

THE EVERYDAY MANAGEMENT OF A HARD OF HEARING IDENTITY

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ABSTRACT

Sociological literature on hearing loss is currently limited to the effects that profound hearing losses have on individuals or to the effects that any kind of hearing loss has on children, adolescents, or adults. By applying the sociological concepts of stigma management, identity management, and emotional labor, this study addresses the gap in the literature through in-depth, qualitative interviews with twenty young people between the ages of 18 and 40 years of age with mild to moderate hearing loss. In exploring the everyday experiences of young, hard of hearing people, this study illustrates that managing a hard of hearing identity is hard work. From adjusting to the diagnosis to managing their hearing loss in everyday situations and interactions to their views of themselves and their futures, hard of hearing people constantly navigate conscious and unconscious decisions about their hearing loss.

PREFACE

Writing is my passageway; writing is my pass; through writing, I pass.
- Brenda Jo Brueggemann (2010:219)

Although my academic concentration in sociology and anthropology indicates my love of and fascination with people, I am the type of person who is more comfortable writing about people than speaking with them. I cannot separate how much of my shyness stems from my personality and how much of it is a result of my hearing loss and subsequent worry that I will not hear people correctly during social interactions. Either way, like Brueggemann, writing serves as a shield behind which I can hide. While people sometimes dislike having to repeat themselves, I can reread a written page as many times as I want. In class, I sometimes lose track of the discussion when people mumble or speak softly, but a written page is always clear. When I speak, I worry that I will mishear part of the conversation and reply incorrectly, thus appearing less intelligent. But in writing, I can respond both cleverly and intellectually. Thus I write because writing allows me to present myself to the world in a way that I fear my hearing loss sometimes prevents me from appearing in person.

At face value, this thesis is based upon the responses gathered from twenty individuals. However, underlying and interwoven into the text is a twenty-first voice: my own. I have a mild to moderate, bilateral, sensorineural hearing loss. Despite learning about my hearing loss at a young age, I did not begin wearing hearing aids until I was seventeen years old and a junior in high school. I consider the day I first started wearing hearing aids to be the day that I actually lost my hearing.

Since I have worn hearing aids for five years and since I am writing a thesis about hearing loss, people often assume that I am comfortable with my hearing loss. I am not. Yet.

Before beginning this project during my junior year of college, I rarely told people about my hearing loss. This thesis represents five years of questions and observations about hearing loss and hard of hearing people that I kept to myself. While it has not always been easy to research a subject so close to my heart, I began this project with the idea that I could not possibly be alone. And I was right. In the following pages, you will read about twenty individuals who have had vastly different life experiences, but who are ultimately bound together by their diagnosis of hearing loss. My experience is caught up in theirs, but it is their voices that articulate what it means to be hard of hearing.

INTRODUCTION

*Eeyore stopped looking at himself in the stream, and turned to stare at Piglet.
"Just say that again," he said.*

"Many hap--"

"Wait a moment."

Balancing on three legs, he began to bring his fourth leg very cautiously up to his ear. "I did this yesterday," he explained, as he fell down for the third time. "It's quite easy. It's so as I can hear better...There, that's done it! Now then, what were you saying?" He pushed his ear forward with his hoof.

"Many happy returns of the day," said Piglet again.

- Winnie-the-Pooh (Milne 1926:Chapter 6)

Eeyore, the grey donkey in A.A. Milne's (1926) *Winnie-the-Pooh* series, has a hearing loss. He can neither identify himself as completely deaf, nor can he consider himself to be completely hearing – he is somewhere in between on the continuum of aural sensory function. In the entire *Winnie-the-Pooh* series, Eeyore hides his hearing loss by withdrawing from social interactions so as to not draw attention to his loss by asking his friends to constantly repeat themselves. Although Eeyore's hearing loss is not often mentioned in the book series, in this particular passage Milne uses disability as a literary device to lend “a distinctive idiosyncrasy to any character that differentiates the character from the anonymous background of the ‘norm’” (Mitchell & Snyder 2010:276). Milne draws the reader's attention to Eeyore's hearing loss in an attempt to poke fun at Eeyore and to explain his pessimistic personality. However, Eeyore does more than create a comic atmosphere: when Eeyore discloses his hearing loss in this one scene, he demonstrates the hard work that hard of hearing people exert in order to interact with others.

According to the Centers for Disease Control and Prevention, the 2010 National Health Interview Survey reported that 37.1 million non-institutionalized adults (eighteen years and older) in the United States have hearing loss. This means that 16.2% of American adults have trouble hearing (CDC 2011). The World Health Organization (2011) defines a hearing impairment as a sensory problem that includes both partial and complete loss of a person's hearing ability in one or both ears. The WHO states that there are two types of hearing loss. Conductive hearing loss indicates a problem in the middle or outer ear that prevents sound from entering the middle ear. Sensorineural hearing loss indicates that either the inner ear or auditory nerve is not functioning correctly. Conductive hearing loss can be treated with surgery but sensorineural hearing loss is almost always permanent. Hearing loss can be inherited from family members or acquired as a result of prenatal factors, environmental factors, or the aging process. Both hereditary and acquired hearing losses can be either congenital (present at birth) or develop later in the person's life. Such a medical definition fails to acknowledge the emotions, experiences, and perceptions that the hard of hearing individual is likely to endure. Americans need to take the time to gain a broader understanding of how we as a society view the human sense that is called hearing.

Hearing loss should matter to American society as a whole because it can no longer be considered solely an affliction of the elderly or a natural process of aging. From 1994-2006 the United States experienced a 30% increase in the prevalence of minimal hearing loss and a 77% increase in the prevalence of serious hearing loss among adolescents (Shargorodsky et al 2010). If more young people are being diagnosed with some form of hearing problem, then more research must be conducted to examine the effects of the everyday experiences of hearing loss.

Every stage of the adjustment to and management of hearing loss involves conscious and unconscious decisions on the part of the hard of hearing individual that can be taxing both physically and emotionally. Understanding how the constant pressures of managing a hard of hearing identity accumulate and affect young adults will be beneficial in helping young people adjust to having a hearing loss.

Further scientific research must also focus on specific demographics of people with hearing loss. In a recent article published in *The Journal of the American Medical Association*, a comparison of two nationally representative studies from 2006 suggests that as many as one in five adolescents (aged 12-19) in the United States have hearing loss (Shargorodsky et al 2010). Despite this statistic, there is relatively little scientific research focused on adolescent or young adult hearing loss. Furthermore, studies have generally limited their scope to the effects that profound hearing losses have on individuals, meaning that observations of the effects of mild or moderate hearing losses are relatively absent. Of the research that does exist about this subset of individuals with hearing loss, even less information can be found that discusses either the quality of life of young adults with hearing loss or their perceptions of hearing loss.

RESEARCH QUESTION

My study explores and seeks to answer several questions. How does a mild to moderate hearing loss affect the everyday experiences of young adults? How exactly do individuals in this population adjust to, explain, and understand their hearing loss? Do hard of hearing people actively manage both how others perceive them and how they perceive themselves?

LITERATURE REVIEW

The literature review is divided into several sections to highlight the relevant literature pertaining to the experience of living with hearing loss. The first section explores research on stigma and the management of stigmatized identities. Second, the sociological concept of emotion work is discussed. The third section addresses the lack of sociological research on the everyday experiences of young adults with hearing losses specifically within the mild to moderate ranges.

Stigma and Identity Management

Stigma is a universal phenomenon that occurs in a society when certain conditions of a person are devalued because they deviate from the norm (Becker 1981, Atcherson 2002). Erving Goffman explored stigma in-depth, noting that people make assumptions about other people based on what they expect each other to be like – if one exhibits evidence of an attribute that differentiates one from the group in an undesirable way, one is “reduced in our minds from a whole and usual person to a tainted, discounted one” who has a *stigma*, or a “failing, a shortcoming, a handicap” (1963:3). Goffman explained that the term originated with the Greeks who considered stigmas to be any “bodily signs designed to expose something unusual and bad about the moral status of the signifier (1963:1). More current definitions of the term are derived from the original Greek meaning but place less emphasis on stigma as a physical sign, instead emphasizing stigmas as some characteristic or attribute of an individual that serves to discredit, spoil, or disqualify that individual (Goffman 1963).

Stigmas are based on individuals’ “objective characteristics,” such as having a hearing loss, but these characteristics “usually have no inherent stigmatizing effect” (Fishbein 2002:14).

Instead, other groups of people identify certain characteristics as stigmatized and use these stigmatized characteristics to dehumanize or depersonalize anyone who exhibits them (Goffman 1963). For example, hearing loss is not stigmatized characteristic in and of itself, but rather it becomes stigmatized as a result of how other people label the condition and react to those who exhibit it.

Although there is no real reason why hearing loss should be stigmatized, individuals who notice that they are starting to lose their hearing are hesitant to publicize this news because of perceptions that hearing loss and the use of hearing aids are stigmatized (Hetú 1996; Kochkin 1990, 1993; Noble 1996). The threat of stigma leads many individuals to deny that they have a hearing problem (Hallberg 1999; Hetú 1996; Kochkin 1993). The stigma of hearing loss influences whether or not the individual initially accepts that hearing loss is occurring, whether or not the individual will decide to be tested for hearing loss or seek some form of treatment, what type of hearing aid the individual eventually selects, and the conditions under which the hearing aid is actually worn (Wallhagen 2009).

Many articles about hearing loss and deafness mention that despite the prevalence of hearing loss around the world and the known ability of hearing aids to improve communication problems, the majority of individuals that could benefit from the use of hearing aids choose not to wear a pair (Surr and Hawkins 1988; Garstecki and Erler 1998; Kochkin 2001). In a time period when technology is ubiquitous, it seems counterintuitive for people to refuse to use hearing aids. Digital hearing aids, first introduced about fourteen years ago, have benefited from technological advances that have resulted in improved signal processing, better amplification and clarity of sound, and a decrease in size (Meister et al 2008). Despite all of these improvements, the stigma associated with hearing loss either prevents people from seeking hearing aids or

results in hearing aid users disguising or hiding their hearing aids (Benderly 1980; Higgins 1980; Gannon 1981; Lane 1984).

Several specific stigmas are associated with hearing loss. Commonly cited stigmas include its association with the aging process, the belief that hearing aids make the wearer less physically attractive, the fear that the hard of hearing individual will be isolated from the rest of society, and the correlation made between being hard of hearing and being a failure (Blood 1997; Atcherson 2002; Wallhagen 2009). A study by Blood et al (1977) presented college students with pictures of school-aged children wearing hearing aids and found that the college students rated the hearing aid wearers more negatively on measures of intelligence and appearance. However, other studies suggest that the age of the observer changes whether or not a hearing aid wearer is considered less competent than people with normal hearing. Iler, Danhauer, and Mulac (1982) conducted a study similar to Blood's (1977) and found that, unlike the younger college students, older adult observers exhibited no signs of a hearing aid effect. Kochkin (1993) reports that sixty percent of adults between the ages of 34-44 cited stigma as a reason for not wearing hearing aids compared to thirty percent of adults between the ages of 75-84. A study by Erler and Garstecki (2002) compared women across three age groups (35-45, 55-65, 75-85) and found that younger women perceived the stigma relating to hearing loss and hearing aid use more negatively than did older women. This study noted that there are several factors contributing to the effect that age plays on perceived stigma. First, older individuals tend to have more peers with hearing loss or hearing aids, so their familiarity with and acceptability of hearing loss increases as they age. Research on mental illness has yielded similar results, indicating that people who are personally familiar with a psychiatric patient tend to exhibit more positive attitudes towards people with mental illness (Arikan and Uysal 1999). Second, participant

responses in the Erler and Garstecki (2002) study show that people are influenced by ageism and stereotypes that older people are incompetent, dependent, or frail (see also Palmore 2000). Thus there might be an age-related stigma associated with hearing loss (a finding supported by Hetú 1996). Third, different age groups experience different communication demands, with younger women citing more frustration with their hearing loss because they are trying to raise children.

Scholars have tried to explain how stigma originates. In the process of analyzing social information about others, people naturally form social categories (Fishbein 2002). Scholars have found that stigmas aid in the formation of these categories. Katz (1979) explains that there are at least three reasons for why stigmatization occurs. First, individuals displace their aggression onto other groups of people in a practice known as *scapegoating*. When individuals or groups are unable to reach certain goals, they blame others for their failures, which serves to stigmatize the recipients of that anger and frustration. Second, people know that it is wrong to mistreat others based on, for example, race or sexual preference, so they justify this mistreatment and their failure to end it by coming to believe that the stigmatized group really is inferior and deserves this treatment. Third, the fact that stigmatized groups exist might serve to make people feel better about themselves. Having a comparison group of stigmatized individuals allows one to feel superior or more fortunate than the 'others.' Thus Katz (1979) explains how stigmatized characteristics are used to organize people into different social groups.

Goffman (1963) further explained that stigma could be experienced in one of two ways: either the individual is discredited or discreditable. A *discredited* individual exhibits visible signs of difference. Someone who is *discreditable* has yet to reveal the stigma but may do so in the future either intentionally (meaning the individual has control over how the stigma is revealed) or unintentionally (by a factor which the individual cannot control). Whereas others stigmatize

discredited people because their undesirable characteristics are visible, discreditable people have hidden undesirable characteristics that might make them discredited people if their status is disclosed. Although individuals with visible stigmas often feel constrained by their inability to control who knows about their condition, they employ various tactics to try to cope with the stress of having a stigmatized condition (Joachim and Acorn 2000). For example, discredited individuals might isolate themselves into groups of similar others in an attempt to normalize the stigmatized condition (Becker 1981) or make jokes about a defect in order to make others feel more comfortable with the difference (Joachim and Acorn 2000). On the other hand, discreditable individuals have more of a choice because they can either pass as normal or disclose their stigmatized condition. However, discreditable people must carefully and actively manage information about their condition by deciding who should know about their condition because disclosure can result in their becoming discredited individuals (Goffman 1963).

Using Goffman's concepts of discredited and discreditable people, scholars have explored how stigmatized groups manage stigma and negotiate identity. Stigma management refers to the attempt by individuals with stigmatized social identities to minimize any consequences of having a stigmatized identity in interactions with others by selectively choosing under what conditions to disclose or conceal the stigmatized condition (Poindexter and Shippy 2010; O'Brien 2011). Decisions about stigma management are neither simple nor discrete; people must constantly "revisit and revise" their decisions in a process that is complex and continuous (Poindexter and Shippy 2010:368). In order to manage information about a stigmatized condition, people analyze the situation they are in and choose a management tactic, such as passing or disclosing, that they believe is most appropriate.

One management tactic is passing. A person is said to ‘pass’ when his/her stigma is successfully concealed (Goffman 1963). Passing is an attempt to conceal the stigmatized characteristic so as to appear like everyone else in the ‘normal’ group (Joachim and Acorn 2000; O’Brien 2011). People choose to pass for a variety of reasons: passing can provide protection from being rejected, judged, or treated differently by others (Poindexter and Shippy 2010). Sometimes people prefer to pass because they have had negative experiences in the past when they have disclosed their condition (Schneider and Conrad 1980). In order to pass, people employ several strategies, such as concealing or obliterating all signs of the stigma, casting the signs of the stigma as signs of another, less stigmatized attribute (e.g. rather than blaming one’s hearing loss, one blames one’s inability to respond to a question on one’s tendency to daydream or not pay attention), or compartmentalizing one’s world into a small group of people who know about the stigma and a larger group of people who do not (Goffman 1963). For example, young diabetics often try to pass for healthy individuals by concealing signs of their condition – when out with peers, they might eat or drink things that they know they should not because they are trying appear similar to their peers (Kyngas and Hentinen 1995). Commonly researched and cited examples of passing include homosexuals passing for heterosexuals (Troiden 1988) and people of one race identifying with and presenting themselves as another race, which is known as racial passing (Khanna and Johnson 2010).

Another management tactic is disclosing. Disclosure is the selective and careful open admission of stigma (Poindexter and Shippy 2010). Scholars have found that individuals with stigmatized identities have a variety of disclosure strategies. Charmaz (1991) differentiates between *protective* and *spontaneous* disclosure, the former meaning that individuals control who, when, how, and what they tell people about the stigmatized condition and the latter indicating an

emotional disclosure that is related to the disbelief or shock that accompanies learning that one has a stigmatized condition. Tröster (1997) says that individuals who have stigmatized conditions that they cannot control employ *preventive* disclosure. People decide to disclose depending on their perception of the risk that others will find out about their condition and what kinds of social consequences will accrue if the stigmatized condition is discovered (Tröster 1997). For example, people with epilepsy manage stigma by preventing negative ideas of them that might arise if they are seen having a seizure by testing the qualities of their relationships with those who might bear witness (Schneider and Conrad 1980; Tröster 1997). Charmaz (1991) also discusses a type of disclosing called *informing* in which the individual objectively announces the condition to others without feeling that disclosure is a risk or appearing concerned about others' reactions. Poindexter and Shippy (2010) add the idea of *stigma resistance* as a form of disclosure: individuals who want to resist the stigma of their condition engage in the widespread, voluntary disclosure of their condition by being consistently open about their condition. Stigma resistance goes beyond stigma management in that these individuals are not intent on hiding their condition from anyone (Poindexter and Shippy 2010).

The decision for anyone to pass as normal or disclose their stigmatized identity depends on numerous factors. For example, Southall et al (2011) studied the factors that lead individuals who developed a hearing loss in adulthood to disclose or conceal their hearing loss in the workplace. In this study, participants discussed a series of reoccurring themes that they considered in deciding whether or not to disclose: their community affiliation, their belief about the importance of the situation or interaction, their sense of control over the situation, the experience of difficulties in communicating, and additional issues related to hearing loss.

Additionally, before making a decision, people must weigh the benefits and consequences of passing or disclosing (Charmaz 1991). Disclosure has been associated with better peer relationships, greater self-esteem, and lower anxiety levels (Dam 2008). Disclosing can also allow the opportunity for an individual to receive help and support from similarly stigmatized individuals or sympathetic allies. Goffman noted that in-group interactions can teach an individual the “tricks of the trade” for managing stigma and that allies can share advice on how the individual can appear to others (1963:20). Ethnographic studies of groups of people sharing racial, economic, or medical stigmas support the idea that in-group members can help each other develop and practice stigma management strategies (Spradley 1970; Schneider and Conrad 1980; Miall 1986).

Despite its benefits, stigma management takes a toll on people. Passing causes stress because discreditable individuals are concerned with becoming discredited individuals. While passing, people worry about both the risk of their being discovered and the embarrassment they will feel if they are found out (Goffman 1963; Thorne 1993). Stigma management can involve psychological costs, like feeling shame or embarrassment, low self-esteem, or a belief that one is perpetuating the negative stereotype about the stigmatized condition (Miall 1986; Snow and Anderson 1987; Steele and Aronson 1995). Risks of both passing and disclosing include facing rejection or stigmatization from others, having to manage other people’s responses, and losing control (Charmaz 1991). While stigma management is hard work, unmanaged stigma can also result in negative consequences for the individual, including social sanctions such as physical or verbal harassment, loss of employment, or institutionalization or imprisonment (Edgerton 1967; Spradley 1970; Schneider and Conrad 1980).

Although the literature on stigma and the management of stigmatized identities is expansive, it still faces some challenges. One such challenge is that many of the social scientists who study stigmatized groups do not belong to those stigmatized groups, so they study stigma from a perspective that is informed by theories rather than by the lived experiences of the people they are studying (Schneider 1988; Kleinman et al 1995; Link and Phelan 2001). For example, Schneider (1988) notes that in studying disabilities, “most able-bodied experts” prioritize “their scientific theories and research techniques” instead of the “words and perceptions of the people they study” (64). Link and Phelan (2001) explain that this disconnect results in a misunderstanding of stigmatized people and the perpetuation of stereotypes. Fine and Asch (1988) suggest that there are five main assumptions that researchers have about disabilities that have had both methodological and theoretical consequences. These assumptions are: (1) disability can be considered an independent variable because it is believed to be located solely in biology, (2) any problems a disabled person faces are a result of the impairment, (3) a disabled person is a “victim,” (4) disability is central to the disabled person’s “self-concept, self-definition, social comparisons, and reference groups” (11), and (5) having a disability means the person always needs help and social support (Fine and Asch 1988). In order to understand the lived experience of stigma, researchers cannot let subjective assumptions or disconnected theories bias their objective research.

Another challenge to this literature is that most stigma research has an individualistic focus. Research on invisible social identities is usually specific to a particular stigmatized identity instead of the more general concept (DeJordy 2008). For example, scanning the literature, one finds studies on gays and lesbians, different ethnic groups, mothers who experience postpartum depression, people with epilepsy, homeless people, the mentally ill, to

name a few (Warren 1974; Ponce 1976; Schneider and Conrad 1980, Cahill and Eggleston 1995; Kaufman and Johnson 2004). However, scholars have been looking at the bigger picture. Clair, Beatty, and Maclean (2005) note that there are some factors prevalent in a range of invisible and stigmatized social identities (including people with multiracial backgrounds, chronic illness, and different sexual orientations) and that people who claim these identities often are faced with common decisions, such as whether to pass as normal or disclose their identities. While this study looks at commonalities across stigmatized groups, Ragins (2008) takes a different approach by exploring disclosure across multiple domains (e.g. work and home). Ragins (2008) explains that stigmatized individuals can struggle if they have different levels of disclosure across each of their life domains.

I would like to add that another challenge to stigma literature is that there are relatively few studies that focus on the stigma management practices of people who have ‘in-between’ identities. Scholars have begun studying people with multiracial backgrounds. Daniel (1992) notes that while most multiracial people identify as black, some have chosen the “path of resistance” by passing as white (91). People from multiracial backgrounds who try to pass as one race belong in Goffman’s (1963) category of discreditable individuals because their stigmatized attribute (in this case, a particular race) is not immediately visible to others so they can choose whether to conceal or disclose it. Having an in-between identity such as a multiracial background or a mild hearing loss is discreditable because the undesirable attribute is invisible but can be readily revealed either on purpose or by accident.

Despite research like Daniel’s (1992) that explores the experiences of people with in-between racial identities, Brunisma and Rockquemore (2001) say that it is still unknown how much “negotiation and strategy” of race is involved in passing (244). Further, other than studying

passing, research has not fully explored how people in-between the black and white races manage their identities in their daily interactions (Khanna and Johnson 2010). However, Khanna and Johnson's (2010) study found that multiracial individuals perform identity work via five strategies that serve to help them pass, cover or conceal an undesirable feature, or emphasize an attribute. First, individuals engage in "identity talk," which allows them to verbally identify with or disidentify from a stigmatizing characteristic (Snow and Anderson 1987). Second, individuals make decisions about when to reveal or conceal their identity in a process called selective disclosure. Third, multiracial individuals manipulate their phenotypes, or manage their personal appearances, in order to appear in a certain way. Fourth, individuals either highlight or downplay cultural symbols that others recognize and associate with certain identities (e.g. clothing, language). Finally, people with in-between identities selectively associate with peers, friends, or romantic partners depending on the identity of those others (i.e. they will only associate with people who are white). Khanna and Johnson's (2010) study finds that rather than having external forces acting on and influencing them, multiracial people have a great deal of agency in asserting their preferred racial identity. Thus the "identity work" (Snow and Anderson 1987) that multiracial people perform requires considerable strategy, conscious effort, and a variety of strategies in order to "do" race (Khanna and Johnson 2010). Scholars have not yet fully studied whether or not the discreditable, in-between identity that comes with having a hearing loss is similar to the experiences of those with multiracial identities.

As this section of the literature review shows, stigma requires individuals with stigmatized identities to exert a great deal of effort throughout all of their interaction. Since hearing loss is stigmatized, hard of hearing people must perform this additional work in order to

manage their stigmatized identities in any interactions. In managing stigma, people with hearing loss also perform emotional labor, the subject of the next part of the literature review.

Emotional Labor

Sociological literature is increasingly focusing on the study of emotions. This “sociology of emotions” developed from the recognition that human behavior is not only motivated by rational economic concerns, but also by our “emotional attachments to others and affective commitments” (Thoits 1989:317). Studying emotions is necessary because humans assume that “what we feel is fully as important to the outcome of social affairs as what we think or do” (Hochschild 1990:117). Early sociological research did not provide theories for studying emotions, but a review of the research conducted over the past few decades shows that sociology has developed several theoretical approaches to understanding human emotions (Turner and Stets 2006). Despite the different forms that the study of emotions might take, sociologists are ultimately concerned with “understanding how emotions are regulated by culture and social structure and how emotional regulation affects individuals, groups, and organizations” (Wharton 2009:148).

Emotional management is key to the sociology of emotions. In *The Managed Heart*, Arlie Hochschild (1983) provided a new way of looking at emotion by explaining how emotional management, a generally private act that is influenced by social and cultural norms, becomes a form of *labor* when transferred into the workplace. People external to the individual do not directly regulate the management of emotions. But Hochschild argues that when the management of private feelings enters the public sphere, it becomes what she calls *emotional labor*, or “the management of feeling to create a publicly observable facial and body display” (1983:7).

Performing emotional labor requires people to manage their emotions so as to create a particular emotional state in others, regardless of their true feelings. Hochschild (1983) defined *feeling rules* as those societal norms that govern the amount and type of emotions people are allowed to exhibit in particular situations. In accommodating the feeling rules, Hochschild explains that people engage in surface acting and deep acting. Surface acting is when people disguise how they truly feel and try to match their outward expression of emotion to normative expectations, which deceives others but does not deceive themselves (Hochschild 1983). On the other hand, in deep acting people try to change how they feel in order to make their private emotions align with normative expectations (Hochschild 1983). Taking all of this into account, emotional labor is hard work: “the human relations skills, communication skills, and emotional effort necessary” to perform emotional labor is “considerable” (Steinberg and Figart 1999:10).

Since Hochschild, sociological research on emotional labor has followed several trajectories. One branch has studied the role that emotion management plays in the job itself – how it influences job requirements and the behaviors expected of employees. Another branch is emotion-focused and studies how emotion management affects people.

The first branch studies how emotional labor is ingrained in occupations. From the job expectations and requirements, to the daily performance of tasks on the job, to the processes by which work is evaluated, emotional labor is an integral part of many jobs (Wharton 2009). Researchers generally focus on service jobs because they entail a high level of contact between workers and customers, are often low-skilled jobs, provide workers little power or autonomy, and allow employers the space to control and script their workers’ interactions with clients or customers (Wharton 2009). For example, Leidner’s (1993) research on fast food and insurance sales shows how employers in both industries control worker and customer interactions by

routinizing them: all interactions were rigidly scripted. Although scripts allow workers the ability to avoid directly engaging with customers, strictly adhering to the scripts can damage one's sense of self and identity (Leidner 1993). In accordance with Hochschild's (1983) observation that people rely on humor as a means for coping with unpleasant feelings, Leidner's participants relied on humor or exaggeration to show their distance from the scripts. Scholars have studied numerous service jobs, including waitresses (Paules 1991), retail clerks (Tolich 1993; Godwyn 2006), strippers (Chapkis 1997), and others.

In addition to studying service jobs, emotional labor research has expanded to include professions, such as doctor and lawyer. Professions differ greatly from service jobs. Whereas service workers are labeled the "emotional proletariat" (Macdonald and Sirianni 1996:3) because they are subject to employers' monitoring and controlling of their interactions and are required to present a friendly and deferential attitude to customers, professionals are "privileged emotion managers" (Orzechowicz 2008:143) because they are trained in emotion management techniques, have resources available to support their emotional labor, and receive recognition and support from peers for their emotional labor. Emotional labor research follows the process through which professional socialization occurs. For example, Smith and Kleinman (1989) found an informal hidden curriculum in medical schools that teaches students the emotional neutrality or detachment expected of physicians by training them how to manage their emotional responses to the bodies of their patients. Medical school students establish their professional authority via their ability to develop the correct level of emotional detachment (Smith and Kleinman 1989). Other scholars have studied the socialization processes for litigators and paralegals (Pierce 1995), cruise ship directors (Tracy 2000), personal trainers (George 2008), and more.

The second branch of sociological research on emotional labor is comprised of studies that analyze either the feelings of the person performing the labor or the feelings of the recipient. Using qualitative studies of jobs involving interactions with others (including caring and family work), researchers can explore how emotional labor affects either the worker or the consumer. Hochschild and researchers following her approach emphasize the work that is involved in performing emotional labor. In part, researchers study workers' private experiences of emotions and their efforts to manage those emotions. Hochschild's (1983) concepts of surface and deep acting apply here in the sense that workers are expected to present a specific emotional display to customers or clients, regardless of their actual feelings. And since emotional labor encompasses the "act of displaying the appropriate emotion" (Ashforth and Humphrey 1993:90), certain factors must be in place to determine which emotions are deemed 'appropriate.' Rafaeli and Sutton (1989) describe three sets of factors that determine which emotions workers present on the job: the norms dictating which emotions are acceptable in particular situations, workers' characteristics (including demographic characteristics and emotional reactions to situations), and the interaction's features (such as the setting). The expression of emotion on the job becomes work because employees are expected to comply with display rules, or the norms for emotional exhibition that are influenced by societal and cultural beliefs about emotional expression (Hochschild 1983). For example, the norms in a bill collection agency lead employers to socialize collectors to display a sense of urgency in their dealings with debtors (Sutton 1991). Regardless of their true emotions, these bill collectors learn to align their emotions with the norms expected by their agency. As another example, Pugliesi (1999) studied university employees and whether or not they felt they had to be friendly or nice to people regardless of how they were treated in return. Their responses led Pugliesi to the idea of "self-focused

emotional labor,” or the degree to which people believe their jobs require them to exhibit certain emotions or to be sensitive to others’ emotions (1999:135).

Other researchers define emotional labor based on the effect it has on others. For this group, emotional labor involves “efforts made to understand others, to have empathy with their situation, to feel their feelings as a part of one’s own” (England and Farkas 1986:91). Thus emotional labor is the work required to deal with other people’s feelings (James 1989) and its purpose is to make others feel a certain way, usually either good or bad (Steinberg and Figart 1999). For example, studies by Stenross and Kleinman (1989) and Rafaeli and Sutton (1991) show that detectives and criminal interrogators perform emotional labor with the intention of making their suspects feel bad, which will lead them to confess.

Other important areas of the sociology of emotions include worker burnout and compensation practices. In terms of worker burnout, researchers have sought evidence linking emotional labor to fatigue, inauthentic emotions, and burnout (Steinberg and Figart 1999). The research focus on the effect of emotional labor on individual well-being stems from the observation that, unlike physical and mental work, emotional work requires people to, “give up something of themselves to others with whom they have no ongoing personal, noninstrumental relationship” (Steinberg and Figart 1999:12). Workers engage in “self-investment” by managing or suppressing their true feelings or emotions in order to make themselves appear to others in an expected or appropriate manner (Van Maanen and Kunda 1989:54). Thus emotional labor can lead to burnout. Burnout is comprised of three factors: depersonalization, a reduced sense of personal accomplishment, and emotional exhaustion (Maslach et al 2001). People face a higher risk of burnout if their jobs involve a great deal of interaction with others (Brotheridge and Grandey 2002), such as social work, counseling, policing, and child care (Maslach 1982).

Studies have shown that people whose work requires them to exhibit emotions that conflict with their true feelings have a higher likelihood of experiencing emotional exhaustion (Glomb and Tews 2004; Dijk and Brown 2006). But other studies have found that people in jobs that are defined as demanding emotional labor are more likely to experience emotional exhaustion as a result of factors external to the jobs' emotional demands (Wharton 1993). Additionally, if people are happy with their jobs, they may have an easier time regulating their emotions at work, regardless of the amount of emotional labor required (Grandey 2003).

As for compensation practices, emotional labor is a relatively invisible factor in people's lives. When emotional labor is inherent in job requirements, people are often not paid for the emotional work that they perform (Steinberg and Figart 1999). Indeed, whether an individual is involved in paid or unpaid caregiving, the individual is not usually compensated for emotional labor expended in the process of caring. But unpaid emotion work requires people to expend a great deal of time and energy (Erickson 2005). For example, in an attempt to draw attention to the unpaid caring activities that people perform in their daily lives, DeVault (1991) highlighted the invisible work that comprises accomplishing family meals. In exploring this topic, DeVault showed that a great deal of emotional labor is performed within the family unit, but most of it goes both unnoticed and unpaid. While people believe that having a paid job is good because it means that they are contributing to society, this moral attitude fails to acknowledge the work that people perform in their daily lives that is necessary, but that is unpaid (Daniels 1987).

As the previous sections of the literature review have shown, the stigma of hearing loss and the emotional labor necessary to manage hearing loss in different situations can have a major impact on the lived experiences of hard of hearing people. Bearing this in mind, the next section

of the literature review will discuss the lack of sociological research exploring the effects of stigma and emotional labor on the target population of this particular study.

Missing Population

The current hearing loss literature includes studies describing a variety of populations that fall along the spectrum of hearing loss. However, the literature is very clearly missing the population that I studied, in terms of both age and hearing ability. The hearing loss literature focuses on school-aged children, adolescents, or adults. Researchers acknowledge that only certain age groups are studied: as Sorri et al explains, most of the literature deals “either with older age groups or targeted subjects like school children” (1997:179). The experiences of individuals who fall into Arnett’s category of “emerging adulthood” (between the ages of 18 and 25) are absent from the literature (Arnett & Tanner 2006). While the perceptions that children, adolescents, or adults have about hearing loss might be applicable to college students and young adults, I think that allowing these individuals to give voice to their own lived experiences with hearing loss will provide a perspective on hearing loss that is absent.

The current literature on hearing loss also contains more studies that explain the effects that severe and profound hearing losses have on individuals, at the expense of a discussion about the effects of mild to moderate hearing losses (Bess et al 1998; Wake and Poulakis 2004). Within any age group, “there can be no doubt about the severe impact of a severe or profound hearing loss, but the impact of a slight, mild, or moderate hearing loss is not that well known” (Brunnberg et al 2007:325). Not only are the effects unknown but Sorri et al (1997) and Bess et al (1998) both noted that the actual *prevalence* of minor hearing losses has historically not been as well documented, which makes it harder to study. Milder forms of hearing loss are more

prevalent than more severe hearing losses, yet researchers still are unclear as to the exact impact of milder hearing losses (Brunnberg et al 2007). The hearing loss research up to this point has focused on simply determining the prevalence of mild to moderate forms of hearing losses rather than on what kinds of effects these types of hearing losses have on people. Perhaps a part of this lack of research stems from the difficulty in locating young adults with mild to moderate hearing losses who are willing to talk about their experiences.

As can be demonstrated by the previous review of research on emotion management and stigmatized identity management, hard of hearing people occupy comparatively less space than people with other stigmatized or in-between identities. Even when researchers do focus on hearing loss management strategies, the target populations are generally very specific groups of people, such as adults in the workforce (Southall et al 2011) or people who acquired hearing loss suddenly (Kröger et al 1996). On a micro-level, this means that the results of these studies are not always generalizable to wider groups of people with hearing loss. On a macro-level, the hard work that hard of hearing people exert in order to manage the hearing loss itself, the stigma of hearing loss, and their own perceptions of themselves as hard of hearing people is not incorporated into the canon of sociological research on emotional labor or stigma and identity management.

Based on the above discussion, my study augments the current hearing loss literature by targeting a population whose experiences are not well documented. Since I apply the sociological concepts of stigma management and emotional labor to the experience of hearing loss, my study also expands current sociological literature. In the following section, I describe the methodology that I used in order to conduct this research project.

RESEARCH DESIGN AND METHODS

This qualitative study investigated the everyday experiences of young adults with mild to moderate degrees of hearing loss. The study examined how individuals' lives have been and continue to be positively or negatively impacted by their hearing loss and whether people experience stigma based on their hearing loss in their daily lives. In order to answer my research question, I chose to conduct in-depth, semi-structured, qualitative interviews. This methodology allowed for guided conversations that were open to in-depth conversation about how the participants adjusted to and learned to cope with hearing loss. The in-depth interview method allowed me to focus on the factors I thought would be important while still allowing participants the opportunity to bring up the factors that they felt influenced their experience of hearing loss. In each interview, I engaged my participants in dialogues that gave me a sense of the factors that have influenced their experience of hearing loss, which would have been difficult to accomplish had I used another research method.

Recruitment

Recruiting participants was difficult, in part because of the stigma associated with hearing loss. I allowed individuals to approach me if they were interested in participating rather than actively seeking them out. I initially thought I could recruit participants via snowball sampling by asking anyone who completed an interview to share my contact information with people they knew who fit my criteria. However, since people with mild hearing losses do not tend to identify with or associate with other hard of hearing people, my participants either had no hard of hearing friends or were only friends with hard of hearing people through the support groups that I contacted (meaning that their friends already knew about my study). Instead of

snowball sampling, I posted and distributed flyers and contacted various organizations with connections to hearing loss.

The flyers (see Appendix A) advertised my research study and made my contact information available to individuals who either fit my research criteria or who knew someone else who did. I posted flyers on the University of Michigan campus and provided the flyer to several hospitals in Ann Arbor, Michigan and Boston, Massachusetts. Around the University of Michigan campus, I received permission to post flyers on public-posting boards in two major classroom buildings. I also posted on restroom doors in a major campus building.

I spent six weeks taking Deaf Studies classes at Boston University during the summer of 2011. My professors directed me to groups to which I could email my flyer, including a Yahoo group for hard of hearing and deaf people in Massachusetts (Mass Deaf-Terp), the Hard of Hearing Advocates, several chapters of the Hearing Loss Association of America, and the AG Bell Association. I contacted the offices for students with disabilities at Boston University, Harvard University, Boston College, Emerson College, Tufts University, and the Massachusetts Institute of Technology. I met with audiologists and otolaryngologists at the Massachusetts Eye and Ear Infirmary (MEEI) and the audiologists agreed to distribute my flyer to potential participants. I contacted individuals at the Children's Hospital Boston and made them aware of my thesis. Finally, I asked my audiologist at the Cape Cod Hearing Center in Hyannis, MA to inform any clients of hers that fit the target population of my thesis.

I sent my information to several Michigan-based groups for the hard of hearing and deaf (Hearing Loss Association of America, AG Bell Association, Deaf C.A.N, and michdhh.org) and posted an advertisement on Craig's List. Audiologists in an off-site audiology clinic associated with the University of Michigan Hospital distributed my flyer and the audiology office at the

Livonia Center for Specialty Care (part of the University of Michigan Health System) posted a flyer. I contacted the individuals in charge of any University of Michigan clubs or groups relating to hearing loss or disability. I asked the University of Michigan Services for Students with Disabilities office and the Hearing Impaired Student Organization to send my flyer via email to the students who are registered with these two organizations. I contacted offices for students with disabilities at Michigan State University, Eastern Michigan University, and Central Michigan University. I posted a comment on the Facebook page of the Alpha Gamma Delta (Alpha Beta chapter) that explained my thesis to my sorority sisters and asked them to help spread the word about my thesis.

In disseminating my contact information in all of these different places, I intended to keep my research project open to a wide range of potential participants (i.e. participants with early versus late onset hearing loss, hereditary versus acquired hearing loss, etc) to recruit as diverse a sample as possible.

Interview Protocol

After seeing my flyer or otherwise finding out about my study, individuals emailed me to ask if I still needed participants or to set up an interview time. I received thirty inquiries regarding participation and twenty individuals were successfully recruited. The other ten individuals were not included either because they did not commit to an interview (four people) or did not fit the study requirements. One contact was twenty years older than the age range I specified, two contacts had more severe hearing loss than I was targeting, one was a parent of a young child with a hearing loss, and two informed me that they did not fit the criteria but would pass my information on to other people.

When an individual contacted me with an interest in being interviewed, I set up a day and a time for an interview. I encouraged them to pick an interview location where they felt the most comfortable. Several interviews took place in small, private rooms in university buildings while others took place in public spaces in university cafeterias or meeting areas. Some participants asked me to meet them at their private homes. Other interviews took place via Skype or over the telephone because of the participants' locations. One participant cancelled a phone interview due to a family emergency but later emailed me responses to the questions on my interview guide.

I began each interview by explaining the Informed Consent document (see Appendix C). For face-to-face interviews, I brought a copy of the document with me. For Skype or telephone interviews, I emailed a copy of the Informed Consent and demographic questionnaire documents to the participant before the interview and then explained the Informed Consent document to them. In each interview, I emphasized that the participants' identities and responses would remain confidential to everyone beyond the researcher, that they could choose not to answer questions, that they were free to end the interview at any time, and that they could contact me in the future with questions or concerns. Next, participants filled out a short demographic questionnaire (see Appendix D). For Skype and telephone interviews, the participants filled out the questionnaire and then emailed me their responses before the interview began. The demographic questionnaire let me analyze variables like age, gender, race/ethnicity, and geographic location. I also asked participants how they categorize themselves (i.e. hearing, hearing impaired, hard of hearing, deaf, etc) and if they knew their specific hearing loss diagnosis (i.e. unilateral/bilateral, high/low frequency, sensorineural/conductive, etc.). Finally, since the Human Subjects Committee did not allow me to ask individuals to provide me with a copy of their hearing tests, the questionnaire listed an adjusted version of the series of ten

questions used by the National Institute on Deafness and Other Communication Disorders (NIDCD) as criteria for recognizing hearing loss (see Appendix F for the original set of questions). The NIDCD indicates that if a person answers “yes” to three or more questions, then they most likely have a hearing loss. Since my target population is young adults with *mild* or *moderate* hearing loss, asking them to fill out this NIDCD survey provided a rough indication of their degree of hearing loss. This allowed me to compare participants’ responses depending upon their hearing ability.

After the participants filled out the questionnaire, I asked if they would be comfortable allowing me to use a digital recorder during our conversation. I then prepared them for the interview by briefly explaining my research project. In telling participants that the interview would center on the narration of their life story (a topic about which they are experts), I hoped to put them at ease before transitioning into the interview. During the interviews, I asked a series of open-ended questions about participants’ life histories, specifically focusing on their experience with hearing loss. I asked the participants how they learned about their hearing loss and had them walk me through how they have experienced, adjusted to, and coped with hearing loss throughout their lives. I followed an interview schedule (see Appendix E), but the interview was semi-structured in the sense that the participants were allowed the flexibility to respond to my questions in a way that best conveyed their personal experiences. Thus the participants often answered questions before I actually asked them. I made notes on my interview guide so that I knew that we had discussed all of the necessary topics. I tried to let my participants do most of the talking, but I spoke up when I felt that the interview was going too far off topic, to ask clarifying questions, or to probe the participant to talk in more depth about a topic.

Upon completion of the interview, I presented the participant with a five-dollar gift card to Starbucks to compensate them for their time. In the case of Skype or telephone interviews, I told the participants that I had a gift card for them and that I was willing to mail it to them if they were comfortable providing me with a mailing address. I asked them to email me their address after our interview was over in order to ensure that they did not feel pressured to give me their address. After mailing the gift cards, I deleted the email with their mailing addresses enclosed.

Throughout my research project, I made every effort to keep participants' identities and responses confidential. All written information was kept on a password-protected computer in a folder labeled in a generic fashion. I did not collect personal information from my participants and I deleted all emails from participants as soon as I completed the interview with them. In written reports, I have only used pseudonyms to refer to my participants. Along with pseudonyms, I identify participants based on their current age, race/gender, cause of hearing loss, and the age of onset of their hearing loss. For example, Interview 01 is Jen, a twenty-two year old white female who acquired her hearing loss in high school. I reference her as: Jen (22, WF, A, 14). Other types of hearing loss include congenital (C), hereditary (H), an auditory processing disorder (APD), and unknown (?).

Sample

My analysis is based on in-depth, semi-structured, qualitative interviews with twenty individuals between the ages of eighteen and forty years old who have a mild to moderate hearing loss (see Appendix H for the full Study Population Characteristics). Interviews ranged in length from twenty minutes to an hour. The longest interview lasted no longer than an hour and a half while the shortest lasted eleven minutes, in part because the participant concisely answered

the questions since her hearing loss is a factor in her life that she rarely thinks about because it does not bother her. Despite the short length, the participant provided useful comments that I frequently cite in my analysis.

The age range originally intended for the sample was eighteen to twenty-four because I wanted to focus on the experience of hearing loss among college-aged individuals. However, I received more inquiries regarding participation from individuals who fell outside of my initial age range (see Appendix I, Table 1 for a breakdown of the participants' ages). Thus I expanded the range to ensure that I could recruit enough participants.

The racial makeup of the sample (see Appendix I, Table 3) appears skewed at first glance. However, the percentages are relatively reflective of the general population of Americans who have a hearing loss. The racial makeup of my sample is representative of the wider population. The 2010 National Health Interview Survey reports that, "Asian adults and black adults were less likely to have experienced some form of hearing difficulty (without a hearing aid) than were white adults" (CDC 2011:24). A similar pattern is found when considering ethnicity. While 18% of non-Hispanic white adults have a hearing loss, 10% of non-Hispanic black adults and 11% of Hispanic adults have a hearing loss (CDC 2011). Although my sample looks skewed because more participants identified themselves as white opposed to Asian or Black/African American, the statistics indicate that more white individuals have a hearing loss than do individuals of other races or ethnicities.

In terms of gender, my sample is skewed because more women participated than men (see Appendix I, Table 2). The 2010 National Health Interview Survey from the Centers for Disease Control and Prevention reports that men are more likely than women to experience hearing trouble (CDC 2011). The higher percentage of female participants in my study can be

attributed to the fact that women are more likely than men to volunteer to participate in research studies (Chang et al 2006; McCrea et al 2009).

Analysis

I began the process of transcribing each digital recording as soon as possible. After I made a verbatim copy of the interview, I stored the sound file in a folder on my computer. I will keep the recordings until I am finished with the thesis project, at which point I will destroy the recordings so that the participants' voices cannot be recognized.

In my initial attempt at analysis, I uploaded each interview transcript into NVivo, a data analysis program, so that I could code the transcripts on a computer. However, I was not comfortable with NVivo so I decided to use Microsoft Word documents to organize the themes that arose from the data. I coded and analyzed my participants' responses inductively by looking for patterns. Searching for similarities and differences across participants allowed me to make an honest and varied analysis of the data. I initially tried analyzing my participants' responses across several factors, such as how the participants responded to my questions based on, for example, whether they had early onset hearing loss or late onset hearing loss. I also compared responses across the cause of hearing loss and whether or not the individual knew anyone with hearing loss. However, I found that it made much more sense to organize the participants' responses around a thematic outline rather than based on specific characteristics. Therefore, I created Microsoft Word documents for each theme, read through each transcript several times, and 'copied and pasted' quotes from each interview into the appropriate document. Although this was time-consuming, it was helpful in writing the body of my thesis because all of the relevant

quotations were easily accessible. I used both Microsoft Word and Microsoft Excel to create tables (Appendix J) to display the numerical data that I discuss in the body of my thesis.

When quoting participants within the body of my thesis, I did not change the content of the interviews. I made minor changes to the quotations in order to clarify what the participant meant to say. For example, if the quotation was hard to understand or unreadable because of missing words or an excess of “likes” or “ums,” I altered the quotation by filling in the missing word or by cutting out the extra, unnecessary words. However, I kept many of the “likes” or “ums,” especially when they indicated that a participant found it difficult to answer a particular question.

Strengths and Limitations

In-depth, semi-structured, qualitative interviews were advantageous for this study because this method allowed me to gain a deep understanding of my participants. The interviews were flexible enough that I could pursue any unexpected topics that participants raised. The validity of the study is strong because the data collected came straight from hard of hearing young adults who were talking about their personal experiences.

One disadvantage is that participants self-selected themselves to participate in the study, so the individuals in this study might be different from those hard of hearing young adults who chose not to participate in the study. Also, recruiting participants was very difficult. These two factors might make it difficult to generalize the findings from the study.

Another disadvantage is that I only got to know my participants on a surface level. While an in-depth interview allowed me to probe my participants, the limited time available to conduct the interview meant that participants had to become comfortable with me very quickly. Perhaps I

could have gained a richer understanding of the experience of hearing loss if I had been able to spend more time with participants or if I had interviewed each a second time. Participants might have felt more comfortable raising different topics during a second interview.

As a young person with a hearing loss, I believe that I had a unique opportunity to connect with my participants on a personal level because of the common experiences we shared as hard of hearing people. I was not able to ascertain that gender, race, or age had any particular effect on the rapport that I was able to develop with my participants. My gender might have affected the willingness of young adult males to participate in the study if they felt uncomfortable talking about their hearing loss with a female.

My personal experience with hearing loss may have affected the rapport that I developed with my participants. During the recruitment stage of my project, I disclosed my hearing loss to everyone I emailed or spoke with and I wrote on my flyer that I have a hearing loss. Individuals might have felt more comfortable participating in this study since they knew the interviewer also had a hearing loss. During the interview, participants might have been more open with me and less likely to elaborate in their responses because they assumed I would understand them. Although I tried to avoid biasing my participants into responding in any particular way, I found myself smiling when participants talked about certain experiences that I had also encountered in my life. I might not have pushed them to explain things as well as they could have because I understood what they were saying, even if they did not fully articulate what they meant.

Critical Insider

The motivation for this research project stems in part from my personal experience as a young adult with hearing loss. Classic ethnography would label me a 'native' because I am a

member of the subject population that I studied. However, my belonging to this group does not necessarily negate the value of my observations. In reality, a growing number of deaf and hard of hearing academics are stressing the importance of writing about hearing loss from the perspective of individuals with hearing loss (Oliva 2004; Bruegemann 2009; Valente 2011). Whereas an out-of-group researcher, or “participant observer,” is an outsider who must ask the group for permission to study its activities, an in-group researcher, or “observing participant,” is a member who asks the group for permission to study the group while simultaneously remaining a part of the group (Lidz 1991:84; Anderson 2002:1537). While the participant observer tries to establish a relationship with the group, an observing participant becomes “close to the subjects, empathizes with them, and is able to articulate their points of view” (Anderson 2002:1537). However, these terms do not fully describe my experience as a researcher in the social sciences because I was a member of the subject group before I initiated this research project. Therefore, my position can best be described as that of a *critical insider*: a member of the group under study who must develop and actively uphold a distanced mental perspective “so as to observe, compare, contrast and question as well as to experience” (Hodkinson 2002:5). I maintained my distance by challenging my ideas of how people experience hearing loss. Rather than assume that I understood my participants’ comments because of my own experience with hearing loss, I asked them to clearly explain their responses to ensure that my initial interpretations were correct.

RESULTS AND ANALYSIS

Having described the background of my thesis in terms of sociologically relevant literature coupled with my research design and methods, I will now discuss the analysis of the

interviews. My participants' stories indicate that having a hearing loss is hard work because it requires people to perform additional labor that people with normal hearing do not take into consideration. The analysis portion is divided into three sections: adjusting to hearing loss, managing hearing loss, and managing a hard of hearing identity. Each section describes the conscious and unconscious decisions that hard of hearing people make in order to cope with hearing loss.

ADJUSTING TO HEARING LOSS

Hard of hearing people perform additional work in adjusting to hearing loss, a process that continues and evolves at various times and in different settings over the entire life course. Acknowledging that one has a hearing loss requires actively making changes in how one thinks and acts. Mentally, hard of hearing people sometimes work to deny their hearing loss, believing that it is temporary or fixable and then later must cope with the realization that their hearing loss is permanent. Physically, hard of hearing people describe focusing harder than their peers in many different contexts, with the end result of feeling exhausted from trying so hard to hear.

Permanence and Fixing

Fourteen of the twenty participants indicated that one part of the process of adjusting to hearing loss is accepting that the hearing loss is permanent and that medical technologies cannot fix the loss (see Appendix J, Table 5). Six of the seven participants that did not mention having trouble adjusting to the permanence of their hearing loss had been diagnosed under the age of eight and the seventh participant was diagnosed at fourteen (the average age was 5.5 years). Although the following analysis shows that individuals with early onset hearing loss are

susceptible to believing their hearing loss can be fixed, the fact that only individuals with early onset hearing loss did not believe that their hearing loss was temporary or fixable suggests that the age of onset of hearing loss influences one's perceptions of hearing loss.

Two participants recalled thinking that they would not actually lose their hearing even though their hearing tests and family histories indicated that they would. Diana's (26, AA, F, H, 14) (see "Research Design and Methods" section for an explanation of my identification system) hearing loss is hereditary: she was born with a hole in each ear, has undergone several surgeries since birth, and shares a condition with her mother and brother. Despite witnessing her family members' hearing deteriorate over time Diana felt "surprised" when her doctor diagnosed her with hearing loss. Although she "always knew" that it was "more difficult" for her to hear, she did not think she had a "problem." Brian (31, WM, H, 8) also has a hereditary hearing loss. Brian and his sister went for regular hearing tests when they were younger and both tested "normal." When Brian started showing loss in the highest frequencies, his mother knew he would follow her hearing loss trajectory. But Brian considered that test an "aberration" and felt that "there's still a chance that next year it'll test normal." The following year, Brian's test again showed that his hearing was not normal, so he switched from thinking that he would not lose his hearing to thinking that his hearing loss "won't get worse too fast." Diana's and Brian's experiences illustrate that hearing loss can be hard to accept in part because it can be invisible outside of the audiograms. Brian struggled to accept that he had a hearing loss:

it was like I had this, I mean, not this disease, but something was wrong with me in practice, but I didn't feel like anything was wrong with me.

Like Brian, many hard of hearing people experience a sort of "grappling to not lose your hearing for a while" until they come to accept that the hearing loss is real.

Five participants described thinking at the time of their diagnosis that their hearing loss would not be permanent. These participants had acquired hearing losses, the diagnoses were made later in the participants' lives (between the ages of fourteen and twenty-three), and the participants remembered thinking that their hearing would return as they recovered from an illness. Sarah (30, WF, A, 23) believes she developed a hearing loss because she has spent a lot of time exposed to "really loud things": she never wore ear protection while shooting guns or attending concerts, and she used to work as a firefighter which meant she constantly heard sirens and explosions on the job. When Sarah went in for a hearing test, the woman testing her hearing only checked the "loud frequencies," so she told Sarah that she did not have a hearing loss. The summer before our interview, Sarah developed an ear infection that led to a ruptured eardrum. Sarah took her doctor's advice and tested her hearing again. After the test, Sarah learned that she did have a hearing loss, but she is still not sure if it is "going to go away or come back."

Although she knows that she has a hearing loss, Sarah still hopes that she can recover her lost hearing because she says, "all I want to do is hear." Ear infections also caused problems for Jen (22, WF, A, 14). Throughout her childhood, Jen's hearing went "back and forth" because she had a lot of ear infections. Due to these fluctuations, Jen and her family assumed that her hearing loss would only be "temporary," not "permanent." Chris (22, AM, A, 20) had an accident that required surgery on his head. Although he thinks he might have had a hearing loss before the surgery, he "could hardly hear after the surgery" because of the swelling. Chris tested his hearing after the surgery to make sure that it "was kind of back to normal after everything." However, he learned that he actually had half the hearing ability that is usually expected of a twenty-year old male. Chris found this diagnosis "kind of scary" because "it was a permanent damage" that he "couldn't do anything about it." Sophie (40, WF, A, 21) and Megan (21, WF, A, 19) both

developed a unilateral hearing loss as a result of sickness. As a senior in college, Sophie thought she had a “temporary hearing loss” because she “was just sick.” However, her doctor informed her that she had lost eighty percent of her hearing in the mid to low frequencies in one ear. In Megan’s case, one day she developed a headache, felt dizzy, and had a ringing in her ear. The following morning, she went to her doctor and learned that she had lost all of the hearing in her right ear. Megan felt shocked by the sudden loss and wondered, “is this forever?” The doctors warned Megan that her hearing would probably never be fully restored, but Megan’s mom told her, “It’ll be fine. This is temporary.” In describing this moment, Megan began to sound frustrated and slightly angry. At the time, Megan felt that everything was *not* fine:

I’m deaf. It’s done. Like, you can’t...it’s not coming back. Like, I don’t know why you’re so hopeful. Like, yeah, you’re my mom so you have to be.

Intellectually, Megan knows that she cannot restore her hearing. However, hearing stories about “people who had this same issue and [then] woke up one morning and could hear everything again” means that Megan is still “waiting for that to happen” to her. In each of these examples, participants demonstrate the emotion work that is required to manage the uncertainty of their diagnosis. A medical diagnosis is important because it “gives meaning and legitimacy to worrying symptoms” (Barker 2010:155). Before participants received their diagnosis, they had to constantly reanalyze their perceptions of themselves as hearing people as their hearing ability fluctuated.

Nine participants said that they had initially believed that medical interventions and technologies would restore their hearing. Sophie (40, WF, A, 21) simply said that her doctors “tried a lot of things” but that her hearing “never came back.” Megan (21, WF, A, 19) also underwent a variety of interventions, including steroid injections every other day for two and a half weeks that restored fifty percent of the hearing in her right ear. But Megan added that

despite the restored hearing, her ear “still rings. Every day. All day long. Nonstop,” suggesting that she expected the injections to address the tinnitus (see Appendix G for a definition) in addition to the hearing loss.

Two participants specifically addressed hearing aids. Brian (31, WM, H, 8) said that his hearing aids made a “big difference” in helping him hear more, but they are not “a silver bullet.” Rachel’s (21, WF, C, 2/3) experience elaborates Brian’s point: since her hearing loss has deteriorated over time, Rachel has had to get different types of hearing aids, each “covering different losses,” but that no pair of hearing aids has made “things perfect.” Rachel used to believe hearing aids would fix her hearing loss. But then she realized:

a lot of people think that if you have a hearing loss and you wear hearing aids, that there’s no problem. Like, if someone can’t see and they wear glasses, then problem solved. But I think it’s more of the case where hearing aids will make it better but they won’t fix the problem.

While hearing aids do help people hear better, they do not meet most people’s expectations because they do not completely restore a person’s hearing to a normal level.

Surgery is another medical intervention that hard of hearing people often believe will restore their hearing. Lindsay (18, WF, A, 7) underwent her last surgery four years ago, and saw a new specialist two years ago to address her concerns about her “decreased hearing ability” and “ringing” and “popping” in her ears. Lindsay went to the appointment thinking she “could fix it again” and that the doctors would be able to “do something” to restore her hearing. But the specialist told her that her ears were “just kind of scarred” so there was “really nothing” she could do. Although it is “annoying” to know that she cannot do anything to fix her hearing, Lindsay says, “I guess it’s just how it is.”

Lynn (34, AF, ?, 14), Tyler (30, WM, C, 0), Fiona (26, WF, C, 5), and Hannah (30, WF, H/C, 6) made very similar comments regarding their expectations for their surgeries. Lynn and

her family decided that she should have a cochlear implant because they all thought it would make her “normal again.” But the doctors told them that Lynn would actually “hear mechanically” rather than normally. Lynn and her parents were upset because they thought the “surgery was supposed to restore” Lynn’s hearing and make her “normal” when in reality the doctors would be “putting some kind of device” into her head that the family feared would turn her “into a robot” without feelings. Thus they postponed Lynn’s surgery. Tyler had a slightly similar, albeit less dramatic response, to the mastoidectomy (see Appendix G for a definition) he underwent in sixth grade. After the surgery, Tyler did not have to wear his “big, bulky hearing aid” and so he began to think, “I had the surgery and I’m normal.” Reflecting on his expectations for the surgery, Tyler said that,

as a kid I thought, *oh, it’s going to be over!* You know? Little did I know that I needed ear drops, regular cleanings...all this stuff. So I saw them, I guess, the medical intervention, as being, like, you know, the end.

Even though his hearing deteriorated when he got to college, Tyler refused to admit that he had a problem because he still wanted to believe that the surgery had made him ‘normal.’

Hannah explained that before her surgery, her left ear had been her stronger ear. But she remembers the doctors telling her that,

after the surgery I might only have to wear one hearing aid. And I was like, *oh cool! So I won’t have to wear my left hearing aid?* And they’re like, *no, no, no. Your right ear.* And I, I never, I never really accepted that *okay my right ear was going to be my strong ear.*

Hannah’s disappointment that the surgery could not fix her hearing loss was compounded by the fact that the ear she relied heavily upon in all of her interactions would now be her weaker ear.

Fiona (26, WF, C, 5) describes a similar experience: after her first surgery in second grade, doctors said, “you’ll have another surgery some day.” Fiona says that she “had this idea that they’re going to do surgery and then, eventually, someday [she] wouldn’t have a hearing

problem.” At a subsequent checkup, Fiona learned that she needed a hearing aid in her other ear. During the car ride home, Fiona started crying because, “there’s just always this idea because [she] had those surgeries that eventually they’d fix” her hearing loss. Her mother tried to explain the situation to Fiona, but she kept asking, “when are they going to fix my ears, though?” Then Fiona acted out, saying,

well, I’m not going to wear it. I want them to fix my ear. I’m not going to wear this hearing aid. You can’t make me wear it. I’m not gonna do it. Well, my mom knew me pretty well and I was like a fashion kid so she said, uhh, well, what if I were to get you that perm you wanted? Would you wear that hearing aid? And I said okay. So I ended up getting a perm and that was kind of my mom’s, umm, way of handling it.

Although Fiona eventually agreed to wear the second hearing aid, she initially resisted the idea because she truly believed that the medical interventions she had undergone were supposed to fix her hearing loss.

Acknowledging that one has a hearing loss requires actively making changes in how one thinks and acts. As the previous section shows, hard of hearing people sometimes work to deny their hearing loss, believing that it is temporary or fixable, and later must acknowledge that their hearing loss is, in fact, permanent. The next section will explore some of the more physical changes that hard of hearing people adapt to in the process of adjusting to hearing loss.

Focus and Exhaustion

While interactions demand effort from all kinds of people, individuals with hearing loss must perform even more work. Specifically, this work takes the form of extra focus, with the process of adjusting to hearing loss at any age often requiring hard of hearing people to learn to pay close attention to the people with whom they are communicating. Steven (26, WM, A, 5)

says that although adjusting to hearing loss was just a part of growing up because he has had his hearing loss “pretty much [his] whole life,” he still had to get used to,

the fact that I have a hearing problem and I need to, like, focus extra hard to be able to understand what people are saying.

For example, since Steven reads lips, he has learned that he must pay close attention to people’s mouths when they speak. Although it is estimated that only about thirty percent of the English language can be distinguished on the mouth (the rest is just guesswork on the part of the hard of hearing person) (Prickett 2004), Steven says that when he is “actually focused” on lip reading, he can “definitely...hear more” and better “understand what people are saying” than if he solely relies on his residual hearing. Similarly, Sophie’s (40, WF, A, 21) hearing loss made communication “different”: after losing the hearing in one ear, Sophie felt a “strain” when talking to people because she “had to really pay attention” in order to hear them. Looking back on her years in graduate school, Sophie believes that, compared to her peers, she had “to work a little bit harder just, you know, concentrating in class.” Kevin (26, AM, A, 1) agrees that having a hearing loss makes interactions, including listening to a lecture, “a little bit harder” for him because his hearing peers “don’t have to spend as much energy” as he does in order to obtain the same information. Megan (21, WF, A, 19) especially struggled in adjusting to her hearing loss because her tinnitus means that she must “work so much harder” to “concentrate and focus” on, for example, her homework rather than the ringing in her ear. Megan forces herself,

to *not* be thinking about my ear, and *not* be thinking about the ringing, and to focus on what I need to be doing.

Thus, in the process of adjusting to hearing loss, participants had to learn how much energy they must expend in order to keep up with conversations.

The interaction work that hard of hearing people perform in order to focus on conversations is draining. Megan (21, WF, A, 19) says that between asking for repetitions, constantly repositioning herself in group situations, and trying to direct her full attention to whoever is speaking, hearing loss is extremely “tiring.” Likewise, in considering her adjustment to having a hearing loss, Sophie (40, WF, A, 21) says that,

everything was just, like, harder. Like, it was kind of exhausting. It just felt kind of exhausting to go through the day [because] I had to concentrate much harder than I had before.

On a similar note, Brian (31, WM, H, 8) summarizes how tiring it can be for hard of hearing people to concentrate on oral conversations:

at the end of the day, you feel exhausted from having to sort of focus all the time and extract every little bit that you can based on whatever little context you get from the conversation.

In order to participate in the world around them, hard of hearing people must maintain a high level of energy so that they can focus on catching any and all conversations. But in their attempt to participate, hard of hearing people exhaust themselves. Thus adjusting to and coping with hearing loss are high-energy tasks that require a great deal of concentration and focus but that leave the hard of hearing person depleted and exhausted.

MANAGING HEARING LOSS

After the period of adjustment to the general idea of hearing loss comes the ongoing management of hearing loss in daily life, the second area in which hard of hearing people perform additional work. Hard of hearing people actively manage their hearing loss on several fronts. The medical aspect of hearing loss requires hard of hearing people to juggle a variety of interventions and technologies aimed at improving their hearing. Although not apparent to the

casual observer, hard of hearing people exert a great deal of labor in order to successfully navigate through the academic environment and through most types of social settings.

Medical Technologies and Interventions

Since hearing loss is considered a medical condition, managing one's hearing loss naturally requires a certain amount of interaction work with the healthcare system. Participants were consciously aware of the amount of time they spent medically managing their hearing loss. However, what is not so obvious is the extent of the emotional labor they perform on themselves in order to cope with the time-consuming nature of managing a hearing loss and the decisions they had to make about their hearing loss.

Broadly, managing one's hearing loss requires a great deal of scheduling and planning ahead. Tyler (30, WM, C, 0) has spent his entire life making adjustments for his hearing loss, and the following comment describes his and many other hard of hearing people's experiences of the extra work involved in having a medical condition:

*if I didn't have this [hearing loss], I would not have to set up all these damn appointments...I'm dealing with it, but I'm like, just think of all the people that don't have this problem and they don't have to set up, every six months, go see this doctor. Go buy these batteries. Go get this. So there are moments...even today where I'm like [smacks hands on table], *Son of a bitch I have to deal with this.**

Participants consistently supported Tyler's comment that having a hearing loss requires people to constantly remember both mundane and urgent details. For example, remembering to "carry a back up [battery] in my wallet just in case a battery runs out" (Kevin, 26, AM, A, 1) is a more minor detail, but scheduling time off from work in order to avoid penalizations from audiologists who will often charge clients if they need a second adjustment to their hearing aids but do not

return within a narrow window of time between two appointments (Hannah, 30, WF, H/C, 6) is a more complicated detail.

In addition to these examples, participants shared many stories about the hard work they exert to medically manage their hearing loss. Participants' responses indicated that from initially diagnosing the hearing loss to seeking upgraded assistive hearing technology, hard of hearing people must schedule numerous appointments with medical personnel in order to monitor their hearing loss. Participants cited hearing tests, therapy, and interventions like surgeries as some of their most time-consuming appointments.

Hard of hearing people can spend a lot of time trying to figure out whether or not they have a hearing loss. Oftentimes, participants who had early onset hearing loss first began to realize that they had a hearing loss when their parents started taking them to audiologists "all the time" for hearing tests (Rachel, 21, WF, C, 2/3; Fiona, 26, WF, C, 5). Participants with later onset hearing loss remember being told by audiologists that they would have to "keep going in for follow up hearing tests" (Sarah, 30, WF, A, 23) to check if their "hearing's in the same place or not" (Sophie, 40, WF, A, 21). For both early and later onset hearing loss, participants said that they "had to" get their hearing tested either every six months or every year in order to monitor their hearing loss (Steven, 26, WM, A, 5). In addition to scheduling multiple appointments to watch for the progression of the hearing loss, Lindsay (18, WF, A, 7) explains her history of seeking a diagnosis in a way that summarizes the manner in which many participants learned about their hearing loss:

in elementary school...we had one of those hearing specialists come in, do, like, the hearing test, and I failed that. So I went back, like, did it again, failed it again. So I went to a specialist and they found, umm, I had fluid in my ear.

While the families of participants with hereditary hearing losses knew early on to monitor their children's hearing, participants with acquired or congenital hearing losses commonly learned about their hearing loss by failing school hearing tests. The families of Steven (26, WM, A, 5) and Tyler (30, WM, C, 0) had to make a serious effort to find a diagnosis for their sons. Steven grew up playing "in big waves, smashing my head around, and getting smacked by waves" which eventually resulted in the shattering of his inner ear bone. His mother took him to a local doctor, who told them that Steven was fine. Steven's mom was not content with this response, so she took Steven to a hospital four hours away in Boston where he was correctly diagnosed and encouraged to have surgery. In Tyler's case, his doctors in rural Wisconsin could not figure out what he had been born with aside from "misshapen" outer ears. Tyler says that his parents were asked if they wanted to "keep your baby" so they "immediately" tried to find other doctors that could diagnose Tyler. His parents sought specialists in Green Bay, Milwaukee, and Rochester and finally learned that Tyler been born without ear canals. Regardless of the age of onset or cause of hearing loss, receiving a diagnosis of hearing loss often involves the scheduling of multiple hearing tests and visits to multiple doctors.

Hard of hearing people sometimes need therapy to help them relearn how to speak or how to hear. Fiona's (26, WF, C, 5) doctor convinced her to wear a second hearing aid after sitting down with her and taking the time to explain why her right ear did not work properly and to help Fiona through "basic therapy" or "rehabilitation" for her ear so that she could "learn to use it again." After her cochlear implant surgery, Lynn (34, AF, ?, 14) had therapy every Wednesday during which her teacher made her,

say words, like... "apple"... "bananas," so you can, like, learn to hear again, you know? Assimilate back to hearing... I mean, it took a while, but then I became better at it.

For the first nine months that Sophie (40, WF, A, 21) had a hearing loss, her audiologists simply said, “*oh, you lost your hearing. That’s it.*” But then she went to an audiology clinic for speech reading that also had a “program to help people with hearing loss...and I was able to talk to them about some of the problems I was having.” In each of these cases, the participants committed a lot of time to therapeutic measures that served to benefit them in the long run.

Ten participants discussed undergoing some form of medical intervention at least once in their lives to try to prevent, correct, or reduce their hearing loss. Megan (21, WF, A, 19) underwent two and a half weeks of oral steroids and then injected steroids every other day into her inner ear in an attempt to restore her hearing. Megan stopped the oral steroids because they made her feel “gross” but the injection into the inner ear also made her uncomfortable because it “deals with your balance so you’re, like, swirling all the time.” Diana (26, AAF, H, 14) has to schedule appointments to get her ears cleaned every once in a while because one result of her hereditary condition is that “wax gets stuck down there” in the holes in her ears which is both “irritating” because it “itches” and problematic because the wax buildup contributes to her hearing loss. The wax is so deep in her ears that Diana cannot clean them on her own but must seek professional help. Other forms of interventions involved surgery. Several participants had at least one set of tympanostomy tubes (see Appendix G for a definition) implanted in their ears to reduce the incidence of ear infections by allowing fluid to better drain from their ears (Jen, 22, WF, A, 14; Steven, 26, WM, A, 5; Kate, 26, WF, C/A, 6; Lindsay, 18, WF, A, 7). Participants also underwent surgeries to remake an ear drum (Jen, 22, WF, A, 14), fix a shattered inner ear bone (Steven, 26, WM, A, 5), create an ear canal (Tyler, 30, WM, C, 0), remove and reshape inner ear bones (Hannah, 30, WF, H/C, 6), address a hereditary condition (Diana, 26, AAF, H, 14), or install a cochlear implant or bone-anchored hearing aid (Lynn, 34, AF, ?, 14; Tyler, 30,

WM, C, 0) (see Appendix G for definitions). Participants were often “clueless” about their surgeries (Hannah, 30, WF, H/C, 6), but could look back and consider them “strange” (Fiona, 26, WF, C, 5) or “horrible” (Tyler, 30, WM, C, 0), depending on how long the surgeries lasted and how many surgeries the participant endured. The medical interventions that participants underwent required them to schedule many appointments, spend numerous hours in surgery and recovery, and then schedule more appointments afterwards to check whether or not the surgeries had been successful.

In addition to managing appointments and medical interventions, the participants who wore hearing aids or other assistive hearing technologies described a variety of additional behaviors they had to employ in order to manage their hearing loss. The decision to wear assistive hearing devices depended on the participants’ ability to think through topics like the comfort, subtlety, stigma, and cost of hearing aids. After deciding to wear such devices, participants had to grow accustomed to managing the technology as well as managing their adjustment to wearing the devices.

Comfort is one factor that participants considered in their decision to wearing assistive hearing technologies. Rachel (21, WF, C, 2/3) says that when she started wearing hearing aids in first grade, she did not like them because they were the “over the ear ones” so she “didn’t think they were very comfortable.” While Rachel began wearing hearing aids despite the discomfort, Chris (22, AM, A, 20) declined his doctor’s suggestion that he get hearing aids because “it’s not comfortable to wear anything” on one’s head or face and that he does not “even like wearing glasses.” Diana (26, AAF, H, 14) wore hearing aids for a short period of time but stopped “because it always just felt weird” to have hearing aids in her ears and because she “never got used to the feeling...Kind of like after you get braces, you get the retainer. Which is kind of

irritating.” Thus participants analyzed the physical comfort of hearing aids before deciding if they would use them.

A second factor that participants considered in their decision about hearing technology is the subtlety of the device. In this category, participants said that hearing aids are problematic because they are visible. Rachel (21, WF, C, 2/3) says that she felt concerned with “the aesthetics of hearing aids” in elementary school because she wanted aids that “no one can see so that no one would know.” Likewise, Charlotte’s (21, WF, C, 2) initial thoughts about hearing aids were “totally aesthetic” because she did not consider her hearing loss “a problem of being able to hear” but rather an “embarrassment of this, like, thing on my ear.” When she was thirteen, Kate’s (26, WF, C/A, 6) doctors suggested she get an FM system but her parents did not want her to be “singled out” from her peers because of the large device so they encouraged her to get inner ear hearing aids. Since the appeal of invisibility is important, it follows that participants often described their pleasure in going from a highly visible to a mostly invisible hearing aid. Charlotte explains that her “favorite change” in assistive technology occurred in fourth grade when she went from wearing “the outer ear to the inner ear hearing aid.” For Charlotte, this was her “favorite transition” because the hearing aids “went from being this big, like, machine, like obvious thing, to this tiny, low-profile...sleek piece of technology.” Kevin (26, AM, A, 1) says that his first FM unit was “pretty noticeable” because it was “the size of a brick” and hung around his neck. But now, “technology has made hearing aids so that they’re smaller, less visible, so people don’t notice it at first, especially with...my hearing aids matching my skin tone.” Although these participants continued to wear their hearing aids despite their visibility, Diana (26, AAF, H, 14) stopped wearing her hearing aid. Despite the small size of the hearing aid, Diana stopped wearing it in part because she felt that it was, “still pretty big” and that, “you

could still see something in someone's ear." Participants had a heightened awareness of how visible their hearing aids are to others and used this knowledge in deciding whether or not to wear hearing aids.

Third, participants discussed the stigma of hearing aids. Comments made about stigma sounded similar to comments about the desire for hearing aids to be subtle – Jen (22, WF, A, 14) says that she initially chose not to get hearing aids because of the fear that people would notice them and Diana (26, AAF, H, 14) does not wear hearing aids because she thinks hearing aids suggest that there is “something wrong with you.” Chloe (21, WF, APD, 14) does not wear hearing aids because they are “embarrassing” and not “worth the stigma” of people assuming that she has “really intense hearing issues.” Likewise, Chris (22, AM, A, 20), simply says that, “there is a stigma that comes with hearing loss and...I didn't want to face that.” Steven (26, WM, A, 5) chose not to wear a hearing aid because he “didn't want to go to school and be made fun of” like his classmate who “was made fun of all the time” because of her deafness and her hearing aids.

When discussing the stigma of hearing aids, participants sometimes brought up the fourth factor, the cost of hearing aids. While his main reasons for not wearing hearing aids are because he functions fine with his residual hearing and because of the stigma of hearing aids, Steven (26, WM, A, 5) acknowledges that hearing aids are “really expensive.” Steven says his mom would have gotten him hearing aids, but his “left ear is fine” and he “wouldn't wear the one that was visible.” Brian (31, WM, H, 8) says that stigma and cost prevent many people from getting hearing aids. Brian says that buying hearing aids and maintaining them take up “a good chunk of [his] income” and when “you couple that with the fact that you're reluctant to get it because of the stigma...there's, you know, two strikes” against getting hearing aids. Tyler (30, WM, C, 0)

says that when he finally accepted that he needed hearing aids, his health insurance would not cover the costs. Even though his employers and family supported his decision, Tyler had to wait until he applied to graduate school and received insurance through his university before he could receive bone-anchored hearing aids. Thus the cost of hearing aids is a relevant factor that can deter people from getting hearing aids.

After deciding to wear assistive hearing technology, participants described the work of managing the technologies. One part of this management involves going to audiologists to either tweak current hearing aids or to discuss getting upgraded technology. Participants explained that having hearing aids “takes a little bit of maintenance” because the hard of hearing person must, “keep tweaking and figuring out, *okay this is too high, that’s too off. What is this that’s not quite sounding right?*” (Hannah, 30, WF, H/C, 6). Participants found that as their hearing changed, they had to, “constantly go in for renewals and different hearing aids covering different losses” (Rachel, 21, WF, C, 2/3). While some participants are “excited about some of the new technology coming out” because it will improve their lifestyles (Charlotte, 21, WF, C, 2), other participants felt more pessimistic about the entire process of adjusting to hearing aids. Clair (24, AF, C, 2½) says that it “takes a lot of time to get the hearing aid tuned correctly” which affects getting new technology because she feels “it’s a lot of effort for...incremental improvement.” Overall, participants said that while their hearing aids did help, they think that the process of adjusting hearing aids and the hearing technology itself “could be better” (Kevin, 26, AM, A, 1).

Another aspect of learning to manage the technologies involved participants trying to figure out how to communicate what they were hearing to their audiologists. Steven (26, WM, A, 5) describes with frustration that getting his hearing tested is “irritating” because he cannot hear the sounds despite trying “so hard to hear.” His frustration is exacerbated because his

audiologists ask, “*did you hear that?* And I’m like, *No! What the heck! No!*” Kevin (26, AM, A, 1) expands on this point by explaining that talking to an audiologist with normal hearing makes it, “harder to explain what you mean or what you hear when they tweak the settings in your hearing aids.” Kevin says that his audiologist relies on audiograms to program his hearing aids, but that the audiograms do not always account for “real world situations.” Thus Kevin’s audiologist makes changes to his hearing aids that are not always helpful.

In addition to working hard to manage their assistive hearing technologies, participants explained that adjusting to the technology requires a certain amount of effort. Participants said that getting hearing aids did not automatically help their hearing loss, but rather their ears and their brains had to relearn how to hear. Several participants described putting in hearing aids and being exposed to sounds they either had never heard before or had not heard for a long time. Will (33, WM, A, 8) says that, “when they first put the hearing aids in and turned them on, I didn’t know what to think” because he could suddenly “hear myself breathe. I could hear the zipper of my coat. I could hear birds.” Brian (31, WM, H, 8) says that he had not been able to hear the turn signal on his car for years, but that hearing aids allowed him to hear it again. While these new sounds can be good, they can also be “traumatic” or “uncomfortable” if the individual needs more time adjusting to hearing sounds in the way that hearing aids transmit them (Clair, 24, AF, C, 2 ½). For example, when Lynn’s (34, AF, ?, 14) cochlear implant was first turned on, “it sound like Darth Vader in...Star Wars.” Lynn could tell that people were talking, “but everyone sounds like, *rooowr rooowr* [makes Darth Vader noise].” Although Lynn felt relieved to hear better after “years of being deaf,” she says that all she could think about at the time was, “*if I’m gonna hear like this for the rest of my life, I don’t know if I can take it!*” Similarly, Charlotte (21, WF, C, 2) says that with new hearing aids, “stuff sounds so weird” and she wonders if she is in a

“microphone” because her “voice sounds really strange.” Adjusting to technology is difficult for many participants because they must learn how to process sounds that are outside their residual hearing range and because they must cope with the fact that technology often distorts familiar sounds until the brain can readjust to the new way of hearing.

Continuing with the topic of the work of adjusting to technology, participants explained that upgrading to new hearing aids or switching back to an old pair also required an adjustment process. Kevin (26, AM, A, 1) says that if the hearing aids have been configured for him, it will take him “less than a day to adjust” to hearing with the new aids. Likewise, Rachel (21, WF, C, 2/3) thinks it is “usually pretty easy to go from one pair to another” but that she pays more attention to sounds during the “first couple of days” because the new features of the hearing aids will make familiar sounds appear different until her brain learns how those familiar sounds should now appear. Returning to one’s own old pair of hearing aids also requires adjustment: Charlotte (21, WF, C, 2) says that using an old pair of her hearing aids is a “weird adjustment” because she must readjust “back to the type of sound” that those hearing aids provided. Likewise, Will (33, WM, A, 8) says that when he sent his new pair of hearing aids in for repairs, he “popped the old ones back in” but could not “hearing anything out of [them].” Even stopping the use of hearing aids can require an adjustment: when Hannah’s (30, WF, H/C, 6) hearing aid broke five weeks before the end of an academic semester, she decided to try getting by with one hearing aid and her one ear. She says that she felt, “completely off. I would hear a sound and I wouldn’t know where the sound was coming from.” Thus adjusting to hearing aids requires a certain amount of effort on the part of the individual’s body before the hearing aid can be effective.

From a medical perspective, managing hearing loss requires a considerable amount of effort. The physical labor involved in managing hearing loss includes scheduling hearing tests and therapy sessions, undergoing major medical interventions such as surgery, and visiting audiologists either to tweak the settings of a current form of assistive hearing technology or to receive upgraded technology. Managing hearing loss also includes emotional labor: hard of hearing people weigh their opinions about the comfort, subtlety, stigma, and cost of assistive hearing technology when deciding whether or not to use such technology, struggle to convey the difficulties they have with their hearing aids to audiologists who have normal hearing abilities, and relearn how to hear each time they switch assistive hearing technologies. While the management of hearing loss necessarily occurs in medical settings because of the medical nature of the condition, the next section will explore the management and work that hard of hearing people perform in a more every day context: school.

Academic Environment

Hearing loss management extends beyond interactions with the medical system and into the daily interactions in which hard of hearing people participate. Since hearing loss is generally “undisclosed discrediting information” (Goffman 1963:42) about an individual, the academic environment becomes a space in which a hard of hearing person must plan ahead and make a variety of decisions about the benefits and risks of making their hearing loss known. Since hearing losses affect people differently, the type of classroom setting that benefits one hard of hearing person might pose a challenge to another hard of hearing person. Despite individual differences, participants consistently said that if they were “sitting in the classroom, it was hard to hear something” (Brian, 31, WM, H, 8). Approaching any classroom situation requires the

hard of hearing person to analyze several factors, including which accommodations one will need, whether or not one discloses the hearing loss to teachers or classmates, and how hard one must work in order to succeed in the class.

First, the hard of hearing person considers the classroom setting and whether or not it will be an environment conducive to learning. Four participants (see Appendix J, Table 6) said that their hearing loss is not a problem in class. These participants believe that they can function well in their classes with few to no accommodations. Charlotte (21, WF, C, 2) said that aside from sitting in the front of the classroom, her hearing loss “hasn’t really affected me in class that much.” Lindsay (18, WF, A, 7) thinks her hearing loss does not affect her behavior in class because although she might “have to, like, really focus more” in class, she usually does not “have to sit up to the front or anything.” For Chris (22, AM, A, 20), school is “fine” because the only time he has a problem is in smaller classes. Steven (26, WM, A, 5) said that although he “took it upon” himself to learn sign language when he was first diagnosed with hearing loss, he did not continue with the language and “totally forgot” everything that he learned from his teacher who knew some sign language. Steven says that he has no need for sign language because he has not “really had a problem, you know, talking to people.”

One participant did not discuss classroom settings in the interview, but the remaining fifteen explained how hearing loss has affected or continues to affect them academically. In terms of structural difficulties, sitting in the back row of a classroom because of assigned or alphabetical seating can be difficult because it “can be a challenge to hear the professor or other people talking in the classroom” (Kevin, 26, AM, A, 1). Participants also struggled to hear teachers and classmates depending on the size of the classroom. On the one hand, “smaller classes,” “class discussions,” or a “seminar class” were cited as problematic because hearing loss

made it hard either to hear what others were saying or to participate well in those settings (Jen, 22, WF, A, 14; Rachel, 21, WF, C, 2/3; Chris, 22, AM, A, 20). Sophie (40, WF, A, 21) expressed this idea differently, saying that she could “hear generally” during a lecture class because such classes provided a “quiet environment” that enabled her to hear better because she was “just listening to one person speaking at a time.” Smaller classes that require students to discuss with one another are more difficult for the hard of hearing person because they have to focus on more than one speaker.

On the other hand, Clair (24, AF, C, 2½) felt that her hearing loss “wasn’t as big of a deal” when “classes are smaller.” Instead, her hearing loss “made a big difference” in the “larger science classes and especially in the math courses because the acoustics are very bad.” Thus smaller classes benefited Clair because the classrooms allowed her to hear people better than she could in large lecture halls.

In addition to discussing the effect of classroom size, some participants focused their responses on teaching styles. Chloe (21, WF, APD, 14) had “issues in school” when teachers faced away from her when they spoke. Chloe missed the information if the teachers were “trying to explain things and doing things on the board at the same time.” Similarly, Diana (26, AAF, H, 14) could not hear if the teacher “ever turned her back as they do when they, you know, write on the blackboard.” In these situations, Diana would “lose out on a lot of stuff that they said.”

Once the classroom setting has been analyzed, the hard of hearing person must consider what kinds of accommodations (if any) will be required. Accommodations that participants make can be divided into two categories: personal accommodations that are made without help from others, and external accommodations that require contacting others for help. One of the most common personal accommodations was making an effort to strategically positioning themselves

in the classroom to maximize their ability to hear. For smaller discussion-type classes, participants chose seats that allowed the better of their two ears to be closer to the teacher (Jen, 22, WF, A, 14) or seats in the middle of the room that enabled them to look at each person that spoke (Rachel, 21, WF, C, 2/3). For all kinds of classroom settings, participants tried to sit close to the front of the room. Participants said that sitting in the first few rows was usually enough of an adjustment to ensure that they could “hear everything” or “really hear things” in class (Charlotte, 21, WF, C, 2; Tyler, 30, WM, C, 0). Fiona (26, WF, C, 5) said that although she did not have “much of a choice” to sit anywhere but the front few rows, she thinks there was a “benefit” in her constrained seating because “statistically, people that sit in the front of the classroom have better...GPAs.” But ensuring that she had access to the front row was sometimes challenging. Fiona explained that if she ever arrives at a class or event late or only “five minutes before it starts, well, now the front row’s filled up. What do I do?” Sitting just anywhere in a classroom is often not an option for a hard of hearing person so they must be extremely conscious to arrive with enough time to ensure that they will have access to a seat that will enable them to hear their professors and classmates.

In terms of external accommodations, participants exhibited varying degrees of comfort with seeking assistance from others. According to Section 504 of the Americans with Disabilities Act (ADA), schools that receive Federal financial assistance are required to provide certain services to students that qualify as disabled. Schools are required to meet the individual educational needs of students with disabilities by providing them with “appropriate academic adjustments and auxiliary aids and services that are necessary to afford an individual with a disability an equal opportunity to participate in a school’s program” (Office for Civil Rights 20011). Despite the ADA requirement that disabled students receive assistance in the classroom

if they request it, when asked about their experiences using disabilities services at their schools, responses from the participants suggested that seeking assistance from disabilities offices requires several decisions. First, the hard of hearing person must decide if they even want to go to the disabilities office to register. Second, the individual needs to decide whether or not to use the services. Finally, the hard of hearing person must decide how to manage having visible or invisible accommodations in the classroom. As participants demonstrated, it is easy for a hard of hearing person to get stuck at any one of these stages.

In the first stage, participants said either that they did not register with the disabilities office because they did not think that they would benefit from services or that they only registered with the office because someone else told them they had to register. Seven participants had not registered with disabilities office when they were in school or were not currently registered. Lindsay (18, WF, A, 7) and Chris (22, AM, A, 20) both felt that their hearing loss did not affect them in school so they felt no need to register with the disabilities office. Diana (26, AAF, H, 14) said that her hearing loss does not “really affect [her] performance” in school. She has not registered with the disabilities office at her graduate school because she believes “there’s little accommodations...that can be done to really help me.”

Of the twelve participants that had registered with a disabilities office, three said that their only reason for registering was because someone else had told them to register. Charlotte’s (21, WF, C, 2) audiologist suggested she register with the disabilities office her freshman year of college because her hearing loss might make “the adjustment to big lecture halls...difficult.” Although she is registered, Charlotte has “never used any of their services” because she can make all the necessary accommodations she needs on her own. Rachel’s (21, WF, C, 2/3) “parents kind of made” her register. Again, Rachel has never used “any of the services that they

give” in part because she is uncomfortable with asking for accommodations and in part because she is “too stubborn” to ask for help. Chloe (21, WF, APD, 14) said that she registered with the disabilities office her first year of college because her mom “sort of forced [her] into it ‘cause she was really concerned about the class sizes and stuff.” One reason Chloe does not use the services is because she believes she does not “need the help” because she has “managed fairly well” without assistance. Since her grade point average is “really high,” she does not think that any of the available services would help her raise her GPA.

In the second stage, hard of hearing people must decide whether or not to use the services offered by the disabilities office. Some participants said that despite registering, they did not “end up needing” the services once they had gone to their classes and analyzed their ability to hear in each setting (Sophie, 40, WF, A, 21). Other participants explained that they were uncomfortable requesting services. For example, two participants said that they had gone to the disabilities office and had learned about a microphone that they could give to their professors to wear during lectures that would project the professors’ voices directly to their hearing aids. One of these participants, Chloe (21, WF, APD, 14), does not wear hearing aids and thought this option sounded like it would be “embarrassing” and too much of a hassle. The other participant, Rachel (21, WF, C, 2/3), wears hearing aids but also says that she does not “feel comfortable” with this option. Sophie (40, WF, A, 21) raised this point when she explained that she did not use any services when she went to graduate school because she was concerned with how she “would be perceived” by others. Since Sophie was worried at the time that she might not be considered “as competent” as her peers if she needed accommodations in the classroom, she acknowledged that her hesitance to seek help was rooted in “a little bit of the fear of stigma” that the accommodations might induce. According to these comments, there appears to be a

perceived risk involved in requesting disability services since these participants are hesitant to seek help because of how they imagine their classmates or professors would respond to their need for assistance in the classroom. Applying Hochschild's concept of 'feeling rules,' hard of hearing people perform emotion work in order to feel the 'right' amount and type of emotions that society expects in certain situations. Perhaps in the context of accommodations hard of hearing people believe that there is a feeling rule in place that requires them to feel uneasy or embarrassed for being different from their peers with normal hearing abilities.

In the third stage, hard of hearing people must learn how to manage the presence of visible or invisible accommodations in the classroom. While the participants in the second stage avoided using disabilities services because of an assumption that they would be stigmatized, Clair (24, AF, C, 2½) has made it to stage three and uses assistive technologies in class. In Clair's experience, "there's a stigma to having the FM equipment and to having CART services" (see Appendix G for definitions). Although these technologies make learning environments more accessible to Clair, using the CART services in college was a "problem" and "awkward" because her friends would not sit with her in class because "everyone stares at the CART." Thus Clair reflects that,

my friends in college treated me differently but that was mainly because I had the FM unit and the CART services. So it was very in your face.

While other participants avoided using disabilities services because of a fear of stigma, Clair suggests that the stigma is real.

However, Megan (21, WF, A, 19) had a more positive experience with assistive technologies in the classroom. Megan's classmates have asked her about the person who does the typing for the CART services: "do you know who that lady is? Why is she typing the whole class? Why do you sit by her?" Megan's response is, "I can't hear. I need her to get by." Overall,

people “respect” this response and show an interest in the CART machine. For example, when Megan had a class with one of her best friends, the friend loved “watching what the girl types. Like, she thinks it’s so cool, like, when she mentions her name or, like, my name.” Positive reactions like these suggest that, while the stigma of hearing loss and assistive technologies exists, it might be reduced if hard of hearing people are able to share their experiences and explain the accommodations they require to hearing people.

Participants also addressed their discomfort with disabilities services when they explained that they do not tell other people that they use those services. Jen (22, WF, A, 14) has note takers in some of her classes but she does not tell anyone about her note takers because she “feels bad” about using disabilities services. Jen is afraid that others will think she is “abusing the system” or “cheating.” Such accusations suggest that Jen is using a service that she does not “really need” when, in reality, Jen benefits from these reasonable accommodations. Tyler (30, WM, C, 0) also does not talk about his hearing loss or his use of disability services unless his inability to hear requires that he seek help. For “extra support” in his classes, Tyler will “use” his hearing loss to get the necessary accommodation so that he does not miss what the rest of the group is hearing. Although he has a valid reason for needing help in certain academic settings, Tyler worries that others might think he is “milking the system.” Although neither Jen nor Tyler allow their concerns to keep them from seeking out disabilities services, perhaps these fears prevent other hard of hearing people from seeking assistance.

Some participants made positive comments about disabilities offices. The services are “really awesome” (Tyler, 30, WM, C, 0) and “so beneficial” (Megan, 21, WF, A, 19) because they allow participants to understand their classmates and teachers. Will (33, WM, A, 8) did not receive accommodations in school, which is a “big thing that upsets” him. In Will’s school,

another boy had both hearing aids and an interpreter. Will regrets that the school never had him learn sign language so that he could have benefited from the same accommodations as the other hard of hearing boy. Despite the stigma associated with the services offered by disabilities offices, accommodations are appreciated by the hard of hearing people who use them.

The second factor that hard of hearing people must manage in a classroom setting is whether or not they will disclose their hearing loss to their peers or teachers (for more discussion on disclosing, see the section in “Managing a Hard of Hearing Identity”). Disclosure is one technique of “information management” that discreditable people use (Goffman 1963:95). Goffman (1963) says that while those with visible stigmas, or *discredited* people, develop consistent routines in order to gain some acceptance in social interactions because constant exposure to the stigma will make others less surprised by it, *discreditable* people (those whose stigmas are invisible but might become visible in the future) constantly manage information about themselves in their interactions in order to either hide or share their stigmatized identity. But disclosure is more complicated than simply telling another person that one has a stigmatized identity: disclosure causes strain and requires both emotion work and unobserved labor on the part of the discreditable individual. As the participants’ responses indicate, their decisions to disclose their hearing loss involve complicated analyses of, for example, the people or the situation. Seven participants said that they generally do not tell anyone about their hearing loss in a classroom setting while ten participants said that they did. Three participants did not discuss disclosing hearing loss in a classroom setting.

The participants that *do not* disclose their hearing loss in class consistently suggested it just was not important for them to tell others. Participants made comments like, “I don’t really tell people,” “I just deal” (Clair, 24, AF, C, 2½; Diana, 26, AAF, H, 14). Chris (22, AM, A, 20)

simply says, “no,” and Lindsay (18, WF, A, 7) says that she does not disclose because her hearing loss is not a “problem” that needs accommodating. When Chloe (21, WF, APD, 14) was younger, she asked her teachers for help when she did not understand something. But Chloe’s college classes are recorded so when she misses something she can listen to the lecture on her own rather than ask her professors for help. Technological advances mean that Chloe no longer needs to disclose to her teachers. Sophie (40, WF, A, 21) is a professor so she considered this question in terms of whether or not she discloses to her students. In the past, Sophie “tried” disclosing to her students but “wasn’t sure that it really made any difference” so now she does not tell them. Charlotte (21, WF, C, 2) does not disclose “unless it comes up.” For classes on human anatomy, Charlotte has “mentioned” her hearing loss “in passing.” Generally, if the hearing loss does not affect the individual in a classroom setting, it will not be disclosed.

Ten participants said that they disclose their hearing loss in classroom settings. These participants “always” tell “all” of their professors (Jen, 22, WF, A, 14; Lynn, 34, AF, ?, 14; Megan, 21, WF, A, 19). Certain participants exhibited comfort with their hearing loss because they will “just tell” their professors because they are “pretty quick to share” their hearing loss with others (Fiona, 26, WF, C, 5) or because it does not “bother” them to talk about their hearing loss (Will, 33, WM, A, 8). Other participants indicated that it is “important” (Lynn, 34, AF, ?, 14) for them to be “upfront” with professors about their hearing loss (Kevin, 26, AM, A, 1; Rachel, 21, WF, C, 2/3). Rather than waiting until other people discover the hearing loss on their own, participants like to make their professors “conscious” of their hearing loss (Rachel, 21, WF, C, 2/3) because then the professors can make certain accommodations, like speaking more clearly. Kevin (26, AM, A, 1) believes that disclosing rather than letting people find out on their own makes others more likely to “treat [him] as a normal person.” Brian (31, WM, H, 8) and

Tyler (30, WM, C, 0) provide the perspectives of a teacher and graduate student instructor, respectively, disclosing to students. For both Brian and Tyler, their hearing loss is “one of the first things” they talk about in the classroom. Brian explains that in the classroom, it is important to be able to “communicate and ask questions,” so he and his students must “figure out a way” to make the classroom into a conducive learning environment via patience on the students’ part and the use of assistive listening devices on his part. Tyler added to this point: he discloses to his students in part so that they know if he needs them to repeat something multiple times, he is “sorry” but that they are going to “have to deal with it.” Overall, the participants’ responses suggest that disclosing is about both creating an academically productive space and providing a reason for why the hard of hearing person exhibits certain behaviors.

The third factor hard of hearing people must bear in mind in an academic environment is how much and what types of outside work they have to perform in order to be academically successful. For example, participants explained that they often found themselves working harder than their classmates in order to gather the same amount of information that their hearing peers received effortlessly. Most of the other graduate students in Lynn’s (34, AF, ?, 14) program are hearing, which means that “whatever the professor is going to be saying up there, they’re probably going to get it before I do.” In addition to delayed information, Kevin (26, AM, A, 1) says that listening to classmates or professors “can be a little bit trickier for me than others who...don’t have to spend as much energy trying to get the same...information.” Not only do hard of hearing people have to work harder to hear the information, but they sometimes miss valuable comments from professors. Diana (26, AAF, H, 14) sighed as she recounted a moment when her inability to hear affected her academically: when a professor,

would explain things on the test and I would miss out on clues that they had given because...I would miss words...And I remember, particularly, taking a final and,

umm, the professor had said something and he said, *Well, I warned you guys to focus on blah blah blah*, you know? ‘Cause I went to him afterwards and I said, *Well, I didn’t know you wanted us to*, like, *blah blah blah blah* and he said, *Well, I told you guys before the test*.

Since Diana sometimes misses what her professors say in class, she says she must work harder to ensure that she is prepared for the examinations.

In addition to deciding whether or not to disclose, another form of extra work that hard of hearing people perform is the actual process of disclosing their hearing loss to their professors outside of class. Although disclosure has many benefits, it is time-consuming. Lynn (34, AF, ?, 14) meets with every professor to “have a chat, tell them what [accommodations] I need,” and to give the professor her letter of accommodation. Lynn says that she is “always running” to meet with professors to explain her hearing loss and subsequent needs. Lynn meets with her professors more than once, offering to “step out for fifteen minutes” or “run over to the other building” to ensure that they understand. For Rachel (21, WF, C, 2/3), the extra work she performs in disclosing her hearing loss is “tedious”:

it’s not necessarily hard *work* to listen in conversations or to try to listen in class discussions, but it’s just more *tedious* because you have to go and talk to your GSI, letting them know that this is not the ideal situation.

For example, when a teacher calls on her in class and she cannot hear the question, Rachel feels “just awful” and, to make up for her embarrassment, she goes to her professors’ or GSIs’ office hours at a later date to explain to them that, “I froze ‘cause I had absolutely no idea what you said to me” because of her hearing loss. Rachel puts in the extra work of meeting her teachers outside of class to prevent them from making assumptions about her in class.

Although the participants were not conscious about it, managing oneself and one’s reactions in the classroom is another form of extra work that hard of hearing people perform. While talking about disclosure, Rachel (21, WF, C, 2/3) said that she tends to “withdraw” during

class because she does not know “what everyone’s saying.” This leads her not to talk in class because, “I don’t know if I’m saying what [another student] said.” Likewise, Jen (22, WF, A, 14) began to slightly rock back and forth in her chair as she said that she tells her professors about her hearing loss because she would find it very “embarrassing” to repeat something in class that a peer had already said. Tyler (30, WM, C, 0) said that he discloses his hearing loss to his students because he worries how students would react if he asked them to repeat multiple times in a class period without knowing about his hearing loss. These three participants want to make their teachers or students aware of their hearing loss in order to prevent the other individuals from making assumptions about them if they behave ‘abnormally.’

Participants also described working harder in order to do well academically. Kate (26, WF, C/A, 6) said that she is an “educated” and “driven” person because her hearing loss made it so that she has “always had to work harder in school.” Lynn (34, AF, ?, 14) slumped on to her desk when asked how hard she worked compared to her peers and said, “I have to work so hard,” mainly because, “I just want to pass the class.” Lynn believes that people with hearing loss (and other disabilities) work hard to “live [and] function normally” and, in the process, work “a lot, lot harder” in order to “compete with the regular people.” For example, Lynn compared her hearing loss to taking a class in a different language. Whereas her hearing classmates listen to a professor lecture in their ‘native language,’ Lynn has to make a greater effort to listen in class because the professor is, essentially, lecturing to her in her second language. Lynn’s peers do not have to work as hard as she does in class because she is struggling to overcome the barrier that her hearing loss creates. When Chloe (21, WF, APD, 14) does not “hear something in class,” she spends extra time reading her textbook or re-watching the lecture (if it is recorded) in order to figure out what she missed. While her hearing peers will also put in the time to listen to lectures

again, Chloe relies on these recorded lectures in a way that her hearing peers do not. Hannah (30, WF, H/C, 6) also spent extra time outside of class to learn the material she was supposed to have learned in class, but Hannah relied on her friends for help. While she did learn from listening to her teachers, Hannah said that a lot of the time she was “hearing wrong.” After class, Hannah “relearned things when my friends and I were talking.” Hannah’s friends learned directly from the teacher whereas Hannah often had to learn the same information secondhand through her friends. This led Hannah to not “feel as smart” as her friends throughout her years in school.

Fiona (26, WF, C, 5) also described how hard she had to work, not only in individual classes, but in order to graduate from college. Although Fiona thinks she is not “unique” because everyone has some difficulty that they must overcome in order to be successful, she does feel that it “was much harder” for her to receive her college degree because of her hearing loss. The college wanted Fiona to fulfill the language requirement with three semesters proficiency in a language, which would have included situations that are “difficult” for Fiona, like conversations with her classmates, group projects, and online videos. Fiona tried to exempt herself from the language requirement because she knew that she would not be able to meet it. The college did not consider her request and Fiona thought she would never “graduate from college because of [her] ears.” Fiona did succeed in getting a degree, but,

I had to fight for a really long time. And I think in that regard...it was kind of the first time I ever felt discriminated against for my hearing.

Before her senior year of college, Fiona believed that, “if I worked hard, I could make up for [my hearing loss] and everything would be fine.” But since it took “way too much work” for Fiona to receive her college degree, she realized that, “I do have to work harder” than hearing peers.

Overall, the academic environment demands a great deal of labor from a hard of hearing person. In order to physically manage hearing loss in a classroom setting, individuals must

analyze where they should sit in the classroom, how the size of the class will affect their ability to hear, and how different teaching styles can help or hinder how much they hear in class. The emotional labor that hard of hearing people perform includes deciding how comfortable or uncomfortable they are with registering with a disabilities office, using accommodations, managing visible or invisible accommodations in the classroom, and disclosing their hearing loss to their peers and/or to their teachers. Due to the stigma of hearing loss and the public nature of the classroom setting, hard of hearing people must decide whether to keep their hearing loss hidden and thus remain discreditable individuals, or to disclose their hearing loss and become discredited individuals. In the process, they manage their private feelings in order to create a public emotional display that might be at complete odds with their true feelings. The emotional management performed by hard of hearing people is further explored in the following section about the effect of hearing loss on social interactions.

Social Networks

In addition to making numerous decisions regarding their hearing loss within academic environments, hard of hearing people learn to manage hearing loss in all of their social interactions. Participants varied in terms of the effect they believed their hearing loss has on their willingness or ability to socialize with others. Participants said that hearing loss did not affect their social life, that it could be beneficial in some social settings, that they tried not to let it influence socializing, or that it did strain their social behavior.

First, most participants rejected the idea that their hearing loss posed any barrier to socializing. These participants shook their heads and simply explained that their hearing losses do not impede their ability to socialize (Charlotte, 21, WF, C, 2; Tyler, 30, WM, C, 0; Lindsay,

18, WF, A, 7). For example, Kate (26, WF, C/A, 6) says that she is generally a reserved person but has become “more social with co-workers, and my hearing loss hasn’t interfered in this.” Participants say that their hearing losses do not “prevent [them] from going” out to socialize (Steven, 26, WM, A, 5) because they “just go anyway” (Chris, 22, AM, A, 20) despite the hearing loss.

Second, participants described the benefits of hearing loss either in terms of the usefulness of assistive hearing technology or in terms of how hearing loss affects their relationships with others. Charlotte (21, WF, C, 2) says that “the good thing” about her “newest technology hearing aids” is that they are advanced enough to “block out” background noise. Although she still has some trouble in crowded restaurants, Charlotte does not feel that her hearing loss affects her ability to participate in conversations because her hearing aids help her focus on the relevant voices. Tyler (30, WM, C, 0) explains that when social settings get too loud, he can turn off his bone-anchored hearing aids. Tyler appreciates the “freedom” or “power” to turn the “noise on and off.” In terms of relationships with others, Lynn (34, A, F, ?, 14) believes that her hearing loss helps her develop “better” friendships. Since Lynn does not hear well in groups, she meets up with each of her friends on an individual basis. These one-on-one activities allow Lynn to get to know her friends’ personalities better, which leads her to feel “closer to them.” While her difficulty hearing in larger group settings means that Lynn has to put “more effort” into her friendships, Lynn thinks her hearing loss ultimately benefits her relationships.

Third, participants responded that they *tried* not to let their hearing loss prevent them from socializing. For example, Kevin (26, AM, A, 1) says,

when I do social events, I try not to let it influence my decisions because I like spending time with friends. So that became more the primary driving factor. Like, *who am I meeting with* as opposed to, umm, *does that person speak well?*

Although he knows he will find it difficult to hear in loud, public spaces, Kevin dislikes letting those considerations influence his willingness to go out. However, other participants admit that their hearing loss influences their socializing to some degree. Participants said that having a hearing loss did not change whether they attended social events; but rather it “changes *when I go*” to social events (Jen, 22, WF, A, 14). Sarah (30, WF, A, 23) elaborates that her hearing loss does not “put a limit on” where she is willing to go to socialize, but it “does limit the type of conversations” she has in each setting. Even studying poses problems: since Megan (21, WF, A, 19) has tinnitus, which causes constant ringing in her ear, she cannot focus in specific environments such as “silent rooms” because she struggles to ignore the ringing and concentrate on her homework. When her friends pick a place to study, Megan often asks them to “pick a different setting” because she cannot “focus” in the places they suggest. Thus hearing loss does not “necessarily stop” a hard of hearing person from meeting up with others, but it does make them “think twice” about going out if they know they will not be able to hear well (Hannah, 30, WF, H/C, 6).

Fourth, several participants acknowledged that hearing loss can be a social barrier for them. These participants felt that hearing loss affects “everything” (Lynn, 34, AF, ?, 14). While these participants said that their hearing loss does not affect their willingness to go out and socialize with people, “there are certain contexts that I don’t like to put myself in” (Fiona, 26, WF, C, 5). Most participants said that they tried to “stay away from” certain locations because they were “loud” or “noisy,” “crowded,” or prone to lots of background noise that can be a “nuisance” (Jen, 22, WF, A, 14; Kevin, 26, AM, A, 1; Charlotte, 21, WF, C, 2; Will, 33, WM, A,

8). Sophie (40, WF, A, 21) further explains that she avoids socializing in these settings because she feels “there’s no point” for her to be there if she will not be able to communicate well with others. Chris (22, AM, A, 20) summarizes the sentiments of the majority of the participants by saying that hearing loss,

is a problem everyday. Every single social interaction is difficult because I have to hear them really, really well.

Therefore hearing loss is an “obstacle” that people must manage in order to make decisions about their participation in many social activities (Kevin, 26, AM, A).

For example, hearing loss becomes an obstacle to being social when it requires hard of hearing people to ask others to repeat themselves continuously. Diana (26, AAF, H, 14) summarizes the sentiments of the participants by saying, “people don’t like to repeat themselves.” After encountering previous negative experiences with asking people to repeat too many times, participants explained that that they learned that it is only acceptable to ask for repetition a limited number of times. While Megan (21, WF, A, 19) gave a vague sense that she asks for repetition until she feels “like giving up on the situation,” other participants had more concrete ideas. The first time Chloe (21, WF, APD, 14) misses something she says, “*Sorry? Excuse me?*” But the second time she will “just smile and nod and, like, walk away.” Diana (26, AAF, H, 14) will ask people to repeat once or twice “if it’s necessary,” but she will not “ask them a third time.” Sophie (40, WF, A, 21) thinks that other people “start getting annoyed” after she asks them to repeat “once or twice.” Hannah’s (30, WF, H/C, 6) comment is especially clear:

I often tell people, umm, you can say “what” three times. You can say it once, you can say it twice, but at the third time it’s no longer acceptable. And I still kind of adhere to that myself.

Based on their previous interactions with people with normal hearing abilities, these participants believe that if they are unable to follow the conversation, it is preferable for them to remain out of the loop than to ask people to repeat themselves more than twice.

Hearing loss is an obstacle because it requires the individual to put in extra work to be able to participate in activities like music and sports. In terms of music, people with normal hearing can usually listen to a song and pick up some of the lyrics. Listening to the radio allows hearing people to partake in a shared culture with their peers. Hard of hearing people, like Fiona (26, WF, C, 5), might not listen to the radio because “there are so many words [they] don’t know.” In order to connect with her peers, Fiona either buys CDs or checks them out from the library and then looks up the lyrics. Similarly, Will (33, WM, A, 8) grew up without knowing song lyrics. He enjoys music more now that he can “actually sit there and look up the lyrics to the song” on the Internet. Whereas hearing people can learn songs after listening to them, Fiona and Will both have to look up the lyrics to make sure that they learn the words.

In terms of sports, hearing loss forces participants to make accommodations on a daily basis. Kevin (26, AM, A, 1) extols the health benefits of swimming but describes the sport as a “hassle” because his hearing aids require him to,

take off the hearing aids, put them in a locker, and then take Q-tips, dry out the ears to remove excess water and then put the hearing aids on.

Charlotte (21, WF, C, 2) makes a similar statement and then indicates that she considers the extra time she spends protecting her hearing aids from short circuiting due to water or sweat to be the most difficult part about playing water polo and Ultimate Frisbee with a hearing loss. Charlotte is very aware of the weather during Frisbee because in wind, rain, or snow, she says she must:

make sure my ears are covered so that they stay drier. So that’s, like, an additional layer of padding or sound proofing, if you will. Or, like, if I’m wearing a hat or hood or anything like that, umm, I’ll have trouble with hearing, like, line calls.

While physical activities can be managed despite having a hearing loss, hard of hearing people have extra factors they must consider while playing sports.

Hearing loss can be an obstacle if the extra effort that hard of hearing people expend in social situations frustrates them to the point where they cancel plans. If, at the end of the day, Clair (24, AF, C, 2½) feels tired, she often does not “want to go to hang out with people because then it takes so much effort to be able to hear.” Sarah (30, WF, A, 23) echoes this sentiment, saying, “there are days I’m already so frustrated by not being able to hear that I cancel plans I have already made.” Additionally, Sophie (40, WF, A, 21) sometimes declines invitations to a “bar-type environment” because she feels it is not worthwhile to show up and not be able to hear. Even when she does attend, Sophie will “just get kind of quiet because...I’m tired of doing it.” Thus before going out, hard of hearing people must weigh their desire to socialize with the realization that they will be putting in a great deal of effort in order to hear their peers. While canceling plans might appear antisocial, in reality it indicates that the physical and emotional labor that hard of hearing people perform can lead to fatigue, inauthentic emotions, and burnout (Steinberg and Figart 1999). The exhaustion that comes from physical labor has already been discussed (see the section, “Focus and Exhaustion”). Emotional exhaustion can occur in the process of managing or suppressing one’s true emotions in order to appear to others in the appropriate or expected manner (Van Maanen and Kunda 1989). Not only does the management of hearing loss physically exhaust hard of hearing people, but it takes a toll in emotional exhaustion as well.

Another obstacle that hearing loss presents for hard of hearing people in social activities is the feeling of isolation. Chloe (21, WF, APD, 14) explains that the,

most annoying part is just when I'm out at, like, a bar or something and I cannot hear a *thing* anybody else is saying. It's just me with my drink [laughs], trying to follow conversations going on around me. And that's a little...isolating, I guess.

When hard of hearing people begin to feel isolated from others, they tend to embark on one of four courses of action (or inaction). First, participants described making an extra effort to hear, which more often resulted in a great deal of guesswork on their part rather than actually hearing the conversation. Second, participants tried to take control of their feeling of isolation by *actively* isolating themselves rather than feeling cornered by it. Third, participants avoided social interactions to the point of appearing antisocial. Fourth, participants displaced blame for their inability to hear in social settings from their hearing loss onto other factors.

First, one coping mechanism that hard of hearing people use to combat the feeling of isolation is to make up for their hearing loss in social settings by working extra hard to try to hear, faking that they can hear, or adjusting the setting to better suit their needs. Similar to other participants, Sophie (40, WF, A, 21) "dreads" attending functions where there are a lot of people because she knows that she will have to work "really hard" to hear people. In an attempt to follow conversations in, for example, crowded restaurants, Sophie tries to "guess hear" people sitting next to her. Sometimes *guessing* the conversation rather than *hearing* and *comprehending* it can be successful, but it is more often just tiring and stressful for a hard of hearing person.

When they know they are missing parts of the conversation despite making the effort to keep up, many hard of hearing people resort to faking that they are following the conversation.

As Sophie further explains:

one of the things that I really struggle with is, umm, when I don't hear fully what someone says, it's like, what percentage of it can I fill in? Like, at what point should I ask them to repeat? Umm, so I think sometimes I'm not fully hearing what someone is saying and pretending that I have.

The act of *pretending* is common among hard of hearing people. When Chloe (21, WF, APD, 14) starts feeling overwhelmed by her inability to keep up with conversations, she will “just try to be happy and be really loud to make up for it.” In situations where she finds it hard to have a conversation with people, including bars or house parties, Jen (22, WF, A, 14) will start “yelling at people so they know to speak up to me.” When they talk loudly, others will respond loudly, which allows hard of hearing people to pretend that their hearing loss is not problematic in the social setting.

In addition to working hard to hear or to fake that they can hear, participants described other ways in which they exerted extra effort in social situations. Although she firmly believes that her hearing loss does not inconvenience her at all, Charlotte (21, WF, C, 2) says that if she hears other people in her house after she wakes up or gets out of the shower (two activities during which she does not wear her hearing aids),

my first beeline will be to put my hearing aids in and then come join the whole group...I'll make sure to put my hearing aids on first and then I can come out, rather than just, like, walk right out of my room.

Hard of hearing people who wear hearing aids have to remember to take the extra step of putting on their hearing aids before engaging in social activities. Although this seems like common sense, it is rather easy for people with a mild or moderate hearing loss to forget to put their hearing aids back in before talking to people. For example, if hard of hearing people prefer to take out their hearing aids while doing homework, they might have to fetch them if someone strikes up a conversation. Thus hard of hearing people must get up, retrieve the hearing aids, and put them in before conversing. Although this expends minor amounts of energy, it is still something that hard of hearing people who wear hearing aids must do in order to socialize.

Extra effort can also manifest in how hard of hearing people situate themselves and others in social settings. In trying to prevent their hearing loss from influencing their social lives, participants paid more attention to their “placement within the social setting” (Megan, 21, WF, A, 19). When they feel comfortable with the group they are with, participants try harder to position themselves and their friends in a way that allows them to hear better. Fiona (26, WF, C, 5) explains that such positioning also has to occur when she goes for car rides with her family:

if I am not in the front seat, I don't know what's going on. Because everybody's voices go forward in the car. Umm, cars, I hate cars...I can't hear anything, there's all this background noise. If I'm not in the front seat, I don't know what's going on. I can't have a conversation. It's not fun for me.

Although her siblings want to rotate who gets to sit in the front seat, Fiona always tries to sit in front because the back seat isolates her from the conversation.

Since group gatherings can be difficult, hard of hearing people often turn to one-on-one social activities. Several participants made remarks such as, “one-on-one relationships are my strength” (Fiona, 26, WF, C, 5). Lynn (34, AF, ?, 14) gestured to a picture on her wall of her with a large group of smiling women and said that although she does not “function in a group with them,” she meets up with each of them individually. Pointing to each friend, Lynn explained what she did with each: one she meets in Chinatown for lunch, one she goes to the gym with, one she walks around Copley Plaza with, etc. But meeting each friend individually is a time commitment because Lynn has to set up one-on-one meetings with each friend in order to accomplish what her friends can do as a group. Most of Lynn's hearing friends prefer large group gatherings because they think they do not “have the time to do, you know, individual stuff.” But since hard of hearing people cannot always follow group conversations, they must take the time to meet up with friends individually in order to develop meaningful relationships.

The second course of action that participants described is one of actively isolating themselves. Rather than struggle with the frustration of trying hard to hear the person sitting next to them yet still being unable to hear, isolating themselves from others gave participants a sense of control. In settings where it is difficult to converse because of the number of people and/or the loud music, participants' behaviors can be characterized as "doing my own thing" (Jen 22, WF, A, 14). At house parties, Jen will go dance with her friends rather than try to socialize with others. Similarly, Chloe (21, WF, APD, 14) says that she avoids "those typical college parties where the music is really loud" because it is too hard to try to follow the conversations. Chloe describes a moment early in her college experience when she and her friends,

went to a club for, for frosh week and there was this one guy and, like, I was trying to talk to him and I, I had no idea what his name was, I had no idea what program he was in, and I was just like, *I'm just gonna go dance over here now.*

Chloe's story illustrates situations that many hard of hearing people experience. Chloe tried to hear what this boy was saying but when she found that, despite her effort, it was impossible to either truly understand or fake an understanding of the conversation, she went off to 'do her own thing' so that she could feel like she had some control over the situation.

A third method of coping with hearing loss in social settings is to engage in avoidant behaviors. Sophie (40, WF, A, 21) says that because she often feels isolated from group conversations, she tends to "shy away" from attending social functions because she feels they are "not really that worthwhile because it's just such a strain to be there." Hannah (30, WF, H/C, 6) says her hearing loss makes her "think twice" about social gatherings because she will not be able to "hear that well" or "communicate with other people the way I want to." Hannah thinks it does not "always feel so good" to return home after socializing with others because she felt "bored, kind of twiddling my thumbs, because I couldn't follow what was going on."

While Sophie and Hannah represent those who question why they socialize but still engage in social activities, other participants described much more avoidant behavior. Brian (31, WM, H, 8) says that he does not “seek out” or “initiate” opportunities to socialize with his friends, but rather will only go out if his friends invite him. Similarly, Will (33, WM, A, 8) does not “care for social interactions” and prefers to “stick by myself” or spend time with his wife and children. At face value, such comments suggest that both Brian and Will are antisocial and make little effort to interact with others. However, as they continued talking, it became apparent that Brian’s and Will’s avoidance of social settings was a defense mechanism.

Brian (31, WM, H, 8) is “not enthusiastic about phone conversations with people,” which is a common sentiment among hard of hearing people. During in-person conversations, the hard of hearing person can try to read facial and body language to pick up additional cues about what the other person is saying. Over the phone, one must rely entirely on one’s ears. Although general phone conversations might be manageable, Brian says that he especially worries about phone conversations that get “serious or important” because “it’s just not good” to “miss something” in those situations. For example, before Brian’s mother got cochlear implants, he felt that his phone calls with her,

progressively got more and more superficial because you felt like you couldn’t have, like, deep conversations, necessarily, because, umm, it wasn’t clear what would be communicated...

Thus, even with his mother, Brian feels that phone conversations can sometimes be more stressful than they are worth.

As another example, when Will makes phone calls, he often uses a teletypewriter (TTY) (see Appendix G for a definition), which means that a relay operator will type out whatever the other person says so that Will can read it rather than hear it. Will likes the TTY because it allows

him to communicate more effectively but he has found that many people hang up on him because they do not like the delay between what they say and when it appears on the screen for Will to read. Similarly, people get frustrated with Will in-person. He says,

I've had people, you know, where I've had to ask them two or three times to repeat themselves and they're like, *You know what? Just never mind.* And they walk away.

Such interactions can negatively impact on a hard of hearing person's desire to socialize.

In addition to avoiding directly interacting with others, several participants described how hearing loss has led them stop participating in activities they used to love. Megan (21, WF, A, 19) describes with frustration how she “used to *love* sitting, hanging out with six friends, watching TV, talking, blah, blah, blah, gossiping” but that her hearing loss prevents her from accessing these situations now. Megan “physically *cannot* handle those situations” because everyone is “talking louder than the next one” and she cannot keep up with her friends. Although she still participates in these social situations, Megan does not always enjoy them as much as she used to because she gets frustrated. Brian (31, WM, H, 8) stopped attending concerts because he cannot “enjoy” them anymore since all he can think about during a concert is, “I’m damaging any residual hearing that I have...this is ridiculous.” The problem is not that Brian cannot hear the music but rather that going to a concert is no longer “fun” since he has to make accommodations in an effort to protect his hearing, such as wearing earplugs. Brian’s fear of losing his remaining hearing led to an “unfortunate” lifestyle change since Brian and his wife no longer go to concerts together. Similarly, Will (33, WM, A, 8) says that his hearing loss has led him to make several lifestyle changes over the years. Will no longer hunts because he “can’t hear the animals in the woods.” He also has not “had much of an interest in sports” because the “noise” level prevents him from enjoying the games. Additionally, two participants say that their

hearing loss interferes with their ability to travel. Lindsay (18, WF, A, 7) says that since flying in airplanes is “painful” for her ear, she is not going to be “the first one to go on a plane to go somewhere.” Kate’s (26, WF, C/A, 6) ears do not “function” on airplanes because they do not “pop with the change in pressure,” so her hearing loss has “effected traveling,” but she still goes on vacations.

The fourth action that hard of hearing people take to cope with their feelings of isolation in social settings is to rationalize that a factor other than their hearing loss is either the primary reason or a contributing reason to their inability to hear while socializing. For example, while participants said they had difficulty hearing in settings with “loud music playing in the background, drinks clinking all over the place, and people talking” (Kevin, 26, AM, A, 1), they argue that, “in those situations, though, other people are having trouble hearing” (Charlotte, 21, WF, C, 2). This suggests that hearing loss is not the problem in settings where participants cannot hear because no one else can hear. On the other hand, one reason why Lynn (34, AF, ?, 14) wants to spend more time with hard of hearing people is because of the shared experience of struggling to hear in social meeting places. Contrary to Charlotte’s point, Lynn’s hearing friends “don’t get it” because they do not have a hard time hearing in restaurants. Thus Lynn wants to be able to commiserate with a hard of hearing person. Perhaps Charlotte’s and Lynn’s comments can be combined to suggest that all people have difficulty hearing in noisy situations, but hard of hearing people are more aware of how much harder they have to work in order to hear.

Another rationalization tactic that hard of hearing people employ is to feign disinterest in participating in any situation in which they cannot hear. Rather than admit frustration (or any other emotion) at being unable to hear in a certain social setting, some participants said that they

were actually not interested in whatever it was that they were missing. Steven (26, WM, A, 5) says that if he has a hard time hearing people, he asks them to speak up. He explains,

When I tell them to speak up, if you have a problem with it, then don't talk to me. You know? It's not worth my time to try to listen to you if you're not gonna, you know, understand the fact that I have a hearing loss problem.

Steven acts like he would prefer not to talk to anyone if he is unable to hear what is being said.

Similarly, although Fiona (26, WF, C, 5) says that her hearing loss has made her miss out on many activities that her peers engage in, she suggests that she was better off for not being able to participate in those activities. Fiona describes herself as “so out of the loop with the culture” of her peers because she does not regularly watch television or listen to music:

I think that there's a lot of stuff that I don't know what's going on. And I don't know that I ever will. Umm, the culture of television [laughs]. I mean, it's probably not the best part of American culture but, I mean, it's certainly something that people talk about, and then I, I feel really left out. And, and that's a...bummer, that it's like that. It's not a big deal, I guess, but it's just...I mean, it definitely influences some things...but...I don't think it's bad to be so out of the loop with television...I actually don't think that that's something bad at all.

Although Fiona is sad and frustrated at being unable to participate in her peers' culture, she rationalizes her feelings by telling herself that, for example, reading books is better for her than watching television. Fiona maintains that her hearing loss does not prevent her from “doing too much;” rather, it prevents her from doing “certain things that I'm not interested in.” As Steven and Fiona demonstrate, hard of hearing people work hard to convince themselves that whatever they cannot hear is unimportant or that they benefit in some way from not being able to hear.

Hard of hearing people must manage their hearing loss across all of their social networks. Whether or not they believe hearing loss impacts their social life, hearing loss can be an obstacle in terms of asking others to repeat, performing extra effort to participate in the same activities that one's peers enjoy, making one so tired that one cancels social plans, and fostering a sense of

isolation from one's peers. Rather than simply enjoying socializing with others, hard of hearing people must constantly analyze and reanalyze the setting and the people they are with in order to determine which strategies, including pretending to hear or adjusting one's placement in the group, to employ in order to follow the conversation. Thus the accumulation of decisions that hard of hearing people make in order to physically and emotionally manage their hearing loss within all of their social networks can be draining. As the next sections explain, hard of hearing people not only manage having a hearing loss but also must manage having the identity of a person with a hearing loss.

MANAGING A HARD OF HEARING IDENTITY

On top of the labor that hard of hearing people exert in order to adjust to and manage their hearing loss, the third area in which hard of hearing people perform additional work is in managing their identities as individuals with hearing loss. Managing the disclosure of hearing loss requires complex decisions and actions. Strategies for distancing oneself from identifying as hard of hearing include displacing blame from one's hearing loss to one's body and personality or dismissing one's hearing loss as minor. But these strategies do not always serve their protective duties when applied to how participants view their hearing loss or how they feel about disability. Questions about dating and the future elicited both the comfort level and the fears that participants have about living with a hearing loss.

Disclosure: Scripts and Reasons

Maintaining control over information about a stigmatized attribute is a way for individuals to manage their identities. Although participants casually discussed how they

disclosed their hearing loss, their responses indicated that the process of disclosing is highly scripted and planned in advance. Even if participants did not usually disclose, they knew what a disclosure script entailed. For example, Clair (24, AF, C, 2½) says that she has never had a “*I’m hearing impaired, this is what you need to know*” discussion.” Sarah (30, WF, A, 23) tells people, “*I’m having a hard time hearing you*” and then points “to my right ear to let them know I can’t hear out of that ear.” Sarah adds that she “would never say something like, “*Well, I’m 35% deaf in one ear.*” Thus certain kinds of disclosure scripts are recognized as acceptable while others are not. Hard of hearing people might use different scripts in different settings, suggesting that disclosure scripts are formulated to serve a certain purpose for the hard of hearing person and the audience. The scripts that the participants used to disclose their hearing loss fell into certain categories depending upon the reason the participants had for disclosing: help-seeking, avoiding negative impressions, asserting normalcy, or making the information easier for the other person to receive.

First, participants commonly disclosed their hearing loss in order to seek help. Participants varied in the importance they assigned to disclosing their hearing loss, but they acknowledged that “if you are clear about your needs” (Brian, 31, WM, H, 8) and make other people “aware of the situation” (Diana, 26, AAF, H, 14), people will be more willing to try to make accommodations. For example, Brian (31, WM, H, 8) says that he “ideally” tells people,

I have hearing loss. If I can’t see your mouth I have... a lot of trouble hearing you.
So I’ll read your lips if you speak clearly. You don’t have to speak loudly but if you speak clearly that helps me understand you.

Chloe’s (21, WF, APD, 14) script includes saying, “*I’m really sorry, I’m really deaf. Can you repeat that, like, really slowly for me?*” Chloe will not immediately disclose her hearing loss but she is comfortable telling people when it will help her. Similarly, Steven (26, WM, A, 5) asks

people to “kinda speak up” when talking to him so that “they can actually talk to me instead of me saying “*huh?*” all the time.” When Megan (21, WF, A, 19) discloses, she begins with,

oh yeah, you know, I can't hear. And they're like, what? And I'm like [deep breathe], I have no hearing in my right ear and, like, I can't hear you so, like, talk to me in my left ear.

Although Sophie (40, WF, A, 21) prefers not to disclose, if she is sitting in a location where she is unable to hear, she summons the “strength” to say, “*I have a hearing loss, like, can I sit here instead?*” As much as she dislikes informing people that she has a hearing loss, Sophie sometimes discloses when she knows it will help her interact better. Hard of hearing people create scripts like these to use when disclosing their hearing loss in order to maximize the likelihood that the disclosure will result in helpful accommodations.

Even when participants disclose their hearing loss, people often do not “go out of their way” (Will, 33, WM, A, 8) to assist them, the accommodations that are made often are not “helpful” (Diana, 26, AAF, H, 14), or people will make changes but then forget as the conversation progresses because they do not “consciously think” about how to keep hard of hearing people involved in the conversation (Chris, 22, AM, A, 20). However, participants *have* benefited from the accommodations that result after disclosing their hearing loss. Will (33, WM, A, 8) says that people will often “speak up” or employers will “try to make stuff louder” by providing him with phones that have high volumes. Kevin’s (26, AM, A, 1) roommate in graduate school did not immediately notice his hearing aids, but Kevin told him,

I take them off at night so I can't really hear you unless it's really loud...so if there's a fire alarm or something like that, just let me know.

In this example, disclosing his hearing loss to his roommate ensures that Kevin will be alerted in case of an emergency.

A second reason why hard of hearing people disclose or feel that they should disclose their hearing loss is to avoid giving people a wrong or negative impression of themselves.

Participants feared that because they could not always hear the conversation, other people might think that they were not paying attention. For example, Rachel (21, WF, C, 2/3) says that,

people perceive that if...they say a paragraph of words and then you look at them and you're like, *what?* You know? And then they're thinking, like, well...*she didn't, like, pay attention to me. She's rude.* And that's not the case!

Sarah (30, WF, A, 23) also experienced people misperceiving her hearing loss: "people would say, *you're not paying attention.* And I would have to say, *no, I just didn't hear you at all.*"

Hannah (30, WF, H/C, 6) says that others think she is purposefully not "working with" them or "not trying" to participate. Jen (22, WF, A, 14) discloses her hearing loss in classroom settings because she worries that her professors and classmates will think she is not paying attention if she repeats something that another student has already said. Although Charlotte's (21, WF, C, 2) friends know that, "when I'm saying 'pardon' it's not because I'm not listening to them," she knows that "some people would get annoyed with how much I will, like, ask people to repeat themselves."

Participants also disclosed because they worried that their inability to hear might annoy people. Diana (26, AAF, H, 14) does not disclose her hearing loss, yet she worries that people will get "angry with me" if she asks them to "repeat themselves, like, ten times." Steven (26, WM, A, 5) says that the amount of times he asks for repetition "gets annoying" so when people first meet him, they often wonder, "*what the heck is going on with this guy?*" Steven discloses his hearing loss so that others know he has "a problem" but is trying his "best to understand what you're saying. But if I ask you to repeat yourself, then please don't get upset with me." Will (33, WM, A, 8) says that from "an average person's standpoint," his requests for repetition are

“annoying” and that others “get frustrated having to repeat themselves.” Thus Will appreciates that his wife “has a lot of patience” for him.

Additionally, participants struggled against assumptions that they were ignoring people or disinterested in conversations. Rachel (21, WF, C, 2/3) and Fiona (26, WF, C, 5) both worry about coming across as “rude” if they do not respond to people because they cannot hear them.

Fiona provides an example:

there’s times where...I’m walking down the street and there’s a bicycle on the sidewalk...they’re coming and they expect me to know. Or a car’s coming. I don’t hear those things. And, umm, I think sometimes people think, *oh, well that jerk*, or something like that because they really don’t have any idea.

Brian (31, WM, H, 8) discloses his hearing loss because he wants to ensure that others know that “if I don’t respond to a question it’s not because I’m ignoring them.” Sarah (30, WF, A, 23) explains that, “people thought I was ignoring them, that I wasn’t interested in their conversations,” when in reality, she “couldn’t add to the conversation because I couldn’t hear it.” Not only do participants work hard to hear the conversations, but they also must work hard to make sure they do not appear disinterested in their companions.

The final wrong impression that participants feared was of appearing unintelligent. Participants worried that if others did not know about their hearing loss, any mistakes they made because they could not hear would lead them to be labeled as an “idiot” (Brian, 31, WM, H, 8) or “not intelligent” (Sarah, 30, WF, A, 23). Tyler (30, WM, C, 0) makes sure that he always discloses in situations like a “conference presentation” because he worries that he might not be able to hear questions from the audience even if they speak into a microphone. Tyler discloses in this type of setting,

just to explain that *I’m not stupid*, umm, *I just can’t hear you*. Because these academic things, and even in classes...I guess the fear is that if I have to keep asking them to repeat, that they think I’m stupid.

Sophie (40, WF, A, 21) shares this fear. When Sophie discloses her hearing loss, she is not afraid of other people knowing that she has a hearing loss, but rather she is afraid that if she meets new people and discloses her hearing loss that their first impression of her will be negative because they will “perceive [her] as less intelligent or less competent.” While other participants felt they should disclose their hearing loss upon meeting people in order to avoid coming across as less intelligent, Sophie shows that disclosing to people whom she does not know well is concerning because they might make assumptions about her intelligence. Thus hard of hearing people use disclosure of their stigmatized condition as a way to manage the impressions that other people might have of them.

A third reason for disclosing is to assert normalcy. Kevin (26, AM, A, 1) finds that he receives more negative reactions from others if he lets them find out about his hearing loss on their own. But when Kevin explains his hearing loss and hearing aids to people “upfront,” they “become more friendly” and “treat me as a normal person” because they realize that Kevin can “communicate without any major problems.” Fiona (26, WF, C, 5) also appreciates the feeling of normalcy she receives when she discloses her hearing loss. Fiona believes she garners respect from others because she is “proud” of her hearing loss, not “ashamed” of it:

I actually think a lot of guys really respect...the things that I do and how I hold myself out there in so many situations and I don't hear and I put my hair up and I don't care. I have cute earrings and I'll bring it up in passing and, umm, people respect that, actually...I've noticed that guys are actually likes, *that's really cool.*

These participants have found that being open to disclosing their hearing loss makes other people more likely to accept them as normal and therefore not treat them differently.

Finally, participants often joked about their hearing loss in order to make it easier for the other person to absorb the knowledge of the hearing loss. When talking to others, participants

would “make jokes” (Fiona, 26, WF, C, 5) or “try to joke” about their hearing loss (Tyler, 30, WM, C, 0). For example, Tyler tells people, “*I have these crazy bionic hearing aids but sometimes they don’t catch everything.*” Chloe (21, WF, APD, 14) and her friends treat her hearing loss as a joke: when she does not hear something, Chloe’s friends say, “oh yeah, you’re so deaf.” In part, joking facilitates the interaction between hearing and hard of hearing people because it is,

harder for people who don’t have hearing loss to relate and to, to accommodate people who, who are not friendly about their hearing loss. (Brian, 31, WM, H, 8)

In line with Hochschild’s (1983) idea that there are ‘feeling rules’ that govern the amount and type of emotions that people are expected to express in any given situation, hard of hearing people learn that no matter how they actually feel about their hearing loss, joking about the loss makes it “easier” (Tyler, 30, WM, C, 0; Chloe, 21, WF, APD, 14) for both themselves and other people to handle the moment of the disclosure.

Part of managing information about a stigmatized identity requires controlling how and why one discloses the presence of the stigma. The different disclosure scripts that hard of hearing people use in different settings are formulated to serve particular purposes, including maximizing the likelihood that the disclosure will result in helpful accommodations, avoiding negative or wrong impressions, asserting normalcy, and making the presence of the stigma easier for others to receive. In order to comply with feeling rules and thus exhibit those emotions that are deemed appropriate for the setting, hard of hearing people must demonstrate a considerable amount of both communication and human relations skills (Steinberg and Figart 1999) in order to disclose their hearing loss in a manner that they and others consider to be proper. In some cases, however, not telling others about the hearing loss is more appropriate than telling others, an aspect of information management that is discussed in the following section.

Nondisclosure

Despite articulating how they disclose their hearing loss, some participants preferred to keep their hearing loss to themselves. Participants explained that they “don’t really tell” (Clair, 24, AF, C, 2½) or “rarely tell” (Charlotte, 21, WF, C, 2) other people about their hearing loss and that, “If I had my way, [other people] wouldn’t ever be able to tell” (Sarah, 30, WF, A, 23). Even if they know disclosure can be beneficial, some participants “try to get by without anyone knowing” (Rachel, 21, WF, C, 2/3) or they “don’t think [they] have to tell people right away” (Lindsay, 18, WF, A, 7). Participants’ reasons for not disclosing their hearing loss included maintaining a sense of privacy, a belief that they do not need to disclose, and a feeling that other people cannot even tell that they are unable to hear.

First, some participants did not disclose their hearing loss because they wanted to keep that part of themselves secret. Charlotte (21, WF, C, 2) thought it would be “weird” to introduce herself to others with, “*Hi! My name’s [Charlotte]. I wear hearing aids.*” Although this is an extreme example, other participants agreed that it would be unnatural to introduce their hearing loss immediately. Participants described themselves as “private and reserved” (Rachel, 21, WF, C, 2/3) people who do not like “to talk about everything” (Sarah, 30, WF, A, 23). Participants said that they “don’t have a tendency to...self-disclose a lot in general” (Sophie, 40, WF, A, 21). Thus their hearing loss is not a “unique thing” that they keep hidden, but rather “there are a lot of other things” about themselves that they “also wouldn’t tell” to acquaintances (Brian, 31, WM, H, 8). In explaining why they do not disclose, these participants suggested that their hearing loss is just like other aspects of themselves that are out of the “norm” that they do not share with others because they do not want to “draw attention” to themselves (Rachel, 21, WF, C, 2/3).

Second, the decision not to disclose hearing loss also stems from hard of hearing people's belief that they do not need anyone else to know because they can hear well enough. Participants rationalize that they do not need to disclose because they are "pretty high-functioning" and thus can manage interactions without alerting other people that they are hard of hearing (Clair, 24, AF, C, 2½). In academic or work settings, participants said that they "don't need to tell [people] if [they] can get by without telling them" (Megan, 21, WF, A, 19) and thus they will often "just deal with" their hearing loss rather than tell others (Chloe, 21, WF, APD, 14). These participants chose not to disclose their hearing loss because they believe that their hearing loss "doesn't really affect [their] performance" (Diana, 26, AAF, H, 14).

Participants' responses indicated that a third reason for not disclosing hearing loss is because they believe that other people do not recognize that they are interacting with a hard of hearing individual. In considering if people notice their hearing loss, participants felt that "a lot of people don't even know that I have [hearing loss]" (Steven, 26, WM, A, 5). Clair (24, AF, C, 2½) does not disclose because her mannerisms and physical appearance do not suggest she has a hearing loss: her hair hides her hearing aids and people "can't really tell from my speech that I have a hearing loss." Sarah (30, WF, A, 23) asserts that others "would never be able to tell" that she has a hearing loss because she makes "a lot of adjustments" in order to ensure that she can hear. For example, Sarah tries to sit to the right of people (to direct her left, and better, ear towards people) and she talks loud, which "naturally makes other people's responses louder." Thus Sarah believes no one notices her hearing loss because people tend to reflect her behavior, which helps her hear better and, therefore, not need to disclose. Diana (26, AAF, H, 14) says that people do not notice her hearing loss because she does not often ask people to repeat their

sentences: “if I don’t hear it...I just don’t hear it.” While she might ask for something to be repeated once, Diana prefers to “miss out” on the conversation than ask for multiple repetitions.

While these participants believed that they hid their hearing loss well, they also suggested that people might pick up on their hearing loss over time. Clair (24, AF, C, 2½) does not disclose her hearing loss, yet she says that, “most people usually figure it out eventually.” Likewise, Rachel (21, WF, C, 2/3) thinks that people will,

just assume after a while of, like, having to repeat things that I have [a hearing loss]. And I don’t even need to tell them, that they’ll just know.

Thus disclosure is a very complicated situation: participants articulate reasons for wanting to disclose and assume that others will notice over time, yet they often want to keep their hearing loss to themselves. Although nondisclosure is an option for discreditable people because their stigmatized attribute is invisible enough that they can, to some extent, control whether or not others know about it (Goffman 1963), assuming that others will find out about the hearing loss over time takes the disclosure of the stigmatized condition out of the control of the stigmatized individual. However, in exploring when and to whom participants tend to disclose their hearing loss, the next section shows that hard of hearing people ultimately prefer to control the dissemination of knowledge about their hearing loss.

Disclosure: Contexts and People

In addition to ensuring that they properly meet “disclosure etiquette” (Goffman 1963:101) by managing how they disclose and their own opinions about why one should or should not disclose, participants also had to make decisions about the types of people or situations in which to disclose their hearing loss. When asked to describe these people and context more specifically, several participants explained that they were simply “open” to telling

anyone because they “don’t care who knows” (Charlotte, 21, WF, C, 2). These participants are “pretty quick to share it with people” but often wait for the subject to come up naturally in conversation (Fiona, 26, WF, C, 5). Fiona and Will (33, WM, A, 8) both say that other people will sometimes raise the topic of their own accord and ask them questions about their hearing loss. People sometimes approach Will and say, “*I noticed you have hearing aids...what happened? Do you mind if I ask?*” Will (and Fiona, too) is comfortable answering their questions because he believes his hearing loss is “a good conversation” starter.

While some participants are generally open to disclosing their hearing loss, others said that they disclose to people “only when I’m comfortable with them” (Lynn, 34, AF, ?, 14). Participants were more inclined to disclose to someone who they “interact with” (Megan, 21, WF, A, 19) or “hang out with the most” (Kevin, 26, AM, A, 1). Brief acquaintances met in “a general social situation” are rarely told because participants prefer to “get to know someone for a while” (Sophie, 40, WF, A, 21) or let the other person “get to know me” before they disclose (Lindsay, 18, WF, A, 7). Brian (31, WM, H, 8) described the sentiments of these participants:

I wouldn’t categorize it as, you know, *this type of person I wouldn’t tell*. I would...categorize it as, *how involved am I going to be with these people? Is it worth the effort?* Umm, if it’s just someone I think I’m going to meet once or twice, or...if I see someone at a bar and we have like a two minute conversation I’m not going to go into my life history.

Jen (22, WF, A, 14) will usually “meet people and then tell them” because by the time she informs them they will know her well enough to either feel comfortable asking her questions or feel that her hearing loss is not an “issue.” For these participants, their relationship with individual to whom they were disclosing was an important factor.

Other participants mentioned certain categories of people in explaining how they decide to disclose. These categories included: significant others, coworkers, and social groups. For the

significant other category, participants' responses fell along a continuum from open to closed. The participants who were the most comfortable with the idea of discussing hearing loss with a potential significant other put their hearing loss "out there" (Kate, 26, WF, C/A, 6) or told the person "pretty soon. I'm sure it probably came up, umm, probably within the same time frame as I would tell anyone else" (Charlotte, 21, WF, C, 2). The next group of participants was slightly less open to disclosing to potential partners. Participants were not uncomfortable talking about their hearing loss with other people, but their significant others often "figured it out" before they told them (Steven, 26, WM, A, 5). Farther along the continuum is the group who consciously waits to disclose their hearing loss to a potential partner. Participants would initially "hide" (Lynn, 34, AF, ?, 14) their hearing loss because they feel more "self-conscious" and "reserved" about their hearing loss when they are on a date (Fiona, 26, WF, C, 5). These participants did not necessarily want to tell a potential partner about their hearing loss while they are on a date, but rather they described waiting to "hook" the person before disclosing the hearing loss (Jen, 22, WF, A, 14). Participants at the 'closed' end of the spectrum did not tell their partners until well into the relationship. Rachel (21, WF, C, 2/3) assumed that her boyfriend knew that she had a hearing loss but when she finally told him, "he didn't even know" and "was just like, *really?*" Participants at this end manage their hearing loss to the point that it is invisible to those closest to them until they choose to reveal it.

Participants varied on whether or not they disclose their hearing loss to coworkers. Four participants that did disclose their hearing loss used their jobs as an example of a situation in which disclosure is important. Brian (31, WM, H, 8) tells his colleagues "right away" because "they need to know" that he is neither "an idiot" nor "ignoring them" if he does not respond to a question. Steven (26, WM, A, 5) discloses his hearing loss to coworkers so that they know to

Speak up when talking to him and so that they do not get frustrated with him if he does not respond when they call him. Lynn (34, AF, ?, 14) feels obligated to disclose at work because she has meetings with “soft spoken” people who “mumble.” Hannah (30, WF, H/C, 6) discloses her hearing loss as soon as she begins a new job because she thinks it is “important for me doing my job” that coworkers and employers know that she might “mishear” or “not hear” them.

Participants also explained the benefits and risks of disclosing their hearing loss at work. When talking to employers, Fiona (26, WF, C, 5) discloses her hearing loss in order to explain why she might frequently ask for repetitions and why she “might need a certain type of...phone in the office.” Employers try to accommodate hard of hearing employees by making “stuff louder” via technology like an amplified head set (Will, 33, WM, A, 8). On the other hand, Jen (22, WF, A, 14) sometimes wishes she had not disclosed her hearing loss in certain situations because people turn her hearing loss into a “continuous joke.” In the past when she has asked someone to repeat something or if she has missed something entirely, people have made her feel “uncomfortable” because they will “start saying things” about her hearing loss. Will (33, WM, A, 8) has also experienced the risk of disclosing hearing loss:

the last place I, I worked at...I was a cashier, you know, and they were planning on putting me on morning shifts and I'm like *well, you know, I can't hear the pumps*. You know, the gas pumps. And you know, because they'd be in, I mean, standing, you know, two feet away from them, if that, people would have to tell me that the pumps, or that the cash registers were beeping for the gas pumps. And I told the manager that, and he's like, *well, you know, let's see what we can do*. Next day he let me go. So. But he didn't specifically state that's why. But [hearing loss] definitely, it definitely has an impact on the work.

While disclosing hearing loss is beneficial, it can also have very real consequences.

Some participants did not disclose their hearing loss at work. Lindsay (18, WF, A, 7) says that when she started her new job, she “didn't tell anyone at work. Like, obviously.” Lindsay does not disclose her hearing loss “upfront” unless someone asks her or points out that she did

not hear them. Megan (21, WF, A, 19) felt conflicted about whether or not to disclose her hearing loss at her internship last summer: “do I tell...the people who I’m working with that this is something that I’m dealing with? Do I not?” Megan ultimately did not disclose because she felt her hearing loss was a personal issue that she needed to deal with alone rather than burden others with the knowledge. Neither Kate (26, WF, C/A, 6) nor Sarah (30, WF, A, 23) disclose their hearing loss on the job because they fear negative repercussions. Kate is a sign language interpreter and believes her hearing loss helps her because she is a visual learner and her hearing aids pick up on missing syllable that her team interpreter cannot hear. Kate does not disclose her hearing loss because interpreters,

can be very back stabbing, so I’m just nice and friendly and then when they see my hearing aids, enough time has gone by that they realize it doesn’t affect my work.

Kate’s deaf clients “don’t understand the range of hearing loss” so although Kate can still hear without her hearing aids, deaf people assume that since she has *two* hearing aids she “can’t hear the person I’m interpreting for or I’m just covering up my deafness.” Thus Kate lets them “see my ASL skills first and then they realize I’m good at what I do.” Sarah did not disclose her hearing loss when she was a firefighter because “you can’t be a firefighter if you have a hearing loss.” At the time, Sarah worried that disclosing her hearing loss would result in her coworkers looking at her “weird because I can’t do all the stuff I signed up for.” Hearing loss would suggest to fellow firefighters that Sarah was incapable of doing her job.

Participants were involved in a variety of social groups and explained their decisions to either disclose or not disclose in each. Disclosure in social groups can sometimes serve to further compliment participants for a job well done. For example, after her audition for a Women’s Chorus, the director told Fiona (26, WF, C, 5) that she sounded really good. In response, Fiona

casually disclosed her hearing loss, saying, “I’ll sound better next week ‘cause I’ll have my new hearing aid back.” The director was “shocked” that Fiona had a hearing loss, and Fiona was proud to show that her hearing loss has never been a “problem” for her.

Disclosure in social groups also allows other people to accommodate the hard of hearing person. For example, Charlotte (21, WF, C, 2) plays two sports for her university. Two of Charlotte’s Ultimate Frisbee teammates have nicknames that sound very similar to her name when her coaches yell them across the field. Since Charlotte disclosed her hearing loss to her team and coaches, they adjusted to Charlotte’s confusion by giving her a nickname that clearly differentiates her name from the others’. Since Charlotte felt comfortable disclosing her hearing loss, her coaches and teammates were able to adjust and help her.

Participants would sometimes disclose their hearing loss but then discuss that disclosure is not always helpful. When Sophie (40, WF, A, 21) discloses her hearing loss, people will “speak louder for, like, a couple of words or enunciate more for a few words and then go back.” Likewise, Chris (22, AM, A, 20) tried disclosing to his church group when they were discussing in a circle, explaining, “*please speak louder because I have a hearing loss.*” The group initially remembered to speak up but soon forgot. Chris realized that “people don’t really consciously think” about speaking up so “there’s no point in me” asking people to accommodate him.

Goffman (1963) wrote that a stigmatized individual handles the “risks” of the stigmatized condition by “dividing the world into a large group to whom he tells nothing, and a small group to whom he tells all and upon whom he then relies” (95). Hard of hearing people confirm this statement because they, too, manage the risk of having a stigmatized identity by carefully selecting to whom they will or will not disclose their hearing loss. However, participants’ responses indicate that this strategy is far more complex than it initially appears because of the

variety of social situations in which they find themselves and because of their own constantly evolving opinions about when they need to disclose.

(Non)Disabled

The management of a hard of hearing identity requires more than making decisions about disclosure in interpersonal interactions – people with hearing loss must determine how they feel about their hearing loss. The questionnaire that participants filled out before the interview explored participants’ perceptions of their hearing loss by asking them to state how they view their hearing loss. Participants identified which of the following categories they believed described their view of their hearing loss: “a disability or handicap,” “a part of who I am,” “a culture or means of relating to a group of people,” “a good thing/something to be proud of,” “a bad thing/something to be ashamed of,” or “none of the above.” The results (see Appendix J, Table 7) indicate that although nine participants said that their hearing loss is a disability or a handicap, almost every participant felt more strongly that their hearing loss is just another part of their being. The only participant to check “none of the above” changed her answer during the interview to “part of who I am,” resulting in a total of nineteen participants selecting this option.

During the interviews, participants’ responses suggested various strategies for distancing themselves from a hard of hearing identity. Participants manage their hard of hearing identities by displacing blame from their hearing loss to other factors, by emphasizing both the mildness of their hearing loss and their belief that hearing loss is a fact of life that is neither a big deal nor something they think about regularly, and by rephrasing ‘hearing loss’ into more positive terms. However, although these strategies sometimes worked effectively, they were also prone to falling apart when the participants were probed to further explain them. Participants especially had

difficulty in their attempts to distance themselves from viewing their hearing loss as a disability and themselves as disabled.

Displacing blame is a tactic many people with stigmatized identities employ. According to Goffman (1963), one of the strategies that stigmatized individuals use to pass for ‘normal’ is to “present the signs of their stigmatized failing as signs of another attribute, one that is less significantly a stigma” (94). Displacing blame from one’s hearing loss, a stigmatized condition, to less stigmatized characteristics, such as their bodies or their personalities, allows hard of hearing people to manage how they present their hearing loss to others as well as to work through their own perceptions of their hearing loss. In terms of body-blame, Diana (26, AAF, H, 14) says,

I don’t know if it’s because of my ears, but loud music just really bothers me. So I can’t go out to...certain social environments just because it really bothers my ears and I get really bad headaches when I do so.

Diana notes that her *ears* might lead her to avoid social gatherings, but she does not specifically suggest that her *hearing loss* is a problem. Although the negative effect that music has on her ears might be a result of the hereditary condition that caused her to be born with holes in her ears, Diana attributes her desire to avoid social interactions to her body, not to her hearing loss.

In terms of personality, twelve participants said that it was not their hearing loss but rather their specific type of person that made them less inclined to socialize. Kate (26, WF, C/A, 6) says that her hearing loss has not interfered with her social life because she is a “quiet, independent person.” Kate attributes her hesitance to socialize to the fact that she has “never been a social butterfly” rather than to any difficulties her hearing loss might create. Likewise, participants said that their hearing loss did not affect them because they were “outgoing and proud and strong-willed” (Steven, 26, WM, A, 5) and “stubborn” (Sarah, 30, WF, A, 23; Tyler,

30, WM, C, 0). Having a confident and “optimistic” personality (Fiona, 26, WF, C, 5) allowed participants to view their hearing loss as “just another thing I had to become confident about” (Charlotte, 21, WF, C, 2).

But displacing blame from hearing loss to personality can get complicated. Clair (24, AF, C, 2½) says that because she is “a pretty introverted person,” her personality affects her social life more than her hearing loss does. However, Clair cannot tell exactly “how much is my personality and how much is the hearing loss.” Likewise, Jen (22, WF, A, 14) wonders, “if I am quiet because of my hearing loss...or am I a naturally quiet person?” Clair and Jen suggest that hearing loss and personality might be intertwined in the sense that hearing loss can determine how one’s personality develops. For example, Hannah (30, WF, H/C, 6) had a hard time socializing as a teenager because her hearing loss prevented her from interacting with others as well as she would have liked to. Hannah believes that she is an “outgoing person” but that she is “held back” in social situations because she cannot always hear. Megan (21, WF, A, 19) also articulates this feeling:

if I was someone who had this problem in elementary school, I just think I wouldn’t have been as...outgoing. I don’t think I would have been as social. I don’t think I would have had all these characteristics that I find in myself today.

While Megan is only “guessing” that a later onset prevented her hearing loss from affecting her personality, Rachel (21, WF, C, 2/3) goes straight to the point in describing the negative effect that hearing loss has on her socially. About her hearing loss, Rachel says:

I think it’s made me more withdrawn, kind of, and slightly more self-conscious in social situations because, like, I don’t know what all is being said.

According to these participants, hearing loss can change a person’s personality in such a way as to inhibit their desire to socialize. While these participants blame their hearing loss to some degree, they still highlight their personalities as a factor in their social habits.

A second strategy that participants use to manage their hard of hearing identities is to emphasize both the mildness of their hearing loss and their belief that hearing loss is a fact of life that is neither a big deal nor something that they think about regularly. Sixteen participants mentioned that they do not believe their hearing loss is *that* bad. Specifically, a few participants explained that they do not wear hearing aids because they can hear “okay” (Jen, 22, WF, A, 14) or “totally fine” (Steven, 26, WM, A, 5) with their residual hearing. Even though Diana’s (26, AAF, H, 14) hearing loss has progressed, she emphasizes that it is “still manageable.” While Diana’s mother and brother have “much worse” hearing loss, Diana says that her hearing is not a “huge problem” because she can hear as long as she faces people or asks them to speak louder.

In claiming that their hearing losses are minor and just a fact of life, participants manage their hard of hearing identities by distancing themselves from hearing loss. In their opinion, hearing loss is not “really on my mind very often” because it has “not been that big of a part of my life” (Charlotte, 21, WF, C, 2) and “it’s not that big of a deal” (Steven, 26, WM, A, 5). Similarly, Kate (26, WF, C/A, 6) does not discuss her hearing loss very often with other people simply because “it’s not really an issue.” Since hearing loss is a “part of who I am,” participants say that they have just had to learn to adapt to and accept that they have a hearing loss (Will, 33, WM, A, 8; Lindsay, 18, WF, A, 7). While Clair (24, AF, C, 2½) says her hearing loss “sometimes...negatively impacts” her life, she does not believe hearing loss is a “wholly negative thing” because she does not think about her hearing loss “very much.” Sarah (30, WF, A, 23) says that the reason she chose “none of the above” in the pre-interview questionnaire is because her hearing loss is not a big deal to her because she has learned how to adapt. Sarah says that she “could have answered that it’s a part of me, but it’s a part of me that I don’t think about.” Some participants explain that they believe their hearing loss makes them no “different”

than other people (Tyler, 30, WM, C, 0) or that it is just a result of “bad luck” (Diana, 26, AAF, H, 14; Lindsay, 18, WF, A, 7). Fiona (26, WF, C, 5) even says that her hearing loss is a “blessing” of sorts because it has taught her to “look everybody in the eye” so that she can read their lips, a practice that has benefited her interpersonal relationships.

Additionally, participants can distance themselves from their hearing loss by finding ways to rephrase ‘hearing loss’ into more positive terms. Rather than stating that they have a hearing loss, participants sometimes explain that they are not “able to hear perfectly” (Rachel, 21, WF, C, 2/3), that they “don’t hear well” (Fiona, 26, WF, C, 5), or that they hear “differently” (Chloe, 21, WF, APD, 14). Such comments were not made to deny the hearing loss, but rather in an active effort to help the participants manage their identities as hard of hearing people. By emphasizing the mildness of their hearing loss, saying that they rarely think about it, and creating alternative ways of describing it, participants perform the “voluntary maintenance of various types of distance” that Goffman (1963:99) expected from stigmatized individuals who try to pass as ‘normal.’

Although strategies for managing a hard of hearing identity that involve distancing are often effective, participants also illustrated the negative consequences of, for example, developing alternative ways of framing hearing loss. Tyler (30, WM, C, 0) says that after his surgeries, he did not have to wear hearing aids anymore and thus felt “normal.” Although he had problems hearing people and often asked people to repeat themselves, Tyler “wouldn’t admit that [he] had a problem” and postponed exploring assistive hearing technology options because of his denial. Likewise, Brian (31, WM, H, 8) knew from a young age that he had a hearing loss but did not get hearing aids until graduate school because,

if I had to estimate how much I was getting, I would say 90-95%. Umm, where that was probably a gross overestimate, but that’s what...I thought I was getting.

Brian did not fully believe that he experienced the hearing loss that his audiograms indicated.

With the help of his wife, Brian began to realize that,

you can convince yourself that you're getting a lot more than you actually are and that, at the end of the day, you feel exhausted from having to sort of focus all the time and extract every little bit that you can based on whatever little context you get from the conversation.

Denying hearing loss or the severity of the loss is one way that people manage their hard of hearing identities. But it can have negative consequences both in the amount of effort that hard of hearing people expend in order to compensate and in their delay in receiving assistive hearing devices.

Strategies for managing a hard of hearing identity are further complicated and tend to fall apart when considering disability. Regardless of how participants responded to the pre-interview question about how they viewed their hearing loss, many had opinions about disability. Although hearing loss is considered a disability, some participants tried to distance themselves from a disabled identity. In considering how he views his hearing loss, Kevin (26, AM, A, 1) says, "I don't view it as a disability. It is technically a disability, but I don't view it as a disability."

Hannah (30, WF, H/C, 6) reflects on when she first learned about her hearing loss when she was six years old:

I remember...driving in the car and seeing the handicapped parking spaces and thinking, *well, you know, I'm handicapped with my hearing*, but I never, it, it never matched. I never felt like...I was impaired, I was handicapped. It was always just who I was at the beginning.

Hannah's comment shows that individuals can intellectualize that hearing loss is a disability, but they cannot (or will not) take on a disabled identity. Tyler (20, WM, C, 0) expands on this point by explaining that while he was growing up he stressed the importance of being "normal," not disabled. Tyler says, "now I can admit that it is a disability. Although sometimes I question it."

Now that he has come to terms with his hearing loss and has learned the benefits of considering his hearing loss a disability because of the accommodations he can receive, Tyler feels able to label his hearing loss a disability. However, he still distances himself from the term. In part, the lack of acceptance of a disabled identity stems from what he calls the issue of “ability versus disability” or, as Fiona (26, WF, C, 5) explains, the fact that “a lot of people with disabilities define themselves by what you can’t do” rather than what they can do.

Lynn (34, WF, ?, 14) also feels the desire to separate her identity from her disability. Although she is proud that she completed her Master’s degree, Lynn says that even now when she goes to her sister-in-law’s house,

all they do is like, [whispering] *Oh! Oh! She’s the one with the hearing problem. Oh my gosh, she’s the one that’s deaf.* And I...it hurts! Because...why can’t they look at my...accomplishment, you know? Why do they always bring in my hearing problem?

Lynn’s sister tells her not to worry about what others say about her hearing loss. But Lynn says:

I think it hurts...I think I’m good at academics, so I want to prove to them that, you know, you have weakness, but you want to build something else...a strength. So you want to prove to them something but I feel like, no matter how much I’m gonna accomplish, they gonna always see me as a deaf person. And that *hurt!*

While some of the people in Lynn’s life cannot look at her without seeing her disability, Lynn would rather that people identify her by her academic accomplishments rather than by her hearing loss.

While the previous participants acknowledged that hearing loss is a disability but then explained that they were not disabled or did not want to be considered disabled, other participants who said that their hearing loss felt like a natural part of them sometimes tried to deny that hearing loss is a disability or that they themselves are disabled. Rachel (21, WF, C, 2/3) used the cause of her hearing loss to explain why she does not identify as disabled. If Rachel

had acquired her hearing loss later in life, she believes she would be more inclined to consider it a disability. But since Rachel was born with hearing loss, she considers it a part of her, not a disability: “if someone tells me that...I have a disability because of this [hearing loss], I’m like, *no I don’t. I function fine. I don’t have any issue.*” Fiona (26, WF, C, 5) emphasizes that she is hard of hearing, not disabled:

I am a person. There’s nothing wrong with me. I’m not disabled but I just don’t hear well...I’ve really taken ownership of the term ‘hard of hearing’...I don’t like to say, like, *I have a hearing disability*. I like to say, *I’m hard of hearing*. Because I am hard of hearing and I used to just kind of say, *well, I’m not disabled. There’s nothing wrong with me. I’m a normal person. My ears just don’t work that well.*

Likewise, Kate (26, WF, C/A, 6) explains that over time she has learned to “identity” herself as hard of hearing not because she wears hearing aids or because she has a hearing loss but rather because she has “a harder time hearing a few things.” Thus participants used labels like ‘hard of hearing’ as a way to indicate that they are not disabled.

One reason participants chose to distance themselves from disability is to avoid the stigma that disability and hearing loss carry. Sophie (40, WF, A, 21) believes that “people are afraid of disabilities” because they “are afraid of becoming disabled themselves.” Sophie feels that there is a “stigma to really almost any type of disability” because non-disabled people assume that people with disabilities are not only disabled, but also that “there’s something else just wrong with them.” Sophie says that she is “afraid of being perceived that way” because of her hearing loss. Chris (22, AM, A, 20) considers his hearing loss a disability or handicap, but he tries to keep others from finding out about it. He believes that when non-disabled people see a disabled person, they tend to “treat this person nicer.” Chris does “not like that kind of treatment.” Although Chris often asks people to repeat themselves, he would prefer them to think, “it’s so annoying that he always asks ‘why’” rather than treat him differently or not speak

to him at all because he has a hearing loss. Thus the stigma of disabilities and hearing loss prevents some participants from wanting to identify as either disabled or hard of hearing.

Another reason participants chose to distance themselves from disability is to avoid what disabilities studies scholars refer to as the wondrous model of disability. Garland-Thomson (2002) writes that the wondrous model “capitalizes on physical differences in order to elicit amazement and admiration” (59). Literature and media that casts disability in a wondrous light does so with the purpose of creating a feeling of amazement and inspiration in non-disabled viewers towards the behaviors that the disabled individual does to overcome the disability (Garland-Thomson 2002). Clair (24, AF, C, 2½) says that since she is “pretty high-functioning” and does not appear disabled, people who find out about her hearing loss before they get to know her as a person tend to look at her as “this disabled person and, you know, *look how well they function.*” In describing this comment, Clair provides the following example:

I played the cello when I was in high school...I wasn't a great cellist or anything...I was kind of mediocre. But it's like, when people found out I was hearing impaired, then they would always, like, tell my mom, for instance, *oh she plays so well considering...* And it's like, that's not the point, right? I mean I know I'm bad cellist [laughs]. That's not why I'm doing it.

Clair played the cello for the musical “experience,” not to prove that she could ‘overcome’ her hearing loss. Charlotte (21, WF, C, 2) also feels frustrated when people make comments about her ability to live with hearing loss:

I mean it's kind of funny because people are the most impressed by how well you have, like, dealt with it or something when honestly, people shouldn't be really impressed because it's, like, not that big of a deal in my opinion. Umm, it'd be like me saying, *wow you're so good for making it through with this...difficultly with...nearsightedness. Good for you! It must be really hard.* So I think it's funny when people are like *wow you can't even tell!* Like, *that's really impressive.*

Charlotte believes that she does not need praise for being able to succeed in life ‘despite’ her hearing loss because her hearing loss is just a part of who she is rather than a negative factor that

prevents her from functioning normally. Clair and Charlotte demonstrate a desire to disconnect themselves from the idea of disability because the expectations and assumptions that come from being labeled as a disabled person.

While the previously discussed strategies for distancing oneself from a hard of hearing identity can result in one's successful passing as an individual with normal hearing, these strategies require a great deal of work to maintain and are prone to disintegrating. Participants make bold claims that their hearing loss does not impact them on a daily basis (which can certainly be true), but a further exploration shows that participants are conflicted by the fact that they do not identify as disabled even though hearing loss is a disability. Thus managing a hard of hearing identity is not a simple task, but rather requires individuals to constantly revise their perceptions of themselves.

Liminality and In-Betweenity¹

The complex nature of the identity work that hard of hearing people perform is further illustrated via a second pre-interview questionnaire for which participants indicated how they labeled themselves by selecting from the terms hearing, hearing impaired, hard of hearing, deaf, or other. Participants were allowed to select as many options as they felt applied. In the results (see Appendix J, Tables 8a and 8b), participants predominantly selected either hearing impaired (three participants), hard of hearing (seven participants), or both of those options (eight participants). Overall, eighteen participants picked some combination of hard of hearing and hearing impaired, two participants selected "hearing" (Chloe, 21, WF, APD, 14; Lindsay, 18,

¹ Brenda Brueggemann uses the term "betweenity" in her book, *Deaf Subjects: Between Identities and Places* (2009), in reference to Deaf people who find themselves stuck in-between on matters of identity.

WF, A, 7), and one participant selected hearing impaired, hard of hearing, and deaf (Clair, 24, AF, C, 2½).

The purpose of this question was to determine how participants felt about their identity as a person with a hearing loss by comparing whether participants considered themselves hearing impaired or hard of hearing. Disability studies scholars stress the importance that language can have on how people with disabilities are viewed. Whereas the historical trend of using medical terminology to discuss people with disabilities in terms of symptoms, diagnostic categories, impairments, and a loss of function, disability studies seeks to reclaim the labels used to describe disability and reassign their meanings in a more positive fashion (Linton 1998). Brueggemann (2009) describes how people within disability studies and deaf studies often discuss “what we do and don’t want to be called” (9). Scanning the literature related to hearing loss, including Brueggemann’s work, indicates that scholars refer to people with hearing loss as Deaf, deaf, hard of hearing, hearing impaired, having hearing loss, “late deafened,” “think-hearing,” among others (2009:11). But in order to ensure that one uses “nice words” instead of “nasty words” (Linton 1998:14-16), which term do people with hearing loss prefer?

According to the terms my participants selected to refer to their hearing loss, there is no clear answer. But Hannah (30, WF, H/C, 6) neatly summarizes one way of analyzing why some people consider themselves hearing impaired while others call themselves hard of hearing:

I think it’s really the identity. It’s how someone chooses to identify themselves. Somebody who is hard of hearing is comfortable with their hearing loss...It’s more a part of who they are. Someone who’s hearing *impaired*, umm, it’s an impairment to them. It’s not something that they’re comfortable with. It’s something that they would fix.

Following Hannah’s logic, I analyzed which labels participants chose depending on whether they considered their hearing loss to be a disability or a “part of who I am” (see Appendix J, Table 9).

Based on the results, it appears that regardless of whether they considered themselves hearing impaired, hard of hearing, or used both terms, more participants felt that their hearing loss was a part of them than a disability. Thus the results do not necessarily provide conclusive evidence as to whether hard of hearing or hearing impaired is the more appropriate term to use in describing people with hearing loss.

Although only one participant selected 'deaf' as an option on the pre-interview questionnaire, several participants made reference to the use of 'deaf' as a labeling term. Some participants said that they could never refer to themselves as deaf because it suggests that one cannot "hear anything" (Diana, 26, AAF, H, 14) or because the fact that they "can hear some" means that they should not take away from what "their [Deaf] culture means" (Sarah, 30, WF, A, 23). Lynn (34, AF, ?, 14) says that people are much more likely to respond with curiosity if they hear the term hearing impaired but that people "freeze up" when they learn that they are talking to a deaf person. But other participants sometimes refer to themselves as deaf because they find it easier. Clair (24, AF, C, 2½) will occasionally tell people that she is deaf "because it's shorter." Sophie (40, WF, A, 21) sometimes says that she is "deaf in one ear" even though she is not "really sure" that she is deaf because she is "basically functioning in the hearing world." Megan (21, WF, A, 19) does not consider herself "deaf overall," but she frequently tells people that she is "deaf to some extent" or "deaf in one ear." In addition to using deafness as a way to disclose their hearing loss, some participants used it in a joking manner. Charlotte (21, WF, C, 2) downplays any effect her hearing loss might have on her social life: Charlotte and her boyfriend get along just fine because he cannot see without glasses and, as she says, "I'm, like, deaf" without hearing aids. Chloe's (21, WF, APD, 14) friends joke with her, telling her, "you're so deaf," whenever she asks them to repeat something. Rachel (21, WF, C, 2/3) "makes jokes about

being deaf.” Rachel does not consider herself deaf but she finds it easier to joke about being deaf by saying that she is “having a really deaf day” when she is particularly struggling to hear people. Although humor can have its place, Megan (21, WF, A, 19) sometimes gets frustrated when her friends with normal hearing joke about being deaf. All of Megan’s friends hear “perfectly fine,” so she gets upset when they make comments like “I feel like I’m deaf,” “I can’t hear anything,” or “I’m deaf from that concert.” These comments are difficult for Megan because she “really can’t hear anything” and has to “deal with this all day,” not just until the temporary hearing loss from listening to loud music goes away.

Thus participants expressed a very conflicting relationship with the various ways of delineating hearing loss and deafness. Since there appears to be no absolutely ‘correct’ way to identify people with hearing loss, this group of individuals is left hanging in a liminal space. Arnold van Gennep (1960 [1909]) first introduced the term *liminality* in reference to rites of passage. A rite of passage involves three stages: separation (one sheds one’s current status or place in preparation for assuming another), transition (the liminal, or in-between, period after one leaves one’s initial place but before one enters the new place), and reincorporation (the rite is completed when one takes on one’s new identity) (Gennep 1960 [1909]). Hearing loss requires a rite of passage: after being diagnosed (or, in the case of individuals born with hearing loss, after realizing that although they live in the hearing world, they are not actually hearing), people must relinquish their identity as a hearing person and transition into a new status, such as hearing impaired, hard of hearing, or deaf. However, I think part of the reason why it is so difficult to find an appropriate term for people with hearing loss is because many people never make it out of the liminal, or in-between, phase.

Several participants tried to articulate the idea of being in-between. Jen (22, WF, A, 14) says that she is not a member of her university's club for hearing impaired students because she thinks attending a meeting would be like "going into a group that wasn't like me." Jen does not think she would fit in with this group of people because everyone would look at her "funny" because her hearing is too good to grant her membership into the group. In this sense, Jen feels she does not have a group to identify with because she feels that being neither hearing nor deaf leaves her "somewhere in-between" the two. Sophie (40, WF, A, 21) says that although she understands that some people view hearing loss as a "cultural difference," she personally views her hearing loss as a "negative" part of her life. Sophie says that acquiring her hearing loss later in life affected her opinion of hearing loss:

growing up...I was completely immersed in the hearing world. And so all my connections are in the hearing world...I guess I developed a few friendships with people who are hearing impaired, but mostly it was a feeling of just being alone. I guess it's a feeling of being alone.

As Jen and Sophie indicate, being in a liminal space can be very lonely.

Tyler (30, WM, C, 0) considers himself a "mainstream person" because he is "resistant" to the practice of "deaf [people] who, like, isolate themselves." Tyler thinks it is good that people come together in groups (such as his university's club for hearing impaired students) so that they can talk about their experiences, but he says that he does not want to single himself out as a "special community" because he views his hearing loss "as just one factor of [his] identity." In Tyler's opinion, having a hearing loss is something he simply has to deal with just as he has to deal with "wearing shoes." But Tyler acknowledges that the fact that he is "in-between" might be the reason why he does not fully understand why deaf people chose to isolate themselves.

Further explaining what it feels like to be in-between, Tyler says:

on the one hand...I fear that [hearing people will] think I'm stupid. But then on the other hand, well, that's just stupid to think that they're thinking I'm stupid. You know? So...I'm constantly going back and forth. But in the end...it doesn't make a difference. It's something I have to deal with and I've gotten over it. Move on!

As Tyler explains, the liminal space between being deaf or hearing is fraught with worry: sometimes one feels that hearing loss will make one appear less competent or intelligent to other people but sometimes one feels that it is not productive to worry about how other people perceive someone because of hearing loss.

While Tyler does not necessarily want to make his hearing loss a primary part of his identity, some participants wanted to explore the world of the deaf to see how it would fit in to their identities. Lynn (34, AF, ?, 14) says, "I'm in-between...I'm not here and I'm not here, so I'm in the middle." Lynn says that growing up in the hearing world prevented her from seeking out the deaf community after she lost her hearing. Although she has spent all of her life in the hearing world, Lynn now wonders if she should "look at the other world" and explore what the deaf community has to offer. Hannah (30, WF, H/C, 6) has had the experience of being a part of the deaf community to some degree. Hannah's comment on her connection to either the hearing world or deaf world is that she is "both and neither at the same time." Hannah says, "it's like I sit in both places." Since Hannah has hearing loss, has worked in the deaf community, and has deaf friends, she feels very "deaf-centered" when she socializes with deaf people. But now that she is working in the hearing world, she finds herself socializing more with hearing people. Hannah says that she does not mind being in-between the two worlds:

I think I'm comfortable being in both...there's pros and cons to both because of my language abilities in both worlds. So some days one is better than the other. But the one thing above all is that when I socialize with deaf people and I'm chatting with them...I always leave that event feeling better inside than I do when I'm struggling to communicate in a hearing environment.

While Hannah does not experience being in-between as altogether a negative experience, she indicates that communication is a major factor that prevents her from being able to feel entirely comfortable in the hearing world.

While participants' responses illustrate that managing a hard of hearing identity requires a great deal of emotional labor and stigma and identity work, the notion that hearing loss requires hard work becomes increasingly complex when one analyzes how they view their hearing loss and how they label themselves. Although participants did not provide overwhelming support for one label over another, their responses indicated something much deeper is at play than a simple preference for, say, 'hard of hearing' over 'hearing impaired.' Perhaps, as mentioned earlier and will be brought up again in the conclusion, people with hearing loss live their lives stuck in a liminal space that is neither quite separate from nor quite reintegrated into society.

Dating

Continuing with the exploration of the identity work that hard of hearing people perform, participants were asked in their interviews if they would be open to dating a person with a hearing loss and whether or not they believed that people with regular hearing abilities would be open to dating people with hearing loss. The purpose of the first question was to see if participants were comfortable and confident enough with their hearing loss to establish close social alliances with "like-situated individuals" (Goffman 1963:112). Some participants, such as Steven (26, WM, A, 5), thought this was "kind of a funny question" because as Clair (24, AF, C, 2½) noted, asking hard of hearing people if they would date other hard of hearing people is "a loaded question about internalized, like, ableism." The second question was intended to explore the concept of the "looking glass self" – a notion developed by Cooley ([1902] 1983) that

suggests that “the self is a social product” (Yeung and Martin 2003:843) and that one’s “self-concepts are formed as reflections of the evaluations of others in [one’s] environment” (Gecas and Schwalbe 1983:77). By asking the participants if they believed that hearing people would date hard of hearing people, I hoped to get a more concrete idea of how my participants viewed hearing loss.

The idea of being *in-between* the hearing and deaf worlds again surfaced as important when considering how participants think about their hearing loss when it comes to dating. Not every participant mentioned this and it did not necessarily come up as the first point that these participants discussed. In response to whether or not hearing people would date hard of hearing people, Tyler (30, WM, C, 0) said, “I hope. I hope so,” and then tried to explain the tricky situation that he believes hard of hearing people face:

the thing that’s interesting about hearing disabilities, especially, I feel like, with having, umm, having a hearing aid, it’s like you’re kind of, I feel like you’re in between. You know? And you’re like kind of bridging the two...

Kate (26, WF, C/A, 6) felt the same way and articulated it this way:

Thank you for finally asking how being hard of hearing affects our dating life, because it definitely does. Being hard of hearing means we’re on the fence: we’re not deaf so we don’t date only deaf guys, and we’re not fully hearing, so we can’t date them and pretend that our hearing aids are not going to be a problem. We kind of have to pick a side: a deaf man or a hearing man, and I think this depends upon the degree of hearing loss a person has and if they use sign language. I can see why someone would say they would not consider dating a person with a hearing loss because they probably just want to feel normal.

Some participants might not necessarily consider themselves in-between the deaf and the hearing worlds, but it is still important to keep this idea in mind throughout the discussion of the impact that hearing loss can have on dating.

Hard of Hearing Dating Hard of Hearing

Participants were divided on whether or not they would be open to dating a person with a hearing loss (see Appendix J, Table 10): half of the participants said that a person's hearing loss is not a factor in who they date and the other half said that they would not be closed to dating a hard of hearing person but list various factors that would influence their decision. Twelve participants are dating or married to a hearing person, one participant is married to someone with a hearing loss (but this hearing loss was neither known when they first met nor is it fully acknowledged by the spouse), and one has dated a hard of hearing individual in the past. The remaining six participants did not mention their relationship status in their responses (see Appendix J, Table 13).

Ten participants are very clear that a person's hearing ability is not a major consideration in their dating decisions. Brian (31, WM, H, 8) simply says that hearing loss "wasn't a factor in who I dated." Sarah (30, WF, A, 23) would be open to dating anyone because "people are people," so she would never oppose dating someone with a hearing loss "because the hearing loss isn't their fault." For these participants, a person's hearing ability is not a "problem," does not "matter," or makes no "difference" to them (Sarah, 30, WF, A, 23; Charlotte, 21, WF, C, 2; Tyler, 30, WM, C, 0; Diana, 26, AAF, H, 14; Hannah, 30, WF, H/C, 6; Lindsay, 18, WF, A, 7). Megan (21, WF, A, 19) captures the opinion of this group by explaining, "I'm not gonna go in search of someone [and] I'm not gonna disregard someone" because of hearing loss. Thus for these ten individuals, hearing loss is a characteristic in others that they simply do not consider so they would neither seek out nor avoid a potential romantic interest based on hearing ability.

As they considered their responses to this question, three of these ten participants remarked that dating a person with a hearing loss could actually be beneficial. Kate (26, WF,

C/A, 6), the only participant who said that she has dated a person with a hearing loss, says that after her experience of dating a hard of hearing man, she will:

continue to look for someone who is hard of hearing themselves or has someone in their family who is; it makes things more comfortable because they are more accepting.

Kate thinks that dating people with a connection to hearing loss can be helpful because they will know how to make the necessary accommodations so that Kate can hear them and they will not be uncomfortable with her hearing aids. Additionally, Kate enjoyed dating this hard of hearing person because he “looked at me as a person” rather than as someone who was different or not normal. Along these lines, the other two participants (Charlotte, 21, WF, C, 2; Steven, 26, WM, A, 5) say that they would not be opposed to dating a hard of hearing person because their own loss would make them “understand” another person with hearing loss. Steven further explains:

It’s like if my girlfriend had a hearing loss in her left ear...umm, I would definitely understand, like, I wouldn’t judge, per say. If I, if I knew that person had a hearing loss, it would actually make us, more in common. So I wouldn’t feel, you know, bad about it. I would, I would definitely, you know, kind of appreciate the situation more seeing as I have the same problem. You know? Umm, so no, I wouldn’t judge.

Although participants in this group do not usually consider hearing loss when they think about potential romantic interests and (aside from Kate) would not base their dating decisions on hearing ability, Steven’s statement reinforces that these individuals do not view hearing loss as a negative trait that would make another person less attractive in their eyes; rather a diagnosis with hearing loss creates a feeling of having shared experiences that they would not have with people who have normal hearing abilities.

Without any prompting on my part, two reasons surfaced for why someone with a hearing loss might not date another person with a hearing loss. Thirteen of the twenty participants addressed either the lack of exposure to other hard of hearing people or the degree of

hearing loss and communication style as two reasons why people might not date someone with a hearing loss. Of the ten who answered that yes they would date someone with a hearing loss, one mentioned a lack of exposure and three discussed the degree of hearing loss and communication style as *potential* reasons. In terms of the lack of exposure, Hannah (30, WF, H/C, 6) says:

I actually met my husband before I became comfortable with my hearing loss. So he met me when my identity was hearing impaired...I don't know when I met him if I would have dated people with a hearing loss, but when I met him I didn't know anybody else with a hearing loss. It was kind of just me.

Earlier in her life, when she did not know any hard of hearing or deaf people, Hannah felt uncomfortable with the idea of dating someone with a hearing loss. Although she is now married, the friendships that Hannah has developed later in life with hard of hearing and deaf people incline her to express no issue with the idea of dating someone who is hard of hearing.

Two of the three participants who talked about the degree of hearing loss and communication style did so to explain reasons for *not* dating hard of hearing people while the third participant said that these factors do not negatively influence dating. Charlotte (21, WF, C, 2) thinks "it would be interesting to try to date someone who was *deaf*" and used sign language to communicate because she neither knows sign language nor knows "how you even go about meeting someone if you can't communicate with them." Thus dating someone with a profound degree of hearing loss would be difficult because of the inability to communicate with them.

Kate (26, WF, C/A, 6) agrees, saying that a hard of hearing woman has to,

pick a side: a deaf man or a hearing man, and I think this depends upon the degree of hearing loss a person has and if they use sign language.

Although Charlotte and Kate both discuss how the degree of hearing loss and communication style can negatively impact one's choice of romantic interest, Sarah (30, WF, A, 23) casts these factors in a more positive light. According to Sarah, she would be open to dating someone with a

hearing loss because “you can connect with anyone...as long as you can communicate how you want to communicate with them, you can be with anyone.” For Sarah, communication was not a barrier but rather something that can be addressed and managed as it arises.

Of the ten participants who expressed uncertainty about dating hard of hearing people, three say it is because of lack of exposure, five say it depends on the degree of hearing loss and communication style, and one explains how both factors can affect one’s decisions. In addressing the lack of exposure, Jen (22, WF, A, 14) simply says, “I never thought about dating” a person with a hearing loss because all of her friends have normal hearing abilities. Fiona (26, WF, C, 5), the participant who addressed both factors, says, “I’ve never found myself in that situation” of having the opportunity to date someone with a hearing loss. Kevin (26, AM, A, 1) says that he has never dated anyone with a hearing loss because “the people I met...the vast majority of them have had hearing. So it’s, it’s just the sample size.” Kevin says that he would “potentially consider” dating a hard of hearing person, but as of our interview, he has not had the opportunity to meet anyone his age with hearing loss. Lynn (34, AF, ?, 14) mentions several times in her response that she feels open to dating someone with a hearing loss but that she does not know anyone with a hearing loss that she would want to date (and she has a boyfriend of six and a half years). Lynn compares her experience to the experience of a hard of hearing woman she knows from a hearing loss organization:

she only [hangs] out with...hearing impaired [people]. And...I can see right there that she gonna just date someone who’s hearing impaired. The chance of her, like, wanting to date somebody hearing could be low. You know? But for me...the chance of me dating somebody who’s, like, hearing impaired is low...Because I don’t know anyone.

Lynn further explains that the problem is not simply a lack of exposure to people with hearing loss but rather a lack of exposure to people with hearing loss that she can “fit in with.” Lynn

would begin a sentence saying that she did not think that she would date a person with hearing loss, but then say that she would be open to such a relationship if she found a person that she could “get along with.” Lynn says that some of the people with hearing loss that she knows are “stubborn, in their own little world” and that she could not date them unless they opened up. But if the “right guy” came along, Lynn would be open to dating him; however, she believes that this will never happen because she does not know anyone with a hearing loss who fits her criteria.

The five individuals who discussed the degree of hearing loss and the mode of communication appeared to place a fair amount of importance on the effect that these two factors can have on any kind of interpersonal relationship. In response to the question, the participants said that their answers depended on if the hearing loss is “significant” or to the “extent” of the hearing loss (Will, 33, WM, A, 8 and Rachel, 21, WF, C, 2/3). Chloe (21, WF, APD, 14) captures the overall opinion of this group in her immediate response to the question:

well, how bad a hearing loss? ‘Cause if they, if they have issues communicating with people then I just see that being a problem.

A person’s willingness to be in a relationship with a hard of hearing individual seems to depend on the degree of the hearing loss. The more profound the hearing loss, the more frustrating it is to try to communicate with the individual. Chloe (21, WF, APD, 14) further explains that she believes that it is difficult to date someone who has a profound hearing loss or is deaf because she says they tend to “hang out in their own groups” and do not “interact” with other people. Fiona (26, WF, C, 5), who also discusses the impact of a lack of exposure to hard of hearing people, shares a similar sentiment, explaining that, “culturally, deaf people tend to date deaf people” and since she herself is not deaf, she feels unable to enter into this dating scene. Both Chloe and Fiona explain that communicating with people with profound hearing losses is difficult because those people tend to separate themselves from other groups of people. Although

it would be interesting to examine why some participants believe that the deaf community is closed to them, only Tyler (30, WM, C, 0) provided a concrete example of being rejected: when he attended a party “with a bunch of guys from Gallaudet [University],” the first university for deaf and hard of hearing people and the only higher education institution in which all services and programs accommodate people with hearing loss, “nobody would talk to” him. Tyler does not know why he was rejected, but he is the only participant to offer a concrete example of the rejection that other participants described.

The other two participants discuss how the degree of hearing loss and the mode of communication could be problematic in a relationship. Sophie (40, WF, A, 21) says that dating a person with a hearing loss would be “twice the problems.” According to Sophie, even if she and another hard of hearing person wanted to talk about their shared experiences, their common “problem” would make it “even harder for us to communicate.” Although she is not closed to a relationship with a hard of hearing person, Sophie would prefer,

someone who either... doesn't have a hearing loss or it's a slight hearing loss, umm, just because, umm, I already have a hearing loss so it's, it's going to compound, it's going to be much more difficult to communicate.

Although Kate (26, WF, C/A, 6) is categorized with the participants that have no issue with dating people with hearing losses, she did mention that dating another hard of hearing person “only really became frustrating with the phone because I can't hear well on my cell phone so I would always wait to call him back on my land line.” Kate is more open to dating hard of hearing people, yet she still acknowledges the difficulty that can arise in trying to communicate with someone who has a hearing loss. Rachel (21, WF, C, 2/3) echoes this idea by explaining that the degree of the person's hearing loss would not matter as much as “how they spoke.” According to Rachel,

some people who have a hearing loss, like, speak really quietly because they can hear themselves in their head. And then if you, if you have a hearing loss and then you're dating someone who speaks really quietly, there's also that constant struggle of telling them to speak up. So I think it would depend more on how they communicate as opposed to what their level of loss was.

Fiona (26, WF, C, 5), who touched on a lack of exposure to hard of hearing people, also explains that although she believes it is more important to date a "good man," she feels that she would "probably find myself very frustrated being with somebody who also had a hearing loss." Fiona acknowledges that she tends to rely on her hearing friends more than she realizes when she goes anywhere with them. Fiona says that for places that she regularly frequents she has figured out how get by without needing too much help from those around her. But when she goes to a new place, Fiona depends on whoever is with her to help her figure out what other people say to her. Although she does not believe she has a "huge reliance" on others, she does ask the friends, family members, or dates that she is with to stay with her and help her know what others are saying. Thus Fiona believes that:

I think counting on another person that's hard of hearing or deaf, I would think that would be hard. That would just be harder 'cause, and I think that I rely on it more than I even realize. To be honest with you, I think I really, I've found that I always am with people and I think part of that is just a natural thing because I don't hear well. You know? Like I want somebody to be with me so I don't get hit by a car when I'm crossing the street or umm, you know?

Sophie, Rachel, and Fiona all demonstrate an underlying sentiment that the need to communicate with another person outweighs the benefits of being able to talk to someone about their shared experiences. Although Sophie says that there would be ways to work around the difficulties that would arise from two hard of hearing people dating (she laughed as she suggested "texting everything instead of talking"), all three participants show the importance of functional oral communication.

Continuing with the discussion of severity and communication, two of the participants specifically explain that they would not date someone who is deaf if that person communicated primarily in American Sign Language. Rachel (21, WF, C, 2/3) says that she would not date a deaf person because she does not know ASL “that well” and thus would be unable to communicate with a deaf person. Clair (24, AF, C, 2½) says that she would date someone with a hearing loss “as long as they were primarily mainstreamed” because she thinks it would be “awkward” to date someone who communicated primarily in American Sign Language because, on the one hand, she does not sign and because, on the other hand, dating someone from the Deaf culture creates “an expectation on my part that I should know how to sign.” Clair is “not opposed” to learning ASL, but has “never had time” to learn. For her, anyone who signs is not available as a romantic interest because it is “just weird” dealing with others’ expectations of hard of hearing individuals and her own inability to sign.

Sociological research has noted that “likes attract” in the sense that people who share similar traits, such as cultural, physical, or attitudinal characteristics, are more likely to interact with each other than with people who have dissimilar traits (Centola et al 2007). However, the idea of ‘status homophily,’ that people tend to feel more comfortable when they interact with others who share a similar background (Lazarsfeld and Merton 1954), is apparently not the case for hard of hearing people. In fact, the shared characteristic of hearing loss can sometimes actually be interpreted as a reason for *not* being attracted to a hard of hearing person.

Hearing Dating Hard of Hearing

Participants had different ways of responding to the question about whether or not they believe that people with normal hearing abilities are open to dating people with hearing losses.

Five of the participants answered yes to this question while one answered no. The remaining fourteen participants leaned towards answering yes but then discussed certain factors that might prevent hearing people from wanting to date someone with a hearing loss (see Appendix J, Table 11).

Of the five who believe that hearing people would date hard of hearing people, three use their hearing boyfriend/girlfriend as an example to support their answers. Two of those participants say that their hearing loss is not a “problem” for their significant others (Charlotte 21, WF, C, 2; Steven 26, WM, A, 5). Although Brian (31, WM, H, 8) is included in the group of thirteen who leaned toward yes, he initially responded to this question by saying that his situation answered the question in a way because he “married someone who doesn’t have hearing loss.” Fiona (26, WF, C, 5) says that the man she is currently seeing found her hearing loss “attractive.” Fiona further explains that many men have made positive comments about her hearing loss:

They’re like, *that’s really cool because you’re not...I’m not ashamed of it. I’m proud of it.*

Thus Fiona feels that hearing people would be open to dating hard of hearing people if those individuals were confident in themselves and not afraid to tell people about their hearing loss. The other two participants agree that hearing loss is not a determining characteristic. Megan (21, WF, A, 19) says, “I don’t think someone’s not dating me because I can’t hear.” Additionally, Megan talks about her friend who also has a unilateral hearing loss and says that she knew “someone who dated him and I don’t think it affected anything.” Thus Megan explains that having a hearing loss is not a reason anyone would cite for not wanting to date someone. Lindsay (18, WF, A, 7) says, “I think they would be. Much to my knowledge. They should be.” Although Lindsay does not sound as strongly convinced as the other four participants, she still believes that hearing loss is not a reason for not dating someone.

Hannah (30, WF, H/C, 6), the one participant who does not think that hearing people would date hard of hearing people, answered this question from the perspective of herself when she was younger and still dating. When she started dating her husband, Hannah believed that no one would want to date her because of her hearing loss. Although she is currently married, she does not know if she has “completely gotten rid of that notion.” Working through her reasons for this response, Hannah says:

I'm thinking back to when I was dating and at that point, I didn't feel hearing loss was a desirable trait so, you know, it was a pain. But I think it was just...I mean I wasn't popular and I think part of that, I at least felt, was due to my hearing loss. So it wasn't a, a positive thing. People wouldn't want to have to deal with it, have to work with it, umm, people would have to see past it. And...people don't always do that.

Hannah says that over time she developed a much more positive outlook on her hearing loss. But her explanation of her previous view of hearing loss shows that she believes that other people would find her hearing loss to be such an undesirable trait that no one would want to date her.

The fourteen participants who did not specifically answer yes had various reasons for hesitating to say that hearing people would date people with hearing losses. Similar to the responses for a hard of hearing person dating another hard of hearing person, one reason that was discussed in response to this question was the degree of the person's hearing loss. Participants made remarks like, “I think they, they would...it depends on the degree of the hearing loss” (Clair, 24, AF, C, 2½) or,

I feel like it in theory...yeah, I think so. I think the main issue, like, at least if we're talking about...people with severe hearing loss or people who are deaf is that they...have their own community, sort of. (Chloe 21, WF, APD, 14)

Another participant feels that hearing people are “intimidated” by people with hearing loss, “especially in the case of full onset of hearing loss” because American Sign Language is a foreign language that is very different from English (Sarah 30, WF, A, 23). Will (33, WM, A, 8)

believes that it would depend on the significance of the person's hearing loss and explains that if he was "completely deaf" and "knew no sign language," then "it would be a lot more, more frustrating for my wife." Sophie (40, WF, A, 21) uses her mild unilateral hearing loss as a benchmark to explain her response:

I don't think too many people would be, like, closed to dating someone with my level of hearing loss...just because mostly I'm able to function. I think if...if I had a more severe hearing loss, where I really, you know, it was very difficult to hear most of the time, I think a lot of people would, would not be open to dating, if it was, if it was really hard to communicate with me most of the time...

According to these participants, the more severe a person's hearing loss, the less likely someone with normal hearing would be willing to date him/her. On the one hand, the participants suggest that having a more profound hearing loss isolates a person from the hearing world because a profound hearing loss or complete deafness indicates that a person communicates in American Sign Language. On the other hand, the participants indicate that hearing people are less willing to accommodate individuals with profound hearing losses because communicating with these people requires more patience. As the next section shows, several participants specifically raised this idea of patience and frustration.

Another reason that the participants cited for why hearing people might not date hard of hearing people was how frustrating hearing loss can be for a person with normal hearing and how much patience that person needs in order to interact with a hard of hearing person. Diana (26, AAF, H, 14) simply says, "I think those [hearing people]...who are patient" would date someone with a hearing loss. Will (33, WM, A, 8) says that "it is kind of frustrating" dealing with someone like himself who has a hearing loss. Will believes that a hearing person would be willing to date someone like him "if the person had a lot of patience." Lynn (34, AF, ?, 14) says that her boyfriend is very "supportive" of her hearing loss but that he "does get frustrated, too."

Lynn describes a common scene in which her boyfriend tries to have a conversation with her when she does not have her cochlear implant connected:

But he's like, *oh are you having your, your device on? I'm like no why? Just talk. I'm listening.* [laughs] He's like, *why would I want to talk to you...I'm going to be saying a lot of stuff.* And I'm like *ahhh* [exasperated sound]. [laughs]

The three participants address how frustrating others can find their hearing loss and the importance of patience in a relationship.

Other reasons that the participants discussed can essentially be encompassed by the idea that people who do not have a hearing loss do not understand hearing loss. Kate (26, WF, C/A, 6) says that she postpones disclosing her hearing loss when on a date because she has found that, in the past, telling her dates led them to “start shouting across the table thinking I couldn't hear.”

Kate tells the story of when she was twenty-two and had set up a date with the gym teacher at the school she worked at:

I wore my hair up one day and he cancelled the date and for the rest of the year, every time he would see me, he would yell and move his mouth slowly to make sure I understood: it was so annoying.

Then Kate tried online dating because she figured if she put her hearing loss “out there” on her profile, she “wouldn't be able to see/get hurt if a guy chooses not to talk to me because of it.”

Kate has since had two short-term relationships with two men who have normal hearing:

The guy that I dated last year had a friend in high school who wore hearing aids...and it didn't bother him in the beginning. It became an issue when I met his roommate because he had told him ahead of time and his roommate treated me very differently. From then on, I never met anymore of his friends or family. I take my hearing aids out when I go to the movie theater and watch TV and this was uncomfortable for him to see me take them out: it was like a reminder that I wasn't like him.

Although the hearing man was initially comfortable dating Kate, his roommate's reaction to her and the constant reminder that Kate had a hearing loss influenced how he felt about dating a

woman with a hearing loss. Kate is not alone in this experience. As another example, when Sophie (40, WF, A, 21) suddenly lost her hearing during college, her boyfriend at the time “didn’t know how to deal with it...and we were still together but I felt like he was kind of distancing from me.” In this case, the boyfriend might have been the type of person who is not capable of helping others through major life events. But, as mentioned before, Sarah (30, WF, A, 23) thinks that hearing people are “intimidated” by hearing loss, so perhaps Sophie’s ex-boyfriend was afraid of her sudden hearing loss and thus did not want to continue the relationship. Another way of looking at Sophie’s situation is by considering what kinds of characteristics people imagine that their ideal partner will have. Brian (31, WM, H, 8) says that he wonders whether,

things have to be perfect in the relationship and...you sort of have this picture of what your partner will be and hearing loss probably isn’t one of those characteristics if you are not hard of hearing.

Perhaps people with normal hearing would not be open to dating someone with a hearing loss because that characteristic is not desirable in a partner. And Brian suggests that people with hearing losses would be more open to dating another person with a hearing loss. Brian is not the only participant whose response touched on the differences in what people with and without hearing losses think about. While explaining the cause of his hearing loss, Kevin (26, AM, A, 1) said that “people who hear, they tend to be much more sensitive to, umm...what type of hearing loss we have as opposed to ourselves.” Kevin explains that people with normal hearing have generally been more likely to ask him what caused his hearing loss and have specifically emphasized whether his hearing loss is genetic or acquired. In part, this kind of conversation has come up with girlfriends and the families of his girlfriends because there is an underlying fear that his hearing loss might be inheritable. Based on his previous experiences, Kevin feels that,

hearing people, they tend to be more sensitive to our type of hearing disability whereas, umm, people like ourselves...don't really think about those things. So...hearing people can tend to react in unexpected ways because they either lack the information or they have certain biases.

Rachel (21, WF, C, 2/3) agrees with Kevin to some extent because although she thinks that hearing people would date hard of hearing people, she believes that they “would be cautious about it.” Rachel says that if given the choice to date either a hearing person or a hard of hearing person, “people on the street” would pick the hearing person.

Cooley ([1902] 1983) believed that life is a matter of social interaction: society shapes the individual and individuals shape society. According to Cooley's concept of the looking glass self, individuals develop a sense of self based on the perceived responses of others, meaning that they see themselves as they imagine others see them ([1902] 1983). Applying this concept to hearing loss, participants believed that people with normal hearing might not want to date hard of hearing people because the severity of the hearing loss can impede the hard of hearing person's ability to communicate, hearing people tend to feel frustrated when hard of hearing people cannot keep up with a conversation, and hearing loss is generally an undesirable trait in a potential partner. Following Cooley's logic, hard of hearing people feel that they are not dateable because they believe that other people view their hearing loss as an undesirable characteristic that makes them not dateable. While Cooley believed that one's sense of self is derived directly from other people's opinions, Yeung and Martin (2003) note that other sociologists have suggested that self-construction can occur through the strategic management of information about one's identity (Goffman 1963) or through the manipulation of the emotional displays that one presents to others (Hochschild 1983). Perhaps a hard of hearing person's sense of self is constructed through a complex interplay of the perceived beliefs of people with normal hearing, the perception that hearing loss is a stigma that must be hidden, and the belief that hard of

hearing people must manage their emotions in order to present themselves to others according to specific feeling rules.

Future: Professional

In addition to asking questions about dating practices in order to elicit my participants' uninhibited opinions about hearing loss, I also asked them if they believed that their hearing loss played any role in how they envisioned their futures, both professionally and personally. The purpose of these two questions was to further indirectly explore how hard of hearing people view themselves and their hearing loss. In the process, however, their answers provided additional examples of the management practices hard of hearing people employ.

In terms of their professional futures, half of the participants believed that hearing loss would play some kind of a role in their future employment status while the other half did not. Although their initial answers are evenly divided, further analyzing their responses shows that some of the participants were very conflicted in their opinions and that hearing loss *does* influence participants' considerations about their futures (see Appendix J, Table 14). Only one participant strongly felt that hearing loss does not affect people's future careers. Hannah (30, WF, H/C, 6) says hearing loss "doesn't affect" her professionally because it has never impeded her ability to find or keep a job. Two participants said that hearing loss would not affect their futures, but then explained positive ways in which it actually has. Charlotte (21, WF, C, 2) says that the only influence she can imagine hearing loss playing on her future is to "spark" her interest in audiology because of her "personal experience" with the field. However, Charlotte makes it clear that she is "naturally just fascinated by anatomy" and physiology, so she wants to go into the healthcare field regardless of her hearing loss. Brian (31, WM, H, 8) thinks that "at

this point” in his life he has not “restricted or altered” his career path or “consciously made any career choices” based on how his hearing loss will progress. But hearing loss will affect Brian in the sense that he will always be “invested in reaching out to other people with hearing loss.” Brian believes that “a good chunk” of his time will always be “devoted to hearing-related endeavors,” such as organizing the fundraiser walk that his hearing loss group hosts.

Seven participants said that hearing loss constrains to some degree the jobs that they believe are available to them. Kevin (26, AM, A, 1) says that hearing loss has affected what he wants “to do” because he took into consideration “different careers that fit well with [his] kind of hearing.” Since technology has helped him hear better, Kevin knew that he wanted to go into a field that allowed him to work with technology. Kevin has decided to pursue a career in finance so that he can intertwine his interests in math, technology, and direct client interaction. Lindsay (18, WF, A, 7) says that hearing loss will influence what kind of an “environment” she will work in because she could not tolerate a job that exposed her to “a lot of loud noises all the time.” In part, this is because Lindsay does not want to further damage her hearing. Jen (22, WF, A, 14) also discusses how hearing loss can impact the location of her work. Jen thinks her hearing loss might be “limiting” her options in the healthcare setting because she worries that she might not hear what patients say to her. Jen is considering getting a hearing aid to make her a stronger candidate for a job in the health field. Clair (24, AF, C, 2½) approaches this question by explaining that, “there are some careers that obviously [she] could never do.” For example, Clair initially considered a career in patent law but decided that a career in which she had “to talk to people that much all day” was not “feasible” because of her hearing loss. Despite the goal change, Clair is happy with her decision to go into academia in the sciences. Megan (21, WF, A, 19) thinks her unilateral hearing loss influences her future “a hundred percent.” She says,

I'm interested in the entertainment industry. I know... a lot of television, a lot of film, a lot of radio, music, all that deals with sound... a lot of those things do involve headphones and do involve, like, having things spoken to you in your ears. And number one, if I do have that, okay, like, I could put it in my left ear. But then, I can't hear anything that's going on around me. So what do I do? So yeah, I see it really affecting my career, my future, and it's like... I don't even know how to express that to someone. Or like... I don't know what jobs I can and cannot do.

Megan is clearly concerned about the extent to which her hearing loss will determine the kinds of jobs she will be able to perform in the future. As described earlier, Will (33, WM, A, 8) had the experience of being fired from a job as a cashier at a gas station because he could not hear when the cash register beeped to indicate that the gas pumps were in use. Thus Will notes that his hearing loss does “impact” the jobs he can hold. Also from a practical perspective, Tyler (30, WM, C, 0) says that he must choose jobs based on health insurance and his ability to “maintain having this technology” that allows him to hear. Tyler explains that each of his bone-anchored hearing aids costs \$8,000 and each screw that they snap in to on his head costs \$14,000. Thus Tyler must ensure that he has either the health insurance or the financial resources to pay for his hearing aids if they break or need to be fixed. Whether they think their hearing loss has a positive or negative impact on their future careers, these participants indicate that they do have to take their hearing loss into consideration when contemplating future jobs.

Although five participants initially claimed that their hearing loss did not affect their future career plans, the rest of their responses suggested otherwise. Two of these participants feel that they will be “alright” (Fiona, 26, WF, C, 5) in terms of jobs, but they describe being “worried” that their opinions might change if their hearing continues to deteriorate (Steven, 26, WM, A, 5). As for the other three participants, Sarah (30, WF, A, 23) does not feel “limited” by her hearing loss because she believes she can “adapt” to any job. However, Sarah further explains that there are certain jobs that she “couldn't get into,” such as working as a phone

operator or going back to being a firefighter (a job that she loved). Sarah emphatically states that, “if a career won’t accept me, then I don’t want it.” Diana (26, AAF, H, 14) begins her answer simply saying “no.” When probed, Diana explains:

No. But I do think it, at some point, you know, limits some career options. Unless I’m going to wear hearing aids or something like that.

Similar to Jen, Diana suggests that hearing aids might provide her with more job opportunities. Chloe (21, WF, APD, 14) believes her hearing loss will not influence her future “too much” because her academic interests indicate that her “career options at this point do not really involve a lot of doing work in crowds” or networking. Although Chloe believes her hearing loss is not a “big concern,” she does admit that her strong dislike for networking is “partially” due to her hearing loss. Thus even though these participants did not want to acknowledge it, their responses indicate that they do believe that hearing loss plays some role in their futures.

Five participants explain that hearing loss affects them professionally because it forces them to work harder. Chris (22, AM, A, 20) says that his hearing loss will affect him “negatively” because he will “have to make an extra effort to make up for it.” Chris emphasizes that his hearing loss will not prevent him from succeeding, but that he will “have to make extra effort to...overcome it.” Lynn (34, AF, ?, 14) notes that her Asian friends who are not native English speakers worry that they will not be able to find jobs because they cannot speak or write English perfectly. Lynn worries that her hearing loss will likewise affect her job prospects. However, Lynn says that she reminds herself that she cannot let her hearing loss prevent her from applying to jobs. Thus Lynn works hard to prove that she is “capable” and has the “abilities” to succeed in any job that she wants. Kate (26, WF, C/A, 6) also works hard to show that she is fit for her job as a sign language interpreter. Since her deaf clients sometimes question her ability to interpret because she wears hearing aids, Kate has to work hard to demonstrate that

she is a good interpreter and that her hearing loss does not negatively affect her job performance. Sophie (40, WF, A, 21) thinks her hearing loss has a “small effect” on her professionally because it is “hard” to teach in big lecture halls. Sophie struggles when students speak out without raising their hands or if they talk to each other in class because she cannot tell from which direction the sound is coming. Rachel (21, WF, C, 2/3) says that hearing loss adds “just another thing” for her to think about in professional settings. Rachel does research at another university in which she has to manually take people’s blood pressures by wearing a stethoscope. However, Rachel cannot put the stethoscope in her ears because she wears hearing aids. Whenever she reaches the point when she needs to take the person’s blood pressure, she says:

I always have to get up, leave, go get, like, someone else who can come in and take blood pressure. And just, like, little things like that, which make me, like, not as capable as, like, someone else who works there. So then you kind of feel like you have to overcompensate yourself in other areas that you can do to, like, prove yourself.

As these responses suggest, having a hearing loss requires participants to consider the extra time and effort they will have to exert in any job they desire.

Overall, participants note that hearing loss will impact their professional futures to some extent. Individuals with hearing loss have to be “self-conscious and calculating” (Goffman 1963:14) about the constraints that their hearing loss will place on their job opportunities in a way that people with normal hearing abilities do not. From thinking about the variety of ways in which hearing loss can affect their job choices, to worrying about how the further deterioration of their hearing will influence their professional lives, to physically working harder in order to compensate for the hearing loss, hard of hearing people must manage their personal opinions and fears about hearing loss as well as other people’s observations of their capabilities in the work

force. Thus hard of hearing people perform a great deal of personal and interpersonal work in order to manage their identities.

Future: Personal

In order to further explore the work that people with hearing loss perform while managing their hard of hearing identities, participants were asked if they felt their hearing loss would influence them “personally” in the future (see Appendix J, Table 15). In response five participants said that they might be more open to getting hearing aids or other technologies in the future and six participants discussed a fear that their hearing loss would progress. Sixteen participants placed a specific emphasis on starting a family.

On the topic of technology, participants who did not wear hearing aids as of the interview suggested that they would be more open to wearing them in the future. Chris (22, AM, A, 20) says that he will consider wearing hearing aids when he is forty. Chris believes that current hearing aid technology is “choppy” but that in twenty years hearing aids “will be quite good” and his hearing “will be quite bad” so it will be “time to wear hearing aids.” Chloe (21, WF, APD, 14) thinks that she might wear hearing aids in the future if her hearing loss progresses. And Jen (22, WF, A, 14) says she might look into hearing aids if they will make a noticeable difference in her performance on the job. However, Jen worries that getting a hearing aid might change her “identity” because she feels that hearing with one ear is “normal” and “comfortable” and she wonders what will change if she can suddenly hear differently. Although Charlotte (21, WF, C, 2) and Fiona (26, WF, C, 5) already wear hearing aids, they both mentioned in their interviews that they are open to any new technologies that will benefit them in the future.

Talking about the future was very difficult for the six participants who expressed concerns about what would happen if their hearing loss progressed. Diana (26, AAF, H, 14) thinks that the fact that her hearing is “getting worse” as she gets older is “scary,” in part because she does not want to have to wear hearing aids while she is still young. Chloe (21, WF, APD, 14) says, “you never know what happens” in the future so she is prepared to get hearing aids or learn sign language in case her hearing loss progresses due to ear infections or “some other sort of damage.” Sophie (40, WF, A, 21) says that after her initial loss of hearing, she feared she “was going to lose all of [her] hearing.” At the time, Sophie says,

it was just a feeling of a loss of control because...it was so sudden and unexpected. And...so I was just scared of the future, like, what this was going to mean...And whether I would go completely deaf. Umm, even though the doctors told me that there was no reason to think that I would. But I was scared that I would...the fear of going deaf stayed with me probably for another year at least, after.

Although she is less afraid of going deaf now, Sophie’s comment illustrates that losing one’s hearing is horrifying. Likewise, Fiona (26, WF, C, 5) says that she does not like to talk about how her hearing loss will affect her future because “it’s probably not going to be easy” because her hearing is “getting worse.” Fiona is “scared” of what will happen if she loses all of her hearing: when she is in her seventies or eighties, she wonders if she will “still be able to listen to music or, umm, sing.” Fiona also worries about how her progressive hearing loss will affect her future family:

I think it would be really weird if I heard my child’s voice and then one day couldn’t anymore...I think that’s the kind of stuff that scares me a little bit.

Will (33, WM, A, 8) echoed this fear, saying that his “biggest fear is not being able to hear them [his family] at all.” If his hearing loss progresses, Will worries about how he will maintain good communication with all of his family members, including those he has to talk to on the phone.

Although Steven (26, WM, A, 5) does not think that his hearing loss affects his future life choices, he has “worried” about what will happen if he starts “losing [his] left ear.” If his good ear starts to fail, Steven says, “I’m going to have to change my life. And obviously learn, you know, a different language.” However, Steven does not want to “sit here and worry about it right now.” Steven hopes his left ear will remain “strong” throughout his life but he realizes that he might have to make many life changes if he starts losing hearing in that ear. But he will “deal with that when it comes.” These responses indicate that participants are aware that they might have to make a variety of decisions in regards to their hearing loss as they age but that they prefer not to think about the consequences of losing more of their hearing.

In terms of family, Clair (24, AF, C, 2½) says that her hearing loss makes the idea of having children something to “consider...do I want to have children who have hearing loss as well?” In considering this question, nine participants said that they would prefer that their children not have hearing loss while seven have no preference for children with normal hearing or hearing loss (four participants, including Clair, did not comment on their preferences).

Of the nine participants who preferred that their children do not have hearing loss, some, like Lindsay (18, WF, A, 7), Chris (22, AM, A, 20), and Will (33, WM, A, 8) simply stated that that they would prefer their children to have normal hearing abilities. Kevin (26, AM, A, 1) phrased his answer such that he would prefer that the child did not have hearing loss because he would “want the child to be as healthy as possible.” Rachel (21, WF, C, 2/3) offers a similar rationale. Basing her answer off of her own experience with hearing loss, Rachel believes that, “as awful as it is,” she would prefer a child to not have hearing loss because “you don’t want, like, your child to have a more difficult life than any child has to.” Sarah (30, WF, A, 23) says that although she could help a child adapt to hearing loss, she would prefer that the child did not

have hearing loss because it would “be easier in life for them.” Brian (31, WM, H, 8) says that hearing loss “doesn’t make your life easier,” so he hopes that his children do not inherit his hearing loss. Although Brian knows that hearing loss is “not a barrier that you can’t overcome,” he does not “want that barrier” for his kids. Likewise, Diana (26, AAF, H, 14) says she would prefer a child with normal hearing abilities because,

you want people to be, I don’t want to say perfect, but...[hearing loss is] definitely a problem. It’s definitely, you know, something that I wish I didn’t have. So I wouldn’t want someone, I wouldn’t wish it upon someone else.

Megan (21, WF, A, 19) agrees with Diana and says, “I really hope this would never happen to anyone else I know.” But Megan adds another point:

I hope my kids do not have this. I would fee so horrible. [pause] And I don’t think...it’s not genetic. So, like, it probably won’t happen to them. I don’t know. I mean, I blame my mom for, like, my mom’s five feet tall and I’m, like, *ugh, my mom’s short so I’m short*. Like, *this sucks*...So, like, they’re like, *oh, I can’t hear ‘cause of my mom*. Like, that’s so much worse.

Megan fears that her children would blame her if they developed a hearing loss.

Seven participants that indicated no preference in their children’s hearing abilities. Chloe (21, WF, APD, 14) sounds the least convinced out of this group because she says, “I hope it wouldn’t matter to me” whether a child had hearing loss or not. She thinks a child with a milder hearing loss would be easier to raise than a child with a more severe hearing loss. Jen (22, WF, A, 14) simply said that she would neither select for nor against a child with hearing loss, although she does not worry about her children having hearing loss because hers is acquired. Hannah (30, WF, H/C, 6) remembers meeting with a genetic counselor while she was pregnant to screen for a different condition. The counselor asked if Hannah wanted to do a blood test to check to see if her child had hearing loss. Hannah responded, “*why?*” According to Hannah:

I wear hearing aids, my house is equipped for hearing loss, my husband and I know sign language, there’s nothing we’re going to do before the child’s born

that's going to change things. I knew that, and here in Massachusetts, they have a newborn screening, so...before the kid's three days old, they're finding out whether there's a potential for hearing loss. So I knew within three days after birth, I know whether I need to be signing more or speaking more to my son. And that's exactly what happened...I have absolutely no problem if a child of mine has a hearing loss because they've got a mother that knows exactly how, how it is to have a hearing loss and, you know, we'll work with it.

Fiona (26, WF, C, 5) thinks it might "be kind of cool" to have a hard of hearing child because then she "could relate" to the child. However, Fiona adds that while on one hand it would be "cool," on the other hand it would be "bad." But Fiona has no preference either way. Kate (26, WF, C/A, 6) says that if she has children with normal hearing, she will teach them to be "more accepting and respectful" of hearing loss. Although Kate will "relate more to a child who is hard of hearing or deaf," this is not her "first preference." But Kate has considered adopting a deaf child in order to "teach and show them a more positive lifestyle." Although Sarah (30, WF, A, 23) and Will (33, WM, A, 8) are included in the first group because they preferred not to have a hard of hearing child, both say that they would be able to serve as positive role models for a hard of hearing child should they have one. Returning to the topic of adoption, Tyler (30, WM, C, 0) has considered adoption because,

there are probably kids who are up for adoption who are just tossed aside because they have "something"...putting that in quotes, they have "something" wrong with them.

Tyler is not opposed to adopting a child with a hearing loss. Although Sophie (40, WF, A, 21) does not think that she would be doing a child a "disservice" by passing along a hearing loss (hers is acquired so she was speaking hypothetically) because a hard of hearing person can "have a full life," she would still wonder, "would I want them to, like, have to go through this?" Since Sophie believes that hearing loss is a disability that does not prevent one from enjoying one's life, she does not think she would have a preference for a child with or without hearing loss.

The difficulty that many participants had in talking about the effect of their hearing loss on their futures is informative. While some participants positively described the increased role that technology will play in their lives as they get older, others explained that their fear of losing their hearing can be paralyzing if they let themselves think about the progression of hearing loss for too long. Furthermore, while a person with a stigmatized condition is said to “*naturally*” belong with individuals who are “fellow-sufferers” of the same condition (Goffman 1963:112), discussing their preferences for either a hearing child or a hard of hearing child indicates that people with hearing loss are conflicted by their status as individuals who are in-between the deaf and the hearing worlds. For hearing parents, hearing loss is a disability to be avoided, and for Deaf parents, deafness is rich culture that they would love to be able to share with their child (Oliva 2004; Brueggemann 2009; Valente 2011). Whereas it can be assumed that both hearing and Deaf parents want children who are like them, hard of hearing people do not have a specific identity based on their audiometric abilities that they would necessarily want to share with their children. Although participants indicated that hearing loss is a manageable disability and that they would personally serve as good role models for a child with hearing loss, they also said that a child with normal hearing abilities (thus a child without a hearing loss) would have an easier life with fewer barriers to overcome. Participants’ hypothetical discussion about having a child with hearing loss reflects their true personal opinions of themselves as individuals with hearing loss: through “hard work and persistent self-training,” hard of hearing people are capable of living their lives according to the “ordinary standards” set forth by the rest of society (Goffman 1963:115). Despite their beliefs that hearing loss is a part of who they are and despite their abilities to manage and normalize their hearing loss and their stigmatized identities, hard of hearing people ultimately find themselves torn between thinking that hearing loss is a positive

part of their identity and thinking that hearing loss is a negative trait that has caused them more harm than good.

CONCLUSION

Based on my findings, I contend that people with hearing loss should be understood to be citizens of a liminal space. Similar to the members of other identity groups (such as race or sexual orientation), hard of hearing people perform stigma management, identity management, and emotional labor in order to allow themselves to pass between the two diametrically opposite groups on either side of them. Since hard of hearing people are afloat somewhere between the hearing and deaf worlds, they turn to tactics similar to those employed by other stigmatized groups. Through the processes discussed in the previous analysis that are involved in adjusting to hearing loss and learning how to manage both a hearing loss and a hard of hearing identity, people with hearing loss use time-tested strategies for coping with a stigmatized identity. As my participants demonstrate, people with mild hearing loss often become particularly adept at passing as hearing people in the hearing world.

But passing between two worlds does not make for the most comfortable of existences. Susan Sontag (1978) describes illness as travel and says that everyone holds two passports, one for the country of the healthy people and one for the country of the sick people. Applying this metaphor to my participants, people with hearing loss have a sort of dual citizenship between the hearing and the deaf worlds. While passing allows people with hearing loss to travel among people with normal hearing abilities in what Sontag would refer to as the world of the healthy, most people with hearing loss “do not live fully in either hearing or Deaf worlds” but rather are stuck in an “in-between” world (Valente 2011:13). In this in-between space, people with hearing

loss struggle to fully understand their identity (Brueggemann 2009) because living in liminality provides only a marginal sense of belonging compared to the sense of identity and belonging that comes from one's ability to identify as fully hearing or fully Deaf.

Further, hard of hearing people feel more deeply entrenched in living in a liminal space because they are not actually sure why their hearing loss is stigmatized. On a superficial level, this means that hard of hearing people do not think that their hearing loss is 'bad enough' to prevent them from functioning in hearing society. On a deeper level, this idea heads straight back to Goffman's (1963) three types of stigma: Goffman differentiated between the physical deformities, the "blemishes of individual character" (such as mental illness, homosexuality, or unemployment), and the "tribal" stigmas including religion or race (4). Other stigmatized groups that rely on passing to maneuver between two different worlds can neatly place their stigmas into one of the three categories. For example, gays, lesbians, and bisexuals can see that their stigma is considered a deviation in a personal trait while the stigmatized attribute of multiracial individuals is a tribal stigma. But hard of hearing people are not quite certain how to interpret their stigma because it is not always physically visible and, unlike Deaf people, they do not view hearing loss as a cultural trait. Thus in every aspect of their lives, hard of hearing people live liminally.

Despite the limitations of my own study, namely the small sample size and skewed demographic characteristics, I believe that I have demonstrated the enormous effort undertaken by hard of hearing people in order to manage the stigma of hearing loss and their identification as individuals with a hearing loss. From this point, I believe that further research is needed to explore what must occur in order for hard of hearing people to move out of their liminal space and whether their space is even a terrible place to reside. While an answer could be extrapolated from research on other stigmatized groups, in order to concretely address these questions, further

research is needed that is specific to the lived experiences of young adults who are hard of hearing.

Another major area of research that should be explored is the effect of microaggressions on people with hearing loss. Microaggressions are “covert expressions of discrimination” towards a particular group of people (Keller and Galgay 2010:243). They appear as “subtle, stunning, often automatic, and non-verbal exchanges which are ‘put-downs’” (Pierce et al 1978:66). Much literature has studied the effect of microaggressions on other minority groups, but the lens of research has only recently turned towards people with disabilities. I believe hard of hearing people would benefit from a close analysis of the effect that the little and apparently insignificant acts of discrimination they experience on a daily basis has on their experience with hearing loss and their perception of themselves as hard of hearing people.

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Appendix B

Recruitment Script

Hello!

My name is Jessica West and I am a senior at the University of Michigan. I am conducting research for my Honors Thesis in Sociology under the supervision of Dr. Elizabeth A. Armstrong in the Department of Sociology. I am interested in learning about the perception of hearing loss among college students who have mild to moderate hearing losses. I chose this topic because I have a hearing loss. If you are between the ages of 18 and 40 and have a mild to moderate hearing loss, I would like to have you fill out a brief questionnaire and then interview you. The questionnaire will ask you about your age, gender, race, university affiliation, and where you are from, as well as ask you a series of questions about how well you hear in certain situations. The interview will last at least half an hour and will not exceed two hours. I will ask questions about your experience of hearing loss: when you first learned about your hearing loss, how you were informed about your hearing loss, the cause of your hearing loss, what kinds of information and expectations you had about hearing loss, and your relationships with hearing and hard of hearing family or friends. Interviews will be digitally recorded, and the recording will be destroyed once I have completed the thesis. Your name and responses will be kept completely confidential. Interviews will be conducted at a time and place that is convenient for you. Please email (jswest@umich.edu) or call (508-221-2713) me with a day and time that works for you and we can finalize a time for the interview.

Thank you for your time!

Jessica West

Appendix C
Informed Consent

Consent to Participate in a Research Study
**THE EFFECTS OF HEARING LOSS ON YOUNG ADULTS WITH MILD TO
MODERATE HEARING LOSSES**

Principal Investigator: Jessica West, Department of Sociology, University of Michigan
Faculty Advisor: Elizabeth A. Armstrong, Ph.D., Department of Sociology,
University of Michigan
Faculty Advisor: Karin A. Martin, Ph.D., Department of Sociology, University of
Michigan

You are invited to participate in a research study about the perceptions of hearing loss among young adults with mild to moderate hearing losses. The purpose of this study is to learn how young people experience, adjust to, and perceive their hearing loss.

INFORMATION

Approximately thirty people will be invited to be a part of this research study. If you agree to participate, you will be asked to complete a brief questionnaire and participate in one face-to-face interview at the time and location of your choice. The questionnaire will ask you about your age, gender, race, university affiliation, and where you are from, as well as ask you to respond to a series of questions about how well you hear in certain situations. The interview will last about an hour and a half, and will not exceed two hours. I will ask questions about your experience of hearing loss: when you first learned about your hearing loss, how you were informed about your hearing loss, the cause of your hearing loss, what kinds of information and expectations you had about hearing loss, and your relationships with hearing and hard of hearing family or friends.

I would like to record the interview to ensure that our conversation is recorded accurately, but you may still participate in the research even if you decide not to be taped. If you are comfortable with our conversation being recorded, I will record the conversation and later transcribe it. The recording will be deleted when I finish my project.

BENEFITS

Although you may not directly benefit from participating in this study, some people find that sharing their stories is a valuable experience. I hope that this study will contribute to the knowledge about how young adults deal with hearing loss so that hearing specialists as well as people with hearing loss and their friends and family can better understand what can be done to make the adjustment to hearing loss easier.

RISKS AND DISCOMFORTS

Answering questions or talking with others about the experience of hearing loss can be uncomfortable or difficult. You may decline to answer any interview question and you can end your participation in this study at any time.

CONFIDENTIALITY

I plan to use the responses from my interviews in my Honors Thesis, but I will not include any information that could potentially connect you to my research. I will not use your real name in the written copy of the interview or in the final thesis. To keep your information safe, the audiotape recordings will be deleted as soon as a word-for-word copy of the interview has been created and all data will be entered onto a password-protected computer. All email communication will be deleted once the interview is finished. My faculty advisors might request to look at the data that I am collecting, but otherwise I will be the only person who has access to your responses.

PARTICIPATION

Your participation in this study is completely voluntary. You may refuse to participate in this study without penalty. Even if you decide to participate now, you may change your mind and withdraw from the study at any time. If you decide to withdraw from the study before your data collection session is completed, your information will be returned to you or destroyed. In exchange for your participation in this research project, you will receive a \$5 gift card to Starbucks.

CONTACT

If you have questions about this research, including questions about the scheduling of your interview or any other concerns, you may contact the researcher, Jessica S. West, a student in the Department of Sociology, Room 3001, 500 South State Street, Ann Arbor, MI 48109, at 508-221-2713, and at jswest@umich.edu. You may also contact my advisors, Elizabeth A. Armstrong (elarmstr@umich.edu) or Karin A. Martin (kamartin@umich.edu).

Appendix D

Pre-interview Questionnaire

Demographic Questionnaire

Directions: Please answer the following questions (circle or write in) as accurately as possible.

1. How old are you currently? _____
2. Are you enrolled in a college? *Yes* *No*
If yes, please indicate which college _____
3. What gender are you? _____
4. What race/ethnicity do you most closely identify with?
White
Black, African-American
Asian
Hispanic
Other, please specify _____
5. Where are you from (state, country, etc)? _____
6. Please indicate which of the following choices you feel best describe you (circle all that apply):
Hearing
Hearing impaired
Hard of hearing
Deaf
Other, please specify _____
7. If you know, please indicate what kind of hearing loss you have. Circle all that apply.
Hereditary *Congenital* *Acquired*
Unilateral *Bilateral*
High frequency *Low frequency*
Sensorineural *Conductive*
Decibel and frequency range _____
Other, please explain _____
8. Do you have a problem hearing over the telephone? (Circle the appropriate response)
Always *Often* *Sometimes* *Rarely* *Never*
9. Do you have trouble following the conversation when two or more people are talking at the same time?
Always *Often* *Sometimes* *Rarely* *Never*

10. Do people complain that you turn the TV volume up too high?
Always Often Sometimes Rarely Never
11. Do you have to strain to understand conversation?
Always Often Sometimes Rarely Never
12. Do you have trouble hearing in a noisy background?
Always Often Sometimes Rarely Never
13. Do you find yourself asking people to repeat themselves?
Always Often Sometimes Rarely Never
14. Do many people you talk to seem to mumble (or not speak clearly)?
Always Often Sometimes Rarely Never
15. Do you misunderstand what others are saying and respond inappropriately?
Always Often Sometimes Rarely Never
16. Do you have trouble understanding the speech of women and children?
Always Often Sometimes Rarely Never
17. Do people get annoyed because you misunderstand what they say?
Always Often Sometimes Rarely Never
18. Do you view hearing loss as (check all that apply):
 A disability or handicap
 Part of who I am
 A culture or means of relating to a group of people
 A good thing / something to be proud of
 A bad thing / something to be ashamed of
 None of the above

Appendix E

Interview Guide

*Before we begin, I would like to tell you a little bit about my research project. The purpose of my study is to find out what happens to young people as a result of their being diagnosed with hearing loss. What factors are most influential in how one comes to perceive hearing loss? Since this kind of information can only be found by talking to someone who has gone through the experience, I want to hear your story.

Onset Category

1. Age of onset of hearing loss and how one is informed about hearing loss
 - Could you begin by explaining to me how you first learned about your hearing loss?
 - How old were you when your hearing loss was first noticed?
 - Who was the first person to notice (is there any story behind what made them notice that you were having difficulty hearing)?
 - When you were diagnosed with hearing loss...
 - What kinds of things were you thinking – what kinds of emotions did you feel?
 - Who was with you at this time? How did they react to this information?
 - In terms of the person who diagnosed your hearing loss:
 - How would you describe the hearing ability of the person who informed you of your hearing loss? Did their hearing ability have any impact on you?
 - Was this person able to answer your questions and help you adjust? Did you feel that your informer prepared you for what changes you should expect?
 - Did your informer teach you how to use your device – help you prepare strategies for how to deal with reactions from friends, family, coworkers, strangers

Onset category

2. Assistive hearing technology
 - Do you use any assistive hearing technology?
 - Is there a reason why you do not?
 - What is it like wearing it or using it on a daily basis?
 - How old were you when you first began using this device?
 - What did you do with the device when you first got it (wear it immediately daily or only sometimes)? What made you wear/not wear the device?
3. Cause of hearing loss
 - How would you describe the cause of your hearing loss?
 - Genetic/hereditary versus nongenetic/acquired – explain what caused it
 - Has the cause of your hearing loss influenced how you feel about your hearing loss?
 - How do you view your hearing loss?

Later Adjustment Category

4. Adjusting to hearing loss
 - Could you tell me what it was like for you to adjust to your hearing loss?
 - Was there a major adjustment at all?

- What kinds of sounds did you hear? How did you describe what you were hearing?
- What did you expect the assistive technology to do for you? Did they live up to your expectations?
- Who was the most helpful during your adjustment?
- Do you think people notice your hearing loss?
- What has school and/or work been like for you?
 - Compared to your peers do you find that you work less hard, as hard, or harder? Why do you think that is?

5. Relationships

- Aside from yourself, has anyone in your family been diagnosed with hearing loss? Can you tell me what this has been like for you?
 - What did you learn from their experiences?
 - How integrated do you feel in your family life (able to participate in events)?
- Could you tell me what it's like for you to disclose that you have a hearing loss? How do you decide whom to tell about your hearing loss? Are there certain contexts or types of people that you tell?
 - Do you tell people about your hearing loss? If no, why not?
 - If yes – who do you decide to tell, how do you decide to tell them, what do you tell them
 - How often do you talk about hearing loss with your family? Your friends?
 - Do you consider yourself deaf or hearing?
- Tell me about your friends. What are their hearing abilities?
 - How important is it for you to have a friend(s) who is diagnosed with hearing loss?
 - Does having a hearing loss make another person more or less attractive to you as a friend – is it more comfortable to talk to one or the other?
 - How close do you feel to other people with hearing losses?
 - Are you involved in any hearing loss groups? Why or why not?
- Since you were diagnosed with hearing loss, how much of the time has this diagnosis interfered with your social activities (e.g. visiting friends/relatives, going to parties, etc)?
- Some people that I have talked to say that they would consider dating a person with a hearing loss while others say that they would not consider dating a person with a hearing loss. What do you think?
 - Do you think hearing-normal people would date a person with a hearing loss?
- Do you think that hearing loss plays a role in how you imagine your future, both professionally (career) and personally (family)?
 - Do you foresee yourself having kids?
 - How important is it for you to have a child with a hearing loss?

- Do you have any last thoughts or stories you would like to share?

Appendix F

National Institute on Deafness and Other Communication Disorders

Ten Ways to Recognize Hearing Loss

The following questions will help you determine if you need to have your hearing evaluated by a medical professional:

Do you have a problem hearing over the telephone? (Circle the appropriate response)

Yes *No*

Do you have trouble following the conversation when two or more people are talking at the same time?

Yes *No*

Do people complain that you turn the TV volume up too high?

Yes *No*

Do you have to strain to understand conversation?

Yes *No*

Do you have trouble hearing in a noisy background?

Yes *No*

Do you find yourself asking people to repeat themselves?

Yes *No*

Do many people you talk to seem to mumble (or not speak clearly)?

Yes *No*

Do you misunderstand what others are saying and respond inappropriately?

Yes *No*

Do you have trouble understanding the speech of women and children?

Yes *No*

Do people get annoyed because you misunderstand what they say?

Yes *No*

If you answered "yes" to three or more of these questions, you may want to see an otolaryngologist (an ear, nose, and throat specialist) or an audiologist for a hearing evaluation.

Appendix G

Definitions of Select Terms²

Auditory processing disorder (APD): Auditory processing skills include the ability to discriminate between sounds that are important and sounds that are ignorable background noise, which direction a sound is coming from, and the timing of a sound. A person with APD experiences difficulty making sense of or understanding sounds because of trouble processing auditory frequency, intensity, and temporal information in the central nervous system. APD can be acquired through neurological problems caused by a variety of factors including surgical accidents, head injury, tumors, oxygen deficiency, strokes, or infections.

Bone-anchored hearing aid: A bone-anchored hearing aid is a type of hearing aid primarily meant for people with conductive hearing losses. The internal portion of the aid is surgically mounted in the person's head and an external hearing processor can then be attached to the internal portion to amplify auditory information based on bone conduction.

Communication Access Real-time Translation (CART): CART is a court recording system that provides real-time and verbatim captions. A CART provider types out the auditory information on a specialized keyboard so that deaf and hard of hearing people can read what is being said.

Cochlear implant: A cochlear implant is an electronic hearing device that is surgically implanted into a person's cochlea, or inner ear. The implant stimulates the nerves of the inner ear, which produces useful hearing sensations. The implant has two parts: an external part that includes the microphone, sound processor, and transmitter system, and the implanted part that includes the receiver and electrode system. A magnet holds the internal and external parts together.

Frequency modulation (FM) system: An FM system uses a similar signal to radios. A microphone transmits sounds from the source directly to the person wearing the receiver. The device is generally worn on the deaf or hard of hearing person's body. In classroom settings, teachers can wear headsets that transmit their voices to a student's FM system.

Hearing aid: A hearing aid is a sound-amplifying device. Hearing aids vary by design, the type of technology used to amplify sound (e.g. analog or digital), and special features. Most hearing aids include a microphone to locate sound, amplifier circuitry that makes sounds louder, a receiver that transports amplified sound to the ear canal, and batteries to power the electronic parts.

Mastoidectomy: A mastoidectomy involves the surgical removal of the mastoid bone or process, which is located on the temporal bone behind the external ear. This surgery is used to treat infections of the mastoid cells that occur when ear infections spread to the bone in the skull. The advent of antibiotics made mastoidectomy a much less common surgical procedure.

² Definitions compiled from the Centers for Disease Control and Prevention website, the Gallaudet University website, the University of Michigan Services for Students with Disabilities website, the U.S. Food and Drug Administration website, and the National Institute on Deafness and Other Communication Disorders.

Text Telephone or teletypewriter (TTY): A TTY is a terminal that allows for two-way text conversation via a telephone line. A person can type a message on a typewriter-sized telecommunication device for the deaf (TDD), and the message will be sent over the telephone line to a compatible device where the message will be displayed electronically for the recipient to read. Telephone services have been developed in which a human relay operator transmits the messages between two people, which allows hard of hearing and deaf people to communicate with hearing people on a regular voice phone.

Tinnitus: Tinnitus is the perception of sound or ringing in a person's head or ears even when no external sound source is present. Tinnitus can affect people with normal hearing.

Tympanostomy tubes: Conductive hearing loss is sometimes caused by ear infections when fluid collects in the middle ear behind the eardrum. If infections do not go away on their own or through the use of medication, small, cylindrical tubes can be surgically inserted into the eardrum to drain the fluid out. Short-term tubes generally stay in place for six months before falling out on their own. Long-term tubes have grips that secure them in to place, and they either fall out on their own or must be removed by a doctor.

Appendix H
Study Population Characteristics

| Participant | Current Age | Gender | Race/Ethnicity | Cause | Onset Age |
|----------------|-------------|--------|------------------|------------------------------|-----------|
| 01 (Jen) | 22 | F | White | Acquired | 14 |
| 02 (Charlotte) | 21 | F | White | Congenital | 2 |
| 03 (Brian) | 31 | M | White | Hereditary | 8 |
| 04 (Clair) | 24 | F | Asian | Congenital | 2 1/2 |
| 05 (Lynn) | 34 | F | Asian | ? | 14 |
| 06 (Steven) | 26 | F | White | Acquired | 5 |
| 07 (Kate) | 26 | F | White | Congenital/Acquired | 6 |
| 08 (Sarah) | 30 | F | White | Acquired | 23 |
| 09 (Tyler) | 30 | M | White | Congenital | 0 |
| 10 (Will) | 33 | M | White | Acquired | 8 |
| 11 (Fiona) | 26 | F | White | Congenital | 5 |
| 12 (Kevin) | 26 | M | Asian | Acquired | 1 |
| 13 (Sophie) | 40 | F | White | Acquired | 21 |
| 14 (Diana) | 26 | F | African American | Hereditary | 14 |
| 15 (Rachel) | 21 | F | White | Congenital | 2 or 3 |
| 16 (Chloe) | 21 | F | White | Auditory Processing Disorder | 14 |
| 17 (Hannah) | 30 | F | White | Hereditary/Congenital | 6 |
| 18 (Megan) | 21 | F | White | Acquired | 19 |
| 19 (Lindsay) | 18 | F | White | Acquired | 7 |
| 20 (Chris) | 22 | M | Asian | Acquired | 20 |

Appendix I
Participant Variables

| Age (years) | Number of Participants | Percent (%) |
|-------------|------------------------|-------------|
| 18 | 1 | 5% |
| 21 | 4 | 20% |
| 22 | 2 | 10% |
| 24 | 1 | 5% |
| 26 | 5 | 25% |
| 30 | 3 | 15% |
| 31 | 1 | 5% |
| 33 | 1 | 5% |
| 34 | 1 | 5% |
| 40 | 1 | 5% |

n = 20 participants

| Gender | Number of Participants | Percent (%) |
|--------|------------------------|-------------|
| Male | 16 | 30% |
| Female | 14 | 70% |

n = 20 participants

| Race | Number of Participants | Percent (%) |
|------------------------|------------------------|-------------|
| Black/African American | 1 | 5% |
| Asian | 4 | 20% |
| White | 15 | 75% |

n = 20 participants

Appendix I (continued)
Participant Variables

| Table 4. Participant Variable – Cause of Hearing Loss | | |
|--|-------------------------------|--------------------|
| Cause of Hearing Loss | Number of Participants | Percent (%) |
| Acquired | 9 | 45% |
| Congenital | 5 | 25% |
| Hereditary | 2 | 10% |
| Congenital/Acquired | 1 | 5% |
| Congenital/Hereditary | 1 | 5% |
| Unknown | 1 | 5% |
| Auditory Processing Disorder | 1 | 5% |
| n = 20 participants | | |

Appendix J
Tables

| Table 5: Thoughts About Permanence and Fixing | | |
|--|-----------------------------------|------------------------|
| | Number of Participants | Percent (%) |
| Permanence and Fixing | 14 | 70% |
| Thought they would not lose hearing | 2 | |
| Thought hearing loss was not permanent | 5 | |
| Thought hearing loss could be fixed | 9 | |
| n = 20 participants | | |

Table 6: The Effect of Hearing Loss on the Academic Environment

| | Number of Participants | Percent (%) |
|---|-----------------------------------|------------------------|
| Academic setting (general) | | |
| Did not talk about academics | 1 | 5% |
| Hearing loss is not a problem in class | 4 | 20% |
| Hearing loss has been or continues to be a problem in class | 15 | 75% |
| Class size | 6 | |
| Teaching style | 2 | |
| Personal accommodations | | |
| Position in class | 5 | |
| External accommodations | | |
| Deciding to register with disabilities office | | |
| Unregistered | 7 | 35% |
| Registered | 12 | 60% |
| Told to register by someone else | 3 | |
| Deciding to use disability services | | |
| Felt uncomfortable using services | 3 | |
| Managing presence of accommodations in the classroom | | |
| Visibility of accommodations | 2 | |
| Do not tell others | 2 | |
| Benefits of disabilities office | 3 | |
| Disclosure in academic setting | | |
| Do not disclose | 7 | 35% |
| Do disclose | 10 | 50% |
| Did not discuss disclosure | 3 | 15% |
| Outside work | | |
| Work harder to get the same information | 3 | |
| Process of disclosing hearing loss | 2 | |
| Managing self and own reactions | 3 | |
| Work harder to do well academically | 5 | |

n = 20 participants

Table 7: Pre-Interview Questionnaire - View of Hearing Loss

| Participant | View of Hearing Loss | | | | | |
|---------------------|----------------------|------------------|---------|------------|-----------|-------------------|
| | Disability/Handicap | Part of who I am | Culture | Good thing | Bad thing | None of the above |
| Jen | x | x | | | | |
| Charlotte | | x | | | | |
| Brian | x | x | x | | | |
| Clair | | x | | | | |
| Lynn | | x | | | | |
| Steven | | x | | | | |
| Kate | | x | x | | | |
| Sarah | | | | | | x |
| Tyler | | x | | x | | |
| Will | | x | | | | |
| Fiona | x | x | | x | | |
| Kevin | x | x | | x | | |
| Sophie | x | x | | | | |
| Diana | x | x | | | x | |
| Rachel | | x | | | | |
| Chloe | x | x | | | | |
| Hannah | | x | x | x | | |
| Megan | x | x | | | | |
| Lindsay | | x | | | | |
| Chris | x | | | | | |
| Total | 9 | 18 | 3 | 4 | 1 | 1 |
| n = 20 participants | | | | | | |

Table 8a: Pre-Interview Questionnaire – Term Used to Identify Oneself

| Participant | Term | | | |
|---------------------|----------|------------------|-----------------|----------|
| | Hearing | Hearing Impaired | Hard of Hearing | Deaf |
| Jen | | x | x | |
| Charlotte | | x | x | |
| Brian | | x | x | |
| Clair | | x | x | x |
| Lynn | | x | | |
| Steven | | x | | |
| Kate | | | x | |
| Sarah | | | x | |
| Tyler | | x | x | |
| Will | | | x | |
| Fiona | | | x | |
| Kevin | | x | x | |
| Sophie | | x | | |
| Diana | | | x | |
| Rachel | | x | x | |
| Chloe | x | | | |
| Hannah | | | x | |
| Megan | | x | x | |
| Lindsay | x | | | |
| Chris | | | x | |
| Total | 2 | 11 | 15 | 1 |
| n = 20 participants | | | | |

Table 8b: Term Used to Identify Oneself

| Term | Number of Participants | Percent (%) |
|--|-------------------------------|--------------------|
| Hearing | 2 | 10% |
| Hearing Impaired | 3 | 15% |
| Hard of Hearing | 7 | 35% |
| Hearing Impaired <i>and</i> Hard of Hearing | 7 | 35% |
| Hearing Impaired, Hard of Hearing, <i>and</i> Deaf | 1 | 5% |
| Deaf | 0 | 0% |
| n = 20 participants | | |

Table 9: View of Hearing Loss versus Term Used to Identify Oneself

| Term Used to Identify Oneself | View of Hearing Loss | |
|--------------------------------------|-----------------------------|-------------------------|
| | Disability | Part of who I am |
| Hearing impaired | 1 | 3 |
| Hard of hearing | 3 | 6 |
| Both | 4 | 8 |
| Hearing | 1 | 2 |
| Deaf | 0 | 1 |
| n = 20 participants | | |

Table 10: Are you open to dating a person with a hearing loss?

| | Number of Participants | Percent (%) |
|-----------------------------------|-----------------------------------|--------------------|
| Yes, hearing loss is not a factor | 10 | 50% |
| Beneficial | 3 | |
| No issue | 6 | |
| Exposure (negative) | 1 | |
| Communication/degree | 3 | |
| Not closed, but raised issues | 10 | 50% |
| Exposure | 3 | |
| Communication/degree | 5 | |
| Both | 1 | |
| Did not elaborate | 1 | |

n = 20 participants

Table 11: Are hearing people open to dating hard of hearing people?

| | Number of Participants | Percent (%) |
|--|-----------------------------------|--------------------|
| Yes | 5 | 25% |
| Use significant other as an example | 3 | |
| Hearing loss is not a determining factor | 2 | |
| No (undesirable trait) | 1 | 5% |
| Yes, but it depends | 14 | 70% |
| Degree of hearing loss | 5 | |
| Patience/frustration | 3 | |
| Fear and lack of understanding of hearing loss | 8 | |

n = 20 participants

Table 12: Personal Openness to Dating People with Hearing Loss versus Perceptions of Hearing People’s Openness to Dating People with Hearing Loss

| Perceptions of Hearing People’s Openness | Personal Openness | |
|--|-----------------------------------|-------------------------------|
| | Yes, hearing loss is not a factor | Not closed, but raised issues |
| Yes | 4 | 1 |
| No | 1 | 0 |
| Yes, but it depends | 5 | 9 |
| n = 20 participants | | |

Table 13: Relationship Status

| | Number of Participants | Percent (%) |
|--|------------------------|-------------|
| In a relationship with a hearing person | 12 | 60% |
| Experience in a relationship with a hard of hearing person | 2 | 10% |
| Married to a hard of hearing person | 1* | |
| Has dated hard of hearing people in the past | 1 | |
| Did not mention relationship status | 6 | 30% |
| n = 20 participants | | |

*The spouse’s hearing loss was not diagnosed until after they were married and he still does not acknowledge his hearing loss.

Table 14: Effect of Hearing Loss on Professional Future

| | Number of Participants | Percent (%) |
|--|-------------------------------|--------------------|
| Hearing loss has no effect | 1 | 5% |
| Hearing loss does not influence career | 1 | |
| Say hearing loss has no effect, but then describe ways that it actually does influence their futures | 7 | 35% |
| Positive | 2 | |
| Negative | 5 | |
| Hearing loss has an effect | 12 | 60% |
| Constrains the types of jobs that they can have | 7 | |
| Makes them work harder | 5 | |
| n = 20 participants | | |

Table 15: Effect of Hearing Loss on Personal Future

| | Number of Participants | Percent (%) |
|---|-------------------------------|--------------------|
| Will be more open to getting hearing aids or other technology | 5 | 25% |
| Fear their hearing loss will progress | 6 | 30% |
| Considerations about family | 16 | 80% |
| Prefer that child does not have hearing loss | 9 | |
| No preference | 7 | |
| Did not specify preference | 4 | |
| n = 20 participants | | |