Spring 5-13-2022

Clarifying Drug Reaction Terminology: Insights from Deaf College Students Allergic to Penicillin

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Recommended Citation

Makarewicz, Andrew, "Clarifying Drug Reaction Terminology: Insights from Deaf College Students Allergic to Penicillin" (2022). *Honors Capstones*. 88.
https://ida.gallaudet.edu/honors_capstones/88

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THE HONORS PROGRAM

Clarifying Drug Reaction Terminology:
Insights from Deaf College Students Allergic to Penicillin

An Honors Capstone Submitted in Partial Fulfillment of the Requirements for Graduation with University Honors
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Date: May 13, 2022

Acknowledgments

This Capstone is a culmination of perseverance, creativity, learning, self-growth, and hard work. I put countless hours into making this project happen, and in return, I have learned so much about what it takes to complete a research project from start to finish. Through every step, forward or backwards, I have gained new skills and knowledge that will benefit me for the rest of my career. There are numerous individuals who made this Capstone possible:

To my participants, thank you for taking time out of your busy schedules to participate. Without you, there would be no data to share with the community. Each of you had unique experiences to share and I'm grateful that you trusted me to write about them.

To my committee (Dr. Gormally and Dr. Lundberg), thank you for graciously offering your time while this project developed over the course of three semesters. When I sent you drafts, your fresh pair of eyes caught my mistakes and identified ways in which I could strengthen my work even further. Dr. Gormally, thank you for teaching me so much about qualitative research. This was an incredibly new experience for me and your guidance has made me a more skilled qualitative researcher. Dr. Lundberg, thank you for inspiring me to choose this topic! I would have likely gone a different direction if it weren't for your super interesting pharmacology class.

To the Honors Program (Dr. Nelson, Dr. KVG, and many others), thank you for giving me the opportunity to complete this research. I grew tremendously throughout the past three semesters and have learned so much for my future endeavors. Dr. KVG, thank you for guiding me through the beginning stages of my capstone project. Dr. Nelson, thank you for guiding me to the finish line!

To my friends, thank you for being my support system on-campus throughout this journey. You were always there to celebrate my milestones and listen when I needed to vent. I could not have done it without you and I'm excited to see where life takes all of you.

To my family, thank you for also being my support system throughout this journey. Even though you weren't on-campus, you were only a phone call away. You listened to me when I was frustrated and found the right words that encouraged me to persevere. I love you so much and thank you for being my rock.

To anyone reading this Capstone, I hope you learn just as much as I did!

Abstract

Penicillin is considered to be the most frequently reported drug allergy, with roughly 10% of the U.S. population reporting an allergy (Lee, 2020; Sakoulas et al., 2019). However, current research suggests that more than 90% of people who report a penicillin allergy are actually not truly allergic (Blumenthal et al., 2015; Pongdee & Li, 2018). Confusion about side effects and allergic responses is a common way for penicillin allergies to be falsely reported (Stone et al., 2020). The Deaf community may experience this confusion at a higher rate due to health literacy barriers that likely hinder their learning and understanding of medication side effects. In order to limit false penicillin allergy reporting in the Deaf community, I used semi-structured interviews to uncover experiences that Deaf college students have with learning about the side effects of their medications.

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Personal Interest

Each time I go to the doctor's office, they always remind me of my allergy to penicillin antibiotics and ask if I have any other allergies. I don't remember having a reaction to penicillin because I was young, but my parents tell me I broke out in a rash when this medications was given. Now that I'm in my 20s, I've always wondered what would happen if I tried taking penicillin again. Would I break out in a rash, or would I respond normally to the antibiotic? I've also wondered why I've never had an allergy test to confirm if I'm actually allergic to penicillin – I don't think I ever saw the need, until now. Through this Capstone, I've educated myself on the importance of allergy testing and I plan to talk with my doctor about receiving a penicillin allergy test.

Introduction

Penicillin is the most commonly prescribed antibiotic class in the United States (Pongdee & Li, 2018; Yip & Gerriets, 2022). Despite its clinical popularity, penicillin is also considered to be the most frequently reported drug allergy, with roughly 10% of the U.S. population reporting a penicillin allergy in their medical records (*CDC*, 2017; Lee, 2020; Sakoulas et al., 2019). However, even though individuals may report having a penicillin allergy, it doesn't necessarily mean they are truly allergic to the antibiotic. Current research suggests that when evaluated by an allergist, approximately 90% of the people who report a penicillin allergy are actually able to take penicillin safely (Blumenthal et al., 2015; Devchand & Trubiano, 2019; Jani et al., 2020; Pongdee & Li, 2018; Stone et al., 2020).

Pongdee and Li provide two broad explanations for why someone may falsely report a penicillin allergy: 1) their penicillin allergy resolved over time, or 2) contrary to their understanding, previous symptoms they had were not caused by a penicillin allergy (Pongdee & Li, 2018). In terms of the latter, the most common scenario is individuals mistaking minor side effects of penicillin for an allergic reaction (Stone et al., 2020).

Confusing Drug Reaction Terminology

It's no surprise that drug reactions are misidentified because the terminology used to classify them is rather confusing. An adverse drug event (ADE) is defined as "any untoward medical occurrence that may present during treatment with a pharmaceutical product but which does not necessarily have a causal relationship with this treatment" (Schatz & Weber, 2018). In other words, adverse drug events not only consist of reactions caused by the drug's pharmacology, but they also include reactions caused by inappropriate use of the drug and medication errors (Schatz & Weber, 2018).

On the other hand, adverse drug reactions (ADR) are a type of ADE that occur when the drug is taken at normal doses (Carr & Pirmohamed, 2018). Allergic reactions and side effects both fall under the umbrella of adverse drug reactions (W. Smith, 2013). A true drug allergy, such as to penicillin, is mediated by the immune system (Devchand & Trubiano, 2019). This can include life-threatening anaphylaxis, which has severe symptoms such as low blood pressure and swelling of the throat and mouth (Bhattacharya, 2010). Contrary to an allergy, side effects depend on a drug's pharmacological effects instead of the immune system (W. Smith, 2013). Minor side effects of penicillin include nausea, vomiting, diarrhea, and headaches (Devchand & Trubiano, 2019; Stone et al., 2020). Although minor side effects may be uncomfortable, they don't typically warrant avoidance of the drug because symptoms are not life-threatening as in the case of anaphylaxis. As it can be seen, the different types of drug reactions have distinct characteristics. Therefore, misidentifying symptoms can lead to an incorrect drug reaction diagnosis, such as what's happening with penicillin.

Risks of having a penicillin allergy

At first glance, overreported penicillin allergies may not seem like a huge issue because patients can just take alternative antibiotics instead of penicillin. However, broad-spectrum antibiotics are most often used as a penicillin substitute, which comes with many risks (Lee, 2020). Broad-spectrum antibiotics expose penicillin allergic patients to suboptimal treatment, antibiotic-resistant infections, and higher costs of healthcare (Lee, 2020; Shenoy et al., 2019).

I. Suboptimal treatment

Penicillin is considered the treatment of choice against many pathogens as opposed to using broad-spectrum antibiotics (Shenoy et al., 2019). Among these pathogens is *Treponema* *pallidum*, the bacteria that causes syphilis (Shenoy et al., 2019). According to guidelines from the World Health Organization, benzathine penicillin G is the recommended treatment for syphilis (World Health Organization, 2016). However, those with a "penicillin allergy" label would likely be prescribed an alternative antibiotic that isn't as effective. Penicillins are also often used for dental, perinatal, and perioperative prophylaxis, meaning they help prevent infections while a patient undergoes a procedure (Lee, 2020; Shenoy et al., 2019). But again, patients with a penicillin allergy would have to receive an alternative antibiotic, exposing them to suboptimal treatment and greater chance of infection. In fact, Blumenthal et al. found that patients with a reported penicillin allergy had a 50% increased risk of surgical site infections due to receiving alternative antibiotics (Blumenthal et al., 2018). Therefore, avoiding penicillin puts patients at risk for suboptimal treatment against many pathogens and surgical infections.

II. Antibiotic-resistant infections

Antibiotic-resistant infections are another consequence of receiving broad-spectrum antibiotics. Antibiotic resistance occurs when bacteria and fungi "develop the ability to defeat the antibiotics designed to kill them" (CDC, 2022). According to the CDC's 2019 Antibiotic Resistance Threats Report, more than 2.8 million antibiotic-resistant infections occur in the U.S. each year, resulting in approximately 36,000 deaths (Centers for Disease Control and Prevention (U.S.), 2019). Of the bacteria and fungi listed in the report, *Clostridioides difficile* is the most urgent, with roughly 224,000 cases and 12,800 deaths per year. This is extremely concerning because penicillin allergic people are known to experience increased rates of *Clostridioides difficile (C. difficile)* due to broad-spectrum antibiotic use (Caruso et al., 2021; Lee, 2020; Shenoy et al., 2019; Stone et al., 2020). In addition to *C. difficile*, penicillin allergic patients also have a higher risk of methicillin-resistant *Staphylococcus aureus* (MRSA) and vancomycinresistant *Enterococcus* (VRE) (Shenoy et al., 2019). Antibiotic resistance is already a public health issue in the general population, but it becomes amplified for those with a reported penicillin allergy.

III. Higher costs of healthcare

Not only do penicillin allergic individuals experience suboptimal treatment and antibiotic resistance, they also face greater health care costs. This doesn't come as a surprise because longer hospital stays, due to suboptimal treatment and antibiotic resistance, will generate more financial expenses for the patient. For example, Macy and Contreras found that extended hospital stays resulted in expenses 9.5 times more than what penicillin allergy testing would cost (Macy & Contreras, 2014). MacFadden et al. also found an increased risk of adverse drug events for those avoiding penicillin, which consequently results in longer hospital stays and more health care expenses (MacFadden et al., 2016). Additionally, prices of broad-spectrum antibiotics are more costly than penicillin antibiotics, generating further expenses for penicillin allergic people (Lee, 2020; Picard et al., 2013; Pongdee & Li, 2018; Stone et al., 2020).

As it can be seen, there are many risks associated with having a penicillin allergy such as suboptimal treatment, antibiotic-resistant infections, and higher costs of healthcare (Lee, 2020). Therefore, it is crucial to address the large frequency of overreported penicillin allergies in the U.S. population. Although confusion about side effects and allergies is playing a role, studies on penicillin allergies need to go deeper than that (Pongdee & Li, 2018). The best place to start is by identifying communities that may be more susceptible to confusion about allergies and side effects, since this is the primary mechanism of false penicillin allergy reporting. Confusion about side effects and allergic reactions may be amplified in systematically oppressed communities that face significant health literacy barriers, such as the Deaf community.

Literature review

Introduction to Health Literacy

Health literacy plays an important role in determining health outcomes (Cajita et al., 2016). Individuals with inadequate health literacy face poor health outcomes such as suboptimal use of preventative services, higher rates of hospitalization, and lower healthcare quality (Miller, 2016). Broadly, health literacy describes the skills that “enable individuals to obtain, understand, and use information” to make health-related decisions (Nutbeam et al., 2018). Definitions of health literacy have evolved and now take into account how societal factors influence health-related decisions (Sørensen et al., 2012). For example, Kushalnagar et al. emphasize the parallel nature of health literacy and health information (Kushalnagar, Ryan, et al., 2018). An individual's access to health information, as Kushalnagar et al. explain, is a strong predictor of their health literacy development and overall health outcomes (Kushalnagar, Ryan, et al., 2018). However, due to systematic oppression, not everyone has equal access to health information and the resources to develop health literacy. Low health literacy is prevalent among vulnerable communities such as older adults, racial and ethnic minorities, low socioeconomic groups, people with disabilities such as Deaf people, and those with limited education (Allen-Meares et al., 2020; Hickey et al., 2018; Nguyen et al., 2015; Rikard et al., 2016; Schillinger, n.d.).

Health Literacy and Penicillin Allergies

After searching the literature, no studies appear to directly examine the relationship between health literacy and penicillin allergies. However, the search term “penicillin allergy knowledge” generated several noteworthy articles focused on patients’ views of penicillin allergies and testing. Interestingly, three key articles were written by the same author in the

United Kingdom (Wanat et al., 2018, 2019, 2021). These articles also included physicians as participants, but for this review, focus will only be on the results from patients. The first article was a rapid review to identify studies exploring patients' views and experiences of penicillin allergy testing (Wanat et al., 2018). The review concluded that there is limited evidence on patients' views of penicillin allergy testing (Wanat et al., 2018).

Another study by Wanat et al. utilized qualitative interviews to identify patients' views on barriers and enablers for penicillin allergy testing (Wanat et al., 2019). Their interviews with patients revealed three themes: personal relevance and benefits of the test, importance of safety and perceived risks of test, and confidence in test result (Wanat et al., 2019). From these themes, patients are more motivated to get tested if they understand the consequences of penicillin allergy labeling, feel safe while being tested, and are confident in their results (Wanat et al., 2019). The most recent study also used qualitative interviews to explore patients views of penicillin allergy (Wanat et al., 2021). Three important themes were identified: making sense of allergy, impact of allergy on managing health, and primary care physician influence on patients' perceptions of allergies (Wanat et al., 2021).

A different study by Harada et al. found that of 88 adult patients at Mount Sinai Hospital with a history of a penicillin allergy, only forty patients (45.6%) were aware of penicillin allergy testing (Harada et al., 2022). Despite this finding, most participants (76.1%) reported interest in being tested (Harada et al., 2022). The main concern of those not interested in being tested was fear of adverse events from testing (Harada et al., 2022). Their study demonstrated the importance of increasing awareness of the availability, accuracy, and safety of penicillin allergy testing (Harada et al., 2022).

Although there are several very relevant studies, research on patients' views of penicillin allergy and testing is quite limited. Additionally, none of the current studies examine how health literacy plays a role in forming patients' views of penicillin allergy and testing. Yes, it's important to know what these views are, but studies need to also examine the factors that influence these views, such as health literacy. Furthermore, there are no studies on side effect knowledge among penicillin allergic patients and how this knowledge might be impacted by inadequate health literacy.

Health Literacy in the Deaf Community

Confusion about side effects and allergic reactions may be amplified in systematically oppressed communities that face significant health literacy barriers, such as the Deaf community. It is important to define Deaf/deaf early on in this discussion. Those who are *Deaf* embrace ASL as their language and identify with Deaf culture (*The SAGE Deaf Studies Encyclopedia*, n.d.). On the other hand, those who are *deaf* do not embrace ASL as their language and identify with Deaf culture (*The SAGE Deaf Studies Encyclopedia*, n.d.). In a study by McKee et al., it was found that Deaf American Sign Language users (n=166) were 6.9 times more likely than hearing participants (n=239) to have inadequate health literacy. There are many reasons why inadequate health literacy persists among the Deaf community. For example, McKee et al. explain that Deaf individuals experience information marginalization and loss of incidental learning opportunities on a daily basis due to language, communication, cultural, and accessibility barriers (McKee et al., 2015). Deaf people experience information marginalization throughout many aspects of life such as friends & family, education, media, work, government, and health care (McKee et al., 2015). Hearing people often take these learning opportunities for granted. When Deaf people have inadequate health literacy, it puts them at risk for poor health outcomes.

After reviewing the literature, there don't appear to be any studies that focus specifically on Deaf health literacy and penicillin allergy reporting. In fact, there are no studies in the hearing population either. Due to a lack of literature, turning to general studies on Deaf health literacy can be insightful. By looking at studies on Deaf health literacy, one can get a glimpse of potential barriers to learning about medication allergies and side effects. Patient-provider communication, access to online and printed health information, and learning health information from family members are all affected by inadequate health literacy among Deaf people. These are likely also barriers for Deaf and Hard-of-Hearing individuals when learning about medication allergies and side effects.

Patient-provider communication

Some Deaf patients are fortunate to see ASL fluent providers such as at the Deaf Health Clinic in Michigan, but that is not the case for the majority of the Deaf community (Panzer et al., 2020). As a result, there is a wide range of experiences among Deaf patients when it comes to communicating with their healthcare provider. For those with negative experiences, difficulties can arise due to being provided with suboptimal or lack of ASL interpreters, poor effectiveness of writing back-and-forth, and navigating expectations from hearing providers to lipread during office visits (S. R. Smith et al., 2015).

Lipreading and writing are often assumed by hearing individuals to be appropriate alternatives to having an interpreter, but they are "limited in their scope of effectiveness in relaying information accurately" (McKee et al., 2015). There are also many scenarios where providers are not willing to take the time to communicate through writing or typing (S. R. Smith et al., 2015). Needless to say, healthcare providers tend to be unaware of how Deaf culture shapes the health needs of deaf people (Kuenburg et al., 2016). Healthcare providers tend to also have minimal training on communicating effectively with Deaf patients in order to provide them optimal care (Panzer et al., 2020).

Hyoguchi et al. mentioned that “Deaf and Hard-of-Hearing patients tend to nod ‘yes’ and pretend to have understood pharmacists’ explanations” (Hyoguchi et al., 2016). This is concerning because the pharmacist is unaware that the Deaf patient actually does not understand what is being explained. One way to fix this problem is by implementing the teach-back method, where the patient re-explains medication information to their healthcare provider in order to show that they understand (Hommes et al., 2018).

Overall, not directly communicating with their provider in ASL may put Deaf patients, whose primary language is ASL, at risk for receiving poor education and guidance about medication side effects. Before prescribing a medication, healthcare providers can explain the possible side effects and how to manage them. They can also clarify symptoms that are normal as well as symptoms that suggest an allergic reaction or anaphylaxis. However, the patient-provider relationship is much more complicated for Deaf patients, which may make it difficult for them to receive the appropriate education and guidance about side effects of medications.

Access to online health information

Due to the communication barriers between Deaf patients and their healthcare providers, Deaf patients are more likely to rely on alternative sources of health information such as health websites (Kushalnagar et al., 2015). Unfortunately, online health information is often difficult for Deaf individuals to utilize because the information is presented in English text. Although many Deaf individuals are bilingual, accessing online health information is particularly difficult for those who are not highly literate in English (Kushalnagar et al., 2015). Therefore, it’s important for Deaf individuals to have the option to receive online health information in ASL or through English text that is easy to read (Kushalnagar, Smith, et al., 2018).

Since online health information is rarely accessible for Deaf individuals, they may not be able to utilize the internet to learn about side effects of their medications. Although it's best to discuss side effects with a healthcare provider, Deaf patients may feel the need to do additional research online because of communication barriers in the hospital. However, as Kushalnagar et al. mentions, "this approach increases the risk of misunderstanding and using health information inappropriately" (Kushalnagar et al., 2015). Deaf individuals who wish to seek out online health information about medication side effects are likely to experience many barriers with accessing this information, which prevents them from furthering their knowledge.

Printed Health Information

As Kushalnagar et al. reports, Deaf patients tend to rely on other sources of health information (Kushalnagar et al., 2015). This can include printed health information such as medication handouts provided at pharmacies. However, Deaf people often struggle with understanding information about their medications when given in the form of written materials (Hyoguchi et al., 2016, 2020; Killick et al., 2018). Deaf individuals report medication handouts being too complex, with "large amounts of information provided without explanations or examples" (Hyoguchi et al., 2016). It can also be difficult for Deaf patients to understand text-based health information when the text is not simplified or supplemented with visuals (Kushalnagar, Smith, et al., 2018; Smith et al., 2015). Printed health information can be useful to educate patients on side effects, but this is clearly not the most effective way to reach the Deaf community.

Learning Health Information from family

For Deaf people, effective communication with family members is crucial for positive health outcomes (Kushalnagar, Ryan, et al., 2018). However, when family members do not know ASL, Deaf individuals miss out on incidental learning opportunities that are important for developing health literacy and knowledge (Hauser et al., 2014; McKee et al., 2015). This mechanism is known as “dinner table syndrome” (McKee et al., 2015). Deaf individuals may be unaware of the terms “allergy” and “side effect” because they missed out on learning opportunities with family members. They may have also missed out on conversations where family members discussed experiences with taking certain medications.

Deaf adolescents often report that their parents oftentimes will fill out medical background forms for them (Smith et al., 2015). In an interview study of ASL interpreters working in healthcare, interpreters shared that hearing parents typically don’t sign during their Deaf child’s doctor’s appointment (Hommes et al., 2018). Both of these situations are dangerous to health literacy if hearing family members don’t effectively share health information with the Deaf individual. Specifically, Deaf individuals may miss out on learning opportunities about medications in general due to family members excluding them from health information. If Deaf individuals don’t read medical background forms or fully partake in doctor’s appointments, then they may not be familiar with terminology about their medications, such as “allergy” and “side effect.”

The Current Study

The health literacy barriers experienced by the Deaf community likely puts them at greater risk of misunderstanding drug terminology such as allergy and side effect. As a result, this would also put them at greater risk of falsely reporting a penicillin allergy. To help begin addressing this complex issue, the current study focused on uncovering personal experiences among Deaf college students with learning about side effects and allergic reactions. Specifically, the current study used a qualitative research design with semi-structured interviews. The goal of this work was to develop a better understanding of how Deaf individuals might be susceptible to confusion about side effects and allergic responses. Personal experiences from Deaf college students can also offer insight into what strategies the healthcare system can use to better educate Deaf individuals on side effects and allergic responses.

Guiding research questions

1. What resources help Deaf college students learn about side effects and allergies?
2. How can these resources be improved to better educate Deaf individuals about side effects and allergies?

Methodology

To reiterate, the current study intended to answer the research questions through personal experiences of Deaf college students. A qualitative research design with semi-structured interviews was determined to be the best approach because semi-structured interviews help reveal “the interviewee’s subjective perspective of a phenomenon” (McGrath et al., 2019). In this case, the phenomenon was how Deaf college students learn about side effects and allergies through specific resources. The semi-structured interviews in this study followed a protocol (Appendix A) developed by the researcher beforehand and also consisted primarily of open ended questions that led to follow-up questions.

Procedure

Once approval was received from the Gallaudet University Institutional Review Board, recruitment began. Participants were recruited through email, flyers, and the snowball method. Snowball sampling works when “a few identified members of a rare population are asked to identify other members, and so on” (Handcock & Gile, 2011). This recruitment strategy was effective because penicillin allergies are most likely infrequent on Gallaudet’s small campus. Details about this study were also shared with faculty members so that they could pass the information along to their students. In order to motivate individuals to participate, each interviewee was compensated $25 for their time.

There were three criteria to participate in this study: 1) allergic to penicillin, 2) Deaf or Hard-Of-Hearing, and 3) current Gallaudet student. Potential participants who met the criteria were directed to complete a Google Form (Appendix C) that asked for basic demographic information. A QR code with the Google Form link was on the recruitment flyer (Appendix B). Qualified participants who completed the Google Form were then asked to sign the informed consent and video release forms (Appendix D and E). Once consent was given, individual semi-structured interviews were scheduled and conducted in American Sign Language following the attached interview protocol (Appendix A). Interviews were conducted through Zoom and took approximately thirty-minutes. Each semi-structured interview was recorded and participants were given a pseudonym to keep their identity confidential.

A total of six semi-structured interviews were completed. Sample size was determined primarily based on the concept of data saturation. Data saturation occurred when no new data, codes, or themes emerged from the interviews (Vasileiou et al., 2018). The researcher believed data saturation had occurred by the sixth interview. Also, it is important to note that this study took place in the midst of the COVID-19 pandemic. It was difficult to recruit participants because Gallaudet students were getting reacquainted with campus after taking classes remotely for a year and a half due to COVID-19. The researcher kept this in mind when deciding on a stopping point.

Interview Protocol

See “Appendix A” for the English version of the Interview protocol. The interview protocol was used to guide conversation throughout the semi-structured interviews.

Data Analysis

In order to analyze the interviews and answer the research questions, thematic analysis was necessary. Without themes, it would have been difficult to derive meaning from the interviews to answer the research questions (Vaismoradi et al., 2016). Thematic analysis in this study consisted primarily of coding, which involved identifying segments of data that had meaning and labeling them with a short word or phrase (Fereday & Muir-Cochrane, 2006; Linneberg & Korsgaard, 2019). Coding was important for thematic analysis because it provided a way to organize the raw data, allowing themes to become apparent (Fereday & Muir-Cochrane, 2006). Specifically, this study utilized an inductive coding approach. Inductive coding, a powerful method in qualitative research, gave a voice to the participants by allowing data to speak for itself. Instead of analyzing the data with a pre-defined list of codes (deductive coding), codes were developed directly from the interviews. In other words, codes were developed from a participant perspective rather than a theoretical perspective (Linneberg & Korsgaard, 2019).

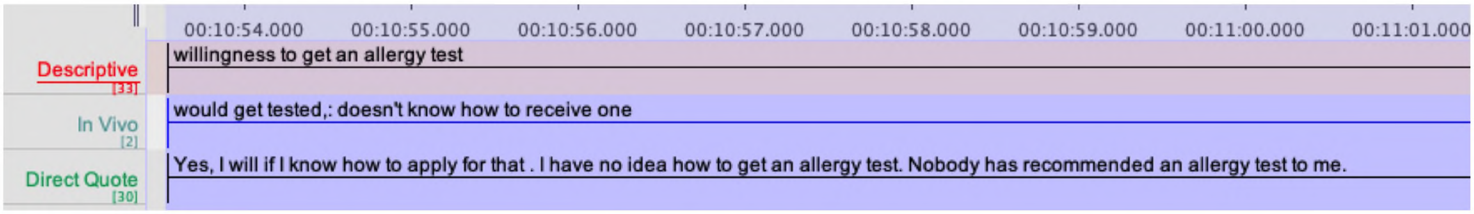
Inductive coding was the most suitable approach because this study intended to address the research questions through personal experiences from the participants.

Interview video files were uploaded to ELAN, a computer software used for annotating audio and video recordings (*ELAN*, 2022). ELAN was chosen for its strong capability as an annotation tool for signed languages, including American Sign Language. A new ELAN document was created for each interview. ELAN has several Modes that were used throughout data analysis. Segmentation Mode was used to establish a start and end time (segment) for each comment made during the interview, which in a sense was like the skeleton of the annotations. Segmentation was a rather tedious process consisting of watching the entire video file and pressing ENTER to start/end a segment. However, this made annotating a lot easier because the time-stamp for each comment was already established through segmentation.

Annotation Mode was used to code the interviews. Annotating relied on the use of tiers, a popular feature in the ELAN software. Tiers are a set of annotations that share the same characteristics. Researchers can define tiers in any way they wish based on how they want to categorize their annotations. For this analysis, three tiers were used for coding in ELAN: 1) descriptive coding, 2) in vivo coding, and 3) direct quotes. Descriptive coding specified the topic, or what a particular segment of data was about (Elliott, 2018; Linneberg & Korsgaard, 2019; Onwuegbuzie et al., 2016). In vivo coding generated codes using the actual signed words of participants (Manning, 2017). Direct quotes were translated from ASL into English for the purpose of data presentation and providing evidence for themes. Figure 1 depicts an example annotation in ELAN following this method.

Once coding in ELAN was completed, all codes (descriptive, in vivo, direct quotes) were transferred to a spreadsheet. This allowed the researcher to visualize the data more clearly. Codes were then connected to help identify themes and patterns among them (Fereday & Muir-Cochrane, 2006). Searching for themes was an active process that required adding, eliminating, and recatgorizing codes until no new patterns emerged. At this point, thematic analysis was considered to be completed.

Figure 1 - An example annotation in ELAN consisting of descriptive coding, in vivo coding, and a direct quote



willingness to get an allergy test

would get tested,: doesn't know how to receive one

Yes, I will if I know how to apply for that . I have no idea how to get an allergy test. Nobody has recommended an allergy test to me.

Results

Demographics

Six individuals who met the study criteria completed a semi-structured interview using Zoom (Table 1). Of the six participants, three identified as female, two as male, and one as nonbinary. The mean age was 23.5 years old with a range from 19 to 30 years old. Two participants identified as Hard-Of-Hearing while the remaining participants identified as Deaf. Three participants identified as Multiracial, two identified as White, and one identified as Latnix/Hispanic. Five of the participants were undergraduate students, with class standings ranging from first year to fifth year. Only one participant was a graduate student. Lastly, four participants were in science programs while two participants were in non-science programs.

In order to protect their confidentiality, each participant was assigned a pseudonym as seen in Table 1. Additionally, because Gallaudet is a small community, the only demographic necessary to pair with pseudonyms was their major/program. If more demographics were paired with pseudonyms, members of the small Gallaudet community might be able to identify someone they know. This needed to be avoided because participants discussed their confidential medical information during the interview. Science vs. non-science major/program was taken into consideration during analysis, but all other demographics were simply collected to describe the sample.

Table 1 - Pseudonym and major/program of each interview participant

Pseudonym	**Major/program**
Ben	Science
Isabel	Non-science
Madelyn	Science
Alex	Science
Jordan	Non-science
Noah	Science

Common themes

Qualitative analysis of the semi-structured interviews revealed five themes: *speaking their language*, *experiences of oneself and others*, *independence*, *multi-sourcing*, and *awareness*. A general idea of how coding was categorized to reveal these five themes is depicted in Table 2, which can be found on page 26.

I. Speaking their language

The importance of *speaking their language* was a theme that primarily emerged as the participants reflected on their experiences with medication handouts and labels. For non-science majors like Isabel and Jordan, they acknowledged the struggle of understanding medication handouts when complex chemical terminology is used.

> *Jordan:* One thing about pharmacy handouts is that I often encounter complex vocabulary. I'm like "wait a second, I don't understand what this means." I'm not a chemistry or biology major so I have to ask other people for clarification which I don't think is very good.....It's better to simplify terminology so I know what it means rather than using complex terminology that overwhelms me.

Many of the participants, including Alex, recognized that the use of complex scientific terminology creates barriers not just for Deaf individuals, but also for the general public who don't have strong science backgrounds.

> *Alex:* I feel for the general Deaf community, materials are not fully accessible because not everyone can understand all of the technical terms used. At the same time, that can be applied to other hearing people too. I feel doctor terminology is not accessible to the general public, but rather is only accessible to people with previous exposure to that kind of terminology.

For Noah, he's able to learn about side effects through medication handouts because he has strong English skills and is a biology major. However, he noted that not all Deaf people have strong skills in English. As Noah mentioned, it's not about whether someone is Deaf, rather, their English skills are influenced by the quality of the Deaf education they have received. Additionally, Noah explained the cons of not majoring in the sciences:

> *Noah:* As a science major, what I learn in class applies to this topic. For example, I've learned about allergies through my Anatomy and Physiology class. I already have a basic understanding of allergies, which helps my ability to navigate my way and find the information I need.....Those who are not science majors are not given the opportunity to learn about allergies in class. Instead, they focus on other classes that apply to their career

> interests. For me, I'm "killing two birds with one stone" because I'm learning content for both my career and personal health.

Noah believes that sharing information about side effects in written English and ASL will benefit everyone. When asked how medication resources can be improved for individuals without a strong scientific background, Noah shared:

> *Noah:* For the general public, obviously it's important to *speak their language*. Big scientific words won't benefit them or help them understand. So, speak their language, explain things based on how they talk, and they should be more likely to understand. That applies to Deaf people too. If they can read and write well, then they can go ahead and read the materials. However, if Deaf people struggle to read and write, then information should be shared through signing. The goal is to *speak the language* of the community you are trying to reach.

Many participants acknowledged that it's not always possible to exclude all scientific language from medication handouts. To help compromise, they offered several suggestions for how to still *speak their language* when using scientific terminology.

> *Isabel:* If they have to use a chemical term, then maybe they can add a form of subtext where the chemical term is expanded on and explained from a non-science perspective. This should be done in written English for the general public but through ASL videos for the Deaf community.
>
> *Madelyn:* If someone needs more information, give them the option to read supplementary material that goes more in depth. However, keep primary materials simple and straightforward.
>
> *Ben:* When I read medication labels and papers, they feel chaotically in order. I feel like they would benefit more people if the writers worked harder to make the important information stand out.
>
> *Alex:* I don't necessarily think the handouts can be improved for Deaf people. Instead of improving access to written English, focus should be on interpreting from English to ASL. People who understand medication terminology could interpret that information into ASL.

Although *speaking their language* is important for reaching individuals who read medication handouts, it's crucial for any type of science communication. Alex offered insight on the bigger picture of this Capstone:

> *Alex:* This study is very interesting because it relates not only to penicillin, but also to the healthcare industry and how they communicate with the general public. I feel like that bridge is very important to recognize.

II. Experiences of oneself and others

All of the participants touched on the importance of learning from the *experiences of oneself and others.*

Noah and Ben had similar experiences growing up because both have parents with allergies. When asked what helps him learn about side effects, Noah explained:

> *Noah:* Hearing about other people's experiences with side effects. Sometimes the side effect was serious while other times it was not. In addition, my parents both share their medication experiences with me. They've had a variety of experiences with taking medicine. They've told me that some medicines often have side effects which I sometimes do experience myself.

Ben has been able to better understand the importance of allergy testing through his dad's experiences.

> *Ben:* It's better to know beforehand what you're allergic to. For example, my dad almost died from eating cucumbers. It's ironic because that's one of his favorite vegetables, but he can't have it. He also got tested for dust and many other allergens. He's been able to figure out that he has a lot of different allergies. I think that's really important because he takes care of himself now and is a lot healthier.

Jordan and Isabel are not fully aware of side effects until after they experience them. Isabel also stressed her desire to know more about side effects beforehand. She didn't fully comprehend how side effects would impact her until she actually experienced them firsthand.

> *Jordan:* At first, I don't know about side effects until I can feel them. If I don't feel like myself then I know something is wrong.

> *Isabel:* When I was growing up, I had no idea about side effects. I knew nothing. It wasn't until later that I experienced my first side effect to birth control…..I feel like in high school there should be more education about side effects…..I had a lot of side effects to birth control such as my hormones changing and frequent headaches. I wish I would have known about them beforehand. Yes, my doctor did warn me, but I didn't understand how the side effects would impact me.

Just like Ben learned the importance of allergy testing from his dad's experience, Alex learned from her own personal experience with penicillin allergy.

Alex: Allergy tests are beneficial because in my situation, if I didn't notice that my body felt different, if I didn't tell my friend to go get the doctor then maybe the doctor wouldn't have come to me in time. My allergic reaction was severe meaning it could have killed me. Knowing exactly what you're allergic to can be very important because if doctors are overworked or not paying attention, they might not realize you're having a reaction and you could die.

Madelyn did not mention any specific experiences from herself or others, but she does use online resources to learn more about the side effects other people experienced.

> *Madelyn:* Sometimes I can find other people's experiences which helps me understand side effects better.

III. Independence

The theme of *independence* emerged through the interviews with Ben, Isabel, Madelyn, and Noah. Each of them described in their own words that they felt more knowledgeable about side effects as they got older and developed *independence*.

Madelyn explained how growing up, she felt that her mom spoke for her at the doctors office. Now, when she speaks for herself, she feels like her questions are answered.

> *Madelyn:* I felt growing up that I didn't talk for myself. My mom did that. But now, I talk for myself and I feel like my questions are answered.

Noah had similar experiences at the doctors office while growing up. Like Madelyn, his mom tended to speak for him. Noah also described how he became more comfortable with asking questions as he got older, especially when an interpreter was present.

> *Noah:* The older I get, the more knowledgeable I am about medications and side effects. I ask more questions and am more interactive than when I was younger. When I was young, my mom [who is Deaf] would write back-and-forth with the doctor. Then when we moved, I started having an interpreter present and that's when I really began asking more questions myself.
>
> Ben offers a unique perspective being that his mom is a nurse.
>
> *Ben:* My mom is a nurse and likes to be the person in control of our medicine. I feel like that limits my knowledge of my own illnesses.

IV. Multi-sourcing

When learning about side effects and allergies, the participants appear to rely on *multi-sourcing* in order to piece information together. Resources that help them learn about side effects and allergies include medication handouts, the internet, discussion with doctors, and discussion with family members. However, as the participants explained, each resource has its own limitations which is why they need to rely on multiple sources.

Madelyn grew up in a small town and had the opportunity to develop a good relationship with her doctor. Although she feels comfortable asking about side effects, she struggles to hear every word her doctor says.

> *Madelyn:* Sometimes I feel that I miss things from the doctor. It's important that I research things myself so I'm sure that I heard everything right. Sometimes I'm not sure if I have the right information.

Ben did not mention having a good relationship with his doctor like Madelyn has. In fact, he feels that doctors rush out the door before he can even ask questions about his medications.

> *Ben:* It depends on the provider, but I think they give you a little less than a basic understanding of your medications.....Often they're trying to rush because they have other patients, but I'd prefer to have more information from them.

To help herself understand side effects better, Alex utilizes resources that best fit her learning style.

> *Alex:* I understand side effects through reading the bottles and papers. I don't depend on the doctor because I can't hear and my way of learning is through pictures and reading.

As Madelyn mentioned, she uses online resources like Google to supplement the information she receives from her doctor. Madelyn, Noah, and Ben appreciate the quick and easy access to online resources, but they all commented on the difficulty of finding credible sources. However, if they believe the source is credible, it'll often be a good supplement to the handouts from pharmacies.

Madelyn: Sometimes online resources are simpler. With papers from the pharmacy, you have to read everything very carefully. I do read those papers, but sometimes I forget what I read and I don't want to reread everything. It's easier to just Google the side effect and make sure it's normal.

Similar to Madelyn, Ben will try his best to read all the labels and handouts first. If he needs supplementary information and finds a credible source, then he will usually take a look at it. Specifically, Isabel needs to find supplementary information to help her understand different chemical terms.

Isabel: The medication handouts have many chemical terms that I don't understand. I have to Google specific chemical terms to see what they mean. Along the way, I find other chemical terms that I don't understand and I always have to come back to the one term I didn't understand in the first place. It's very confusing and inaccessible not just to Deaf people, but also to the general public that doesn't have a strong scientific background.

V. Awareness

Interviews also unveiled a lack of knowledge about penicillin allergy testing among the participants. Like Noah explained, "old allergies will resolve and new ones will appear later in life." Everyone but Alex was labeled as "penicillin allergic" at a young age. Isabel, Ben, and Jordan have received an allergy test, but Madelyn and Noah have not. Isabel, Ben, and Jordan haven't received a follow-up test since becoming grown adults. Noah's situation of becoming "penicillin allergic" is rather unique:

> *Noah:* I took penicillin and my mom noticed that I got a rash. My mom knew it had to be penicillin because my dad is allergic; maybe he passed it down to me. I stopped the medication and went to see the doctor. It was never actually officially confirmed if I'm allergic, but my doctor thought it was more than likely. After that, I've never taken penicillin.

Despite the lack of allergy testing, several participants expressed interest in being tested.

> *Madelyn:* I want an allergy test because I want to check…..I would get tested if I knew how to apply for that. I have no idea how to get tested.

> *Ben:* I definitely will get tested again just to get the extra information. Like I've said, I did get tested when I was very young, so I think it's also my responsibility to get tested again just to make sure.

Noah also shared his curiosity about the genetic factors of penicillin allergies:

> *Noah:* I'm wondering about the effects of genetics on penicillin allergies because I think I got it from my dad. I feel like he gave it to me. I'm curious, is that a true thing? I don't know.

Alex ended by expressing her frustrations with penicillin:

> *Alex:* Penicillin really sucks. That's it. An allergy to penicillin can be very dangerous because it's a very common antibiotic. This means that if you're allergic, it can be very dangerous because people just assume you're not allergic.

Table 2 - Categorization of codes to reveal themes

Themes	Codes	Quotes
Speaking their language **Noah**: The goal is to *speak the language* of the community you are trying to reach.	General public	**Alex:** This study is very interesting because it relates not only to penicillin, but also to the healthcare industry and how they communicate with the general public. I feel like that bridge is very important to recognize. **Noah:** For the general public, obviously it's important to *speak their language*. Big scientific words won't benefit them or help them understand.
	Non-science	**Jordan:** One thing about pharmacy handouts is that I often encounter complex vocabulary. I'm like "wait a second, I don't understand what this means!" I'm not a chemistry or biology major so I have to ask other people for clarification which I don't think is very good. **Noah:** Those who are non-science majors are not given the opportunity to learn about allergies in class.
	Deaf community	**Isabel:** If they have to use a chemical term, then maybe they can add a form of subtext where the chemical term is expanded on and explained from a non-science perspective. This should be done in written English for the general public but through ASL videos for the Deaf community. **Noah:** Not everyone can read and write well enough to understand medical instructions or side effects.....It's not about whether someone is Deaf, rather, it's about their experiences as a Deaf person getting education.....Having the option of a written or signed version will benefit everyone. **Alex:** I don't necessarily think the handouts can be improved for Deaf people. Instead of improving access to written English, focus should be on interpreting from English to ASL. People who understand medication terminology could interpret that information into ASL.

Experiences of oneself and others	Firsthand experience (me, my, I)	**Isabel:** When I was growing up, I had no idea about side effects. I knew nothing. It wasn't until later that I experienced my first side effect to birth control…..I wish I would have known about them beforehand. Yes, my doctor did warn me, but I didn't understand how the side effects would impact me. **Jordan:** At first, I don't know about side effects until I can feel them. If I don't feel like myself then I know something is wrong. **Alex:** Allergy tests are beneficial because in my situation, if I didn't notice that my body felt different, if I didn't tell my friend to go get the doctor then maybe the doctor wouldn't have come to me in time. My allergic reaction was severe meaning it could have killed me. Knowing exactly what you're allergic to can be very important because if doctors are overworked or not paying attention, they might not realize you're having a reaction and you could die.
	Parents/Friends	**Noah:** Hearing about other people's experiences with side effects helps me learn about them. Sometimes the side effect was serious while other times it was not. In addition, my parents both share their medication experiences with me. They've had a variety of experiences with taking medicine. They've told me that some medicines often have side effects which I sometimes do experience myself. **Noah:** I was exposed to allergies growing up, so this language is something I'm familiar with. However, that is not the case for everyone. **Ben:** It's better to know beforehand what you're allergic to. For example, my dad almost died from eating cucumbers. It's ironic because that's one of his favorite vegetables, but he can't have it. He also got tested for dust and many other allergens. He's been able to figure out that he has a lot of different allergies. I think that's really important because he takes care of himself now and is a lot healthier. **Ben:** I feel like from my experiences…not specifically my own, but also remembering the experiences my family and friends have had with allergies…I feel

		confident that I could respond appropriately to a new allergic reaction.
Independence	Talk for myself	**Madelyn:** I felt growing up that I didn't talk for myself. My mom did that. But now, I talk for myself and I feel like my questions are answered.
	Ask more questions myself	**Noah:** The older I get, the more knowledgeable I am about medications and side effects. I ask more questions and am more interactive than when I was younger. When I was young, my mom [who is Deaf] would write back-and-forth with the doctor. Then when we moved, I started having an interpreter present and that's when I really began asking more questions myself.
	In control	**Ben:** My mom is a nurse and likes to be the person in control of our medicine. I feel like that limits my knowledge of my own illnesses.
Multi-sourcing	Barriers with doctor	**Madelyn:** Sometimes I feel that I miss things from the doctor. It's important that I research things myself so I'm sure that I heard everything right. Sometimes I'm not sure if I have the right information. **Alex:** I understand side effects through reading the bottles and papers. I don't depend on the doctor because I can't hear and my way of learning is through pictures and reading. **Ben:** It depends on the provider, but I think they give you a little less than a basic understanding of your medications…..Often they're trying to rush because they have other patients, but I'd prefer to have more information from them.
	Barriers with pharmacy handouts	**Madelyn:** Sometimes online resources are simpler. With papers from the pharmacy, you have to read everything very carefully. I do read those papers, but sometimes I forget what I read and I don't want to reread everything. It's easier to just Google the side effect and make sure it's normal. **Isabel:** The medication handouts have many chemical terms that I don't understand. I have to Google specific

		chemical terms to see what they mean. Along the way, I find other chemical terms that I don't understand and I always have to come back to the one term I didn't understand in the first place. It's very confusing and inaccessible not just to Deaf people, but also to the general public that doesn't have a strong scientific background.
	Double-check	**Noah:** Google is fast and dependable most of the time depending on what website you're looking at. Of course, I double check with my doctor for their opinion too.
Awareness		**Madelyn:** I want an allergy test because I want to check…..I would get tested if I knew how to apply for that. I have no idea how to get tested. **Ben:** I definitely will get tested again just to get the extra information. Like I've said, I did get tested when I was very young, so I think it's also my responsibility to get tested again just to make sure. **Noah:** I'm wondering about the effects of genetics on penicillin allergies because I think I got it from my dad. I feel like he gave it to me. I'm curious, is that a true thing? I don't know.

Discussion

Penicillin allergies are overreported for two main reasons: 1) they resolve over time, and 2) individuals mistake side effects for an allergy (Pongdee & Li, 2018). Due to health literacy barriers, the Deaf community is likely to miss out on learning opportunities about side effects and allergies, which could subsequently lead to misidentification of drug reaction symptoms. The aim of this capstone was to identify resources that help (or would help) Deaf college students learn more about the side effects of their medications in order to determine strategies to better educate Deaf individuals on drug allergies and side effects.

Qualitative analysis of the six semi-structured interviews revealed five themes: *speaking their language*, *experiences of oneself and others*, *independence*, *multi-sourcing* and *awareness of allergy testing*.

The first theme that emerged was *speaking their language*. Two specific groups of people were mentioned in which it's important to *speak their language*: those without a strong scientific background (the general public) and those whose English skills may not be as strong as their first language. When designing medication handouts and papers, it is important to write using plain language that the general public will understand. Using scientific jargon about medications will not help the general Deaf community understand drug allergies and side effects because they may not have been exposed to that kind of language. Not only is it important to keep in mind their exposure to scientific language, but also their first language growing up. For the Deaf community, many individuals' first language is ASL, not English. It would benefit the Deaf community to have more resources about drug allergies and side effects in ASL.

The second theme was the *experiences of oneself and others*. It really benefited Noah and Ben to have parents with allergies. They grew up in a home where terminology and concepts about drug allergies and side effects were used often, which has benefited their understanding. Jordan and Isabel felt that they don't fully comprehend the side effects of their medications until after they experience them firsthand. This point from Jordan and Isabel is concerning because it applies to misunderstandings about penicillin side effects and allergies. If they don't fully comprehend side effects until after they experience them, then it's possible that they could misidentify a side effect as an allergy. It would benefit the Deaf community greatly to provide resources about side effects and allergies that share other people's personal experiences, especially for those that don't have parents with allergies.

The third theme was *independence*. Many of the participants expressed that they have learned more about side effects as they grew older. Specifically, several participants described their parents as barriers to learning about side effects. When parents ask questions about side effects on the child's behalf, this will limit their understanding unless the information is shared with them too. For example, Madelyn and Noah became more knowledgeable of side effects when they specifically asked questions and not their mom. Yes, the parents need to be aware of side effects too, but it's important that both parties are asking questions so that everyone is learning. If a healthcare provider notices that a parent is the only person engaged in the conversation, they should intervene and include the Deaf child too. It's important that healthcare providers receive the proper training on how to effectively work with deaf individuals and other communities with low health literacy.

The fourth theme was *multi-sourcing*. This theme is strongly related to the lack of *speaking their language*. When participants were overwhelmed by the chemical jargon in medication handouts, they found helpful websites that *speak their language*. They also described using websites to verify the information they heard/saw in the doctor's office. Because Deaf people tend to rely on online resources to help piece information together, it's important that credible and accessible websites are available.

Lastly, the fifth theme was *awareness*, specifically of penicillin allergy testing. None of the participants have received an allergy test as an adult, but several have expressed their interest. Madelyn shared that she doesn't know the process of getting tested, but she would get tested if she knew how. This emphasizes the importance of raising *awareness* on resources that are available to confirm or delabel penicillin allergies.

Limitations

As discussed, sample size was a significant limitation of this study. The nature of the COVID-19 pandemic made it difficult to recruit participants. For the scope of this study, six participants was enough to reveal several important themes that provide a foundation for future research. However, it is important to remember that quotes from each participant represent their own thoughts and perspectives. The interview quotes should not be taken as a full picture of the Deaf community's experience with learning about side effects.

Although qualitative methods are invaluable when researching personal experiences, they don't provide statistical data like quantitative methods do. Quantitative methods would strengthen this study by providing clearer information on how demographics are involved. For instance, the correlation between socioeconomic status and awareness of allergy testing would be better revealed through quantitative methods. Due to the strengths and weaknesses of both methods, a mixed-methods approach would likely be a good choice.

Lastly, data analysis for this study was only completed by one researcher. Like other qualitative studies, the researcher likely did not identify all of the possible themes in the data. For future research, it would be best if more researchers are involved with data analysis.

Conclusion

Penicillin allergies continue to be over reported due to individuals mistaking side effects for allergic reactions. There are many risks associated with having a penicillin allergy such as suboptimal treatment, antibiotic-resistant infections, and higher costs of healthcare (Lee, 2020). Although no studies have directly examined the relationship between health literacy and false allergy reporting, it's likely that low health literacy can lead to lack of knowledge and understanding of side effects. This capstone examined how Deaf college students learn about side effects and allergies in order to find ways to improve resources for better health outcomes. Qualitative semi-structured interviews revealed five themes: *speaking their language*, *experiences of oneself and others*, *independence*, *multi-sourcing*, and *awareness*. These themes provide a better picture of how Deaf individuals are susceptible to false penicillin allergy reporting, but more research needs to be done on a larger scale.

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Appendix A

Interview protocol in English. Interviews were conducted in American Sign Language.

Knowledge of medication side effects and allergies

1. Can you tell me what you know about side effects of medications?

   Follow-up questions: What are some examples of side effects? If a patient experiences a side effect, do you think they should stop taking the medication? What do you think causes a side effect?

2. Can you tell me what you know about a medical drug allergy?

   Follow-up questions: What are some signs of a drug allergy? If a patient has symptoms of a drug allergy, do you think they should stop taking the medication? What do you think causes a drug allergy?

3. Is a side effect different from an allergic reaction? If so, how?

Penicillin Allergy History

4. How old were you when you became allergic to penicillin? (i.e. when did you first have symptoms of an allergic reaction?)

5. Describe the symptoms that you experienced and the events that took place. Were you old enough to remember the reaction, or did a parent/guardian tell you what happened?

6. When you visit a healthcare provider, do they review a list of your allergies? Is penicillin mentioned? Describe any discussion you've had with a healthcare provider about your penicillin allergy.

7. How has your penicillin allergy affected your medical care?

8. Have you ever had an allergy test to confirm your penicillin allergy? If not, has one ever been suggested?

9. (Follow-up question to #8) Do you think penicillin allergy tests are beneficial? Why or why not? If encouraged by your healthcare provider, would you consider undergoing an allergy test?

10. Is there anything else you would like to share about your penicillin allergy?

Education on Side Effects and Allergic Reactions

11. Do you feel aware of the possible side effects of your current medications? If you're currently not taking any medications, did you feel aware of the possible side effects of medications you have taken?
    a. Describe how you learned about the side effects. What resources helped you the most? (Ex. talking with a healthcare provider, handouts from pharmacies, online resources, etc.)
    b. If applicable, explain why you don't (or didn't) feel aware of the possible side effects.
    c. What would help you learn more about the side effects of your medications?

12. Describe your experience with discussing the side effects of your medications with a healthcare provider.
    a. When prescribing a medication, do you feel that healthcare providers properly educate you on the possible side effects? Why or why not? What would help you better understand the side effects?
    b. How could your communication with a healthcare provider be improved to better understand your medications, specifically the possible side effects?

13. Have you ever used an online resource to learn more about your medications, specifically the side effects? Why did you seek out this resource?

14. Describe your experience with written handouts provided by pharmacies.
    a. Did they help you understand the side effects of your medication?
    b. Were they accessible? How could they be improved?
    c. Were you overwhelmed by the amount of information, or is there not enough information?

15. Do you feel that you know the signs of an allergic reaction? If you experience an allergic reaction, do you feel prepared to respond? How did you learn about the signs of an allergic reaction and how to respond to one?

16. (Follow-up question to #15) Do pharmacy handouts and healthcare professionals explain the signs of an allergic reaction? What would help you be better prepared in the event of an allergic reaction?

17. Do you feel that you understand the difference between a side effect and an allergic reaction? Why or why not?

18. When receiving information about side effects and allergic reactions, do you feel that their differences are effectively communicated? (Ex. In medication handouts from pharmacies, are there separate sections for side effects and allergic responses?)

19. As a Deaf individual, what other barriers do you face that hinder your education on the side effects of your medications?

20. Is there anything else you would like to add?

Appendix B

Are you allergic to penicillin?

You qualify for a study about side effects and allergic reactions <u>if you are:</u>

- **Allergic to penicillin**
- **Deaf or Hard-Of-Hearing**
- **A current Gallaudet student**

Participants will receive $25 after completing a one hour interview on Zoom.

If you have questions contact:

Andrew Makarewicz
Andrew.Makarewicz@Gallaudet.edu

This study has been approved by the Gallaudet University Institutional Review Board (IRB)

Appendix C

Demographic Survey

(Participants completed this demographic survey using Google Forms)

1. Name __________
2. Gallaudet email address __________
3. Age __________
4. Hearing Status
    - Deaf
    - Hard-Of-Hearing
    - DeafBlind
    - Hearing
5. Are you allergic to penicillin?
    - Yes
    - No
6. Are you a current student at Gallaudet?
    - Yes
    - No
7. Are you an undergraduate or graduate student?
    - Undergraduate student
    - Graduate student
8. If applicable, what is your current undergraduate class standing?
    - Freshman
    - Sophomore
    - Junior
    - Senior
    - 5+
    - I'm a graduate student

9. If you're an undergraduate, please share your major, minor, or if you're undecided. __________

10. If you're a graduate student, what program are you in? __________

11. Which state (or country) are you from? __________

12. How do you identify?
    - Male
    - Female
    - Nonbinary
    - Prefer not to say
    - Other ________

13. Which of the following best describes you? (choose all that apply)
    - African American/Black
    - American Indian/Native American
    - Asian
    - European American/Caucasian/White
    - Latinx/Hispanic
    - Middle Eastern/Arab/Persian
    - Pacific Islander
    - Other ________

Appendix D

Informed Consent Form

Project Title: Is it an allergy or a side effect? : Barriers to Drug Side Effect and Allergy Education among Deaf college students with a penicillin allergy

Principal Investigator: Andrew Makarewicz
Address: Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002
E-mail: Andrew.Makarewicz@Gallaudet.edu
Faculty Sponsor: Dr. Daniel Lundberg
Department: Honors Program

I am an undergraduate student at Gallaudet University. For my Honors Capstone, I am conducting research on drug allergy and side effect education in the Deaf community. I am recruiting Deaf college students with a penicillin allergy to participate in this study. I would like you to consider participating in this study. It is hoped that this study can be used to determine better strategies for educating Deaf individuals on drug allergies and side effects.

This study:

You will be asked to participate in a 1:1 interview on Zoom in American Sign Language. I will ask questions about your penicillin allergy, your knowledge of drug allergies and side effects, and the resources that help you learn about the side effects of your medications. With your consent, the 1:1 Zoom interview will be recorded and used to identify common themes surrounding my research questions. Please see the video release form for more information.

It is anticipated that your participation will take approximately one hour.

You will be paid $25 for your time.

Language:

I will accommodate your preference for language and communication style as much as possible. Interviews will be conducted in American Sign Language to ensure accessibility. Please let me know about any particular communication requirements that you require.

Risks:

By participating in this study, we will discuss your penicillin allergy and experiences with learning about drug side effects and allergies. There are no anticipated risks associated with this research.

Benefits:

Your participation in this study will help determine better strategies for educating Deaf individuals about drug allergies and side effects. Your participation will also help reveal how penicillin allergies present in a sample of Deaf college students.

Confidentiality:
Individual data will not be reported with identifiers. You will be given a pseudonym (ex. Participant A) so that your identity remains confidential. Direct quotes may be used from the interview, but will not be shared with any identifying information.

Voluntary participation:
Your participation in this study is voluntary. If you decide not to participate in this study, your relationship with Gallaudet University will not change in any way. You may withdraw from the study at any time before or during data collection, for any reason and without penalty.

Results:
You will not be given individual results obtained during this study at the end of participation. Results will be de-identified and assigned a pseudonym in order to keep your identity confidential. The results will be analyzed for common themes surrounding my research questions.

Contacting the Researcher or the IRB:
Contact the researcher, Andrew Makarewicz, if you have questions about any risk to you because of participation in this study. Use the e-mail account at the top of this consent form. You may also contact the Chairperson of the Gallaudet University Institutional Review Board for the Protection of Human Subjects (IRB) at irb@gallaudet.edu. This project was approved by the Gallaudet Institutional Review Board.

Intent to Participate:
If you agree to participate after reading this far, then read the following, print and sign your name below, and enter the date.

I have read the Informed Consent Form and agree to participate in the study conducted by Andrew Makarewicz. I understand that I can withdraw from this study at any time without penalty or prejudice. I understand that I will receive $25 as payment for my participation in the 1:1 Zoom interview.

Your name ____

Your signature ____________________________ **Date** __________

Appendix E

Video Release Form

I. Acknowledgement of Video Recording

I, ____, agree to be video recorded as part of my
Participant Name
participation in the study, "Is it an allergy or a side effect? : Barriers to Drug Side Effect and Allergy Education among Deaf college students with a penicillin allergy," conducted by Andrew Makarewicz.

II. Confidentiality and Storage

I understand that the video will not have my name on it. I understand that the original video will be kept in a secure place and destroyed upon completion of the study. I understand that direct quotes from the interview may be used, but will not be shared with any identifiers.

III. Access and Dissemination

I understand that access to the original video will be limited to the principal investigator, Andrew Makarewicz. I understand that the video will be analyzed for common themes and that direct quotes may be used in study findings, which will be viewed by those who read Andrew's Honors Capstone.

____ _________________________
Name **Date**

____ _________________________
Signature **Date**