: classes	5
Level 2: Assumptions made by others in college	1
Level 2: Family experience during college	1
Level 2: 2nd audiologist appointment at 23 years old	5

	34
Level 3: Receiving donated hearing aids	11
Level 3: Working full-time while completing a 2nd BA	1
Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss	1
Level 3: Explaining hearing loss to your niece	11
Level 3: Going to Universal Studios with friends	17
Total	63

Q36 - Which of the following scenarios within the experience did you enjoy the least overall?

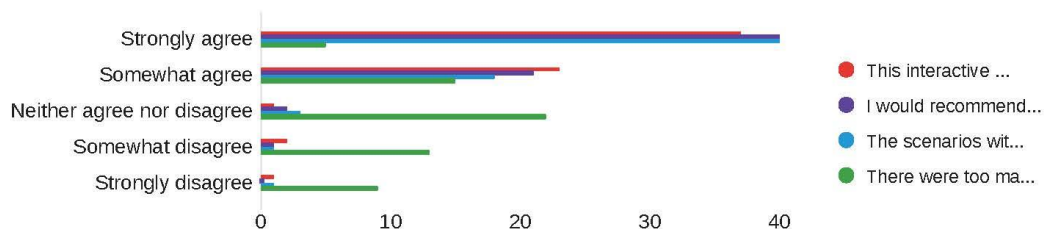


Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Which of the following scenarios within the experience did you enjoy the least overall?	1	15	7	4	16	63

Field	Choice Count
Level 1: Initial diagnosis	7
Level 1: school experience	1
Level 1: friends	2
Level 1: work experience	1
Level 1: family experience	22
Level 1: hearing loss through neglect	9
Level 2: roommates	3
Level 2: classes	0
Level 2: Assumptions made by others in college	2
Level 2: Family experience during college	2
Level 2: 2nd audiologist appointment at 23 years old	2

	36
Level 3: Receiving donated hearing aids	1
Level 3: Working full-time while completing a 2nd BA	5
Level 3: Realizing the 2nd BA was a bad fit for you with your hearing loss	5
Level 3: Explaining hearing loss to your niece	1
Level 3: Going to Universal Studios with friends	0
Total	63

Q37 - Please rate the following statements based on your experiences playing Under the Rock:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
This interactive fiction experience was useful to me for learning about hearing loss.	1	5	2	1	1	64
I would recommend this experience to others that want to learn more about hearing loss.	1	4	1	1	0	64
The scenarios within this experience were helpful for learning about hearing loss.	1	5	1	1	1	63
There were too many scenarios.	1	5	3	1	1	64

Field	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Total
This interactive fiction experience was useful to me for learning about hearing loss.	37	23	1	2	1	64
I would recommend this experience to others that want to learn more about hearing loss.	40	21	2	1	0	64
The scenarios within this experience were helpful for learning about hearing loss.	40	18	3	1	1	63

						38
There were too many scenarios.	5	15	22	13	9	64

Q38 - Please enter your age range:

Please enter your age range:

22

44

25-30

21

30-40

20

21

22

22

22

21

21

20-25

22

22

21

20-25

22

38

26

21

21

25-35

41

34

45

18-24

21

21

18-25

22

21

30

21-22

21

20

22

21

23

28

21-25

38

45-50

30s

18-22

40-45

32

43

45 - 55

31

49

45-50

37

30-45

35-40

25-35

35-50

60s

35-40

21

Q39 - With what gender do you identify?

With what gender do you identify?

Female

Woman

Female

FEMALE

female

female

female

female

female

Female

Female

non binary

female

Female

female

female

female

Female

Male

Female

Female

female

Male

Female

Female

Female

Female

Female

female

Female

female

female

Female

Female

female

female

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Male

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Male

male

Female

Female

male

Female

Female

Female

Female

female

Male

male

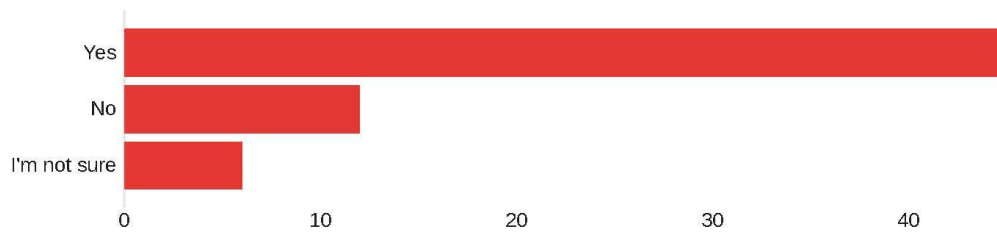
F

female

F

agender

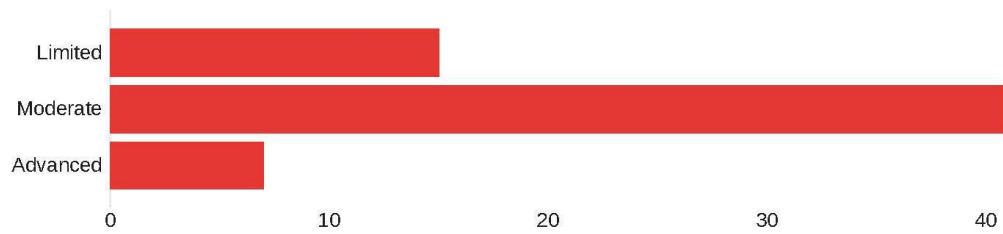
Q40 - Do you personally know someone that has hearing loss?



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Do you personally know someone that has hearing loss?	1	3	1	1	0	63

Field	Choice Count
Yes	45
No	12
I'm not sure	6
Total	63

Q41 - Please rate your knowledge related to hearing loss:



Field	Min	Max	Mean	Standard Deviation	Variance	Responses
Please rate your knowledge related to hearing loss:	1	3	2	1	0	63

Field	Choice Count
Limited	15
Moderate	41
Advanced	7
Total	63

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