2014

I Can't Hear You But I'm Not Sure I'm Going to Tell You: Perceptions of Stigma and Disclosure for Individuals who are Deaf or Hard of Hearing

Brittany Nicole Lash
University of Kentucky, brittany.lash@uky.edu

I CAN'T HEAR YOU BUT I'M NOT SURE I'M GOING TO TELL YOU:
PERCEPTIONS OF STIGMA AND DISCLSOURE FOR INDIVIDUALS
WHO ARE DEAF OR HARD OF HEARING

—————————————————————

DISSERTATION

—————————————————————

A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information
at the University of Kentucky

By
Brittany Nicole Lash

Lexington, Kentucky

Director: Dr. Donald W. Helme, Associate Professor of Communication

Lexington, Kentucky

2014

ABSTRACT OF DISSERATION

I CAN'T HEAR YOU BUT I'M NOT SURE I'M GOING TO TELL YOU:
PERCEPTIONS OF STIGMA AND DISCLSOURE FOR INDIVIDUALS
WHO ARE DEAF OR HARD OF HEARING

Communication processes can be affected by stigma – a negative evaluation of an individual's attributes that discredits or identifies the individual as not normal (Goffman, 1963). One such communicative process that is affected by stigma is disclosure. Disclosure is when individuals share personal information that reveals something not previously known (Charmaz, 1991). One such group of individuals who may be forced to choose between disclosing (to get accommodations or social support) and avoiding stigma (by not disclosing) is individuals with disabilities (Braithwaite, 1991; Charmaz, 1991).

This study focuses on one particular population of individuals with disabilities – those with a hearing loss. Through the use of interactive interviewing and Communication Privacy Management (CPM) theory, this study examines hard of hearing and deaf individuals' perceptions of both the disclosure process and stigma. CPM examines how and why people conceal or reveal private information, such as hearing loss (Petronio, 1991, 2002). Using CPM, this study poses research questions surrounding how hard of hearing individuals disclose and manage turbulence surrounding their hearing loss. Further, participants' perceptions and responses to stigma surrounding hearing loss are also examined.

Based on the participants' responses, managing the boundaries surrounding their hearing loss includes considerations of identity, the other person/people in the interaction, risks of not disclosing, timing, and how much to disclose. Further, participants viewed boundary turbulence as positive only when it was helpful; otherwise, they reported a feeling of a loss of control. In examining stigma and other consequences of disclosure, participants talked about being labeled, not being worth others' time, and being seen as incapable. Finally, participants reported a wide variety of responses to stigma

surrounding their hearing loss. In this study, I also discuss the implications of these findings, both theoretical and practical implications, and how they reflect the lives of the deaf and hard of hearing. Finally, I address the directions for future research on this topic as well as the limitations to this study.

KEYWORDS: Stigma, Disclosure, Hard of Hearing, Deaf,
                      Communication Privacy Management

Brittany Nicole Lash

April 28, 2014

I CAN'T HEAR YOU BUT I'M NOT SURE I'M GOING TO TELL YOU:
PERCEPTIONS OF STIGMA AND DISCLSOURE FOR INDIVIDUALS
WHO ARE DEAF OR HARD OF HEARING

By

Brittany Nicole Lash

Dr. Donald W. Helme
Director of Dissertation

Dr. Timothy L. Sellnow
Director of Graduate Studies

April 28, 2014

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

CHAPTER ONE: INTRODUCTION

Communication, Stigma, and Hearing Loss

Communication can be affected by the perceptions of others and the effects these perceptions have on the individual being evaluated. One perception that may influence communication and relationships between individuals is stigma. According to Goffman (1963), stigma results from society's categorization of an individual, based on a negative evaluation of his or her differences, that identifies such individual as weak, dangerous, bad, or not normal. The person "is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). This devaluation of an individual can result in the discrediting of the individual (Goffman, 1963). Crocker, Major, and Steele (1998, as cited in Southall, Gagne, & Jennings, 2010) provide a similar definition of stigma as "the possession of, or belief that one possesses an attribute or characteristic that conveys a social identity that is devalued" (p. 804). Attributes that may cause societal devaluation include disabilities and handicaps as individuals who have a disability, such as hearing loss, do not fit into the able-bodied mind-set that is prevalent in U.S. culture (Davis, 2005). In order to better understand stigma from the perceptions of those who are stigmatized, this study will examine stigma and its effect on disclosure, especially in the context of individuals with hearing loss.

Stigma

Stigmatized individuals are often aware of the stigma placed upon then by society and they may begin to internalize society's beliefs about their "blemished" identity (Goffman, 1963). Additionally, stigmatized individuals may perceive that they are not truly accepted – oftentimes an accurate perception (Goffman, 1963). "The standards he

has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be" (Goffman, 1963, p. 7). Stigmatized individuals may be aware of the negative attitudes surrounding their blemished identity and may in turn begin to internalize these attitudes.

Goffman (1963) describes stigma as a relationship between an attribute (such as a disability) and the stereotypes society has surrounding that particular attribute or individuals with the attribute. However, one should note the differences between two overarching types of stigma – *personal* and *perceived* stigma. Perceived stigma is the perception of the stigmatized individual about the beliefs that others hold surrounding the stigmatized attribute – how the individual feels about how others evaluate or respond to the attribute. Personal stigma manifests as the internalized beliefs of the stigmatized individuals themselves about their stigmatized attribute – how a person feels as an individual about the stigmatized attribute (Corrigan & Watson, 2002).

One population that is often stigmatized is those with physical disabilities, such as hearing loss. The differences of their attributes, in this case the loss of normal hearing, result in a negative stereotype when society labels them as less than "human" or as having a 'dis'ability (Braithwaite, 1991; Goffman, 1963). Studying these populations and the effects stigma may have on their communication is essential due to the relatively high number of individuals who fit into this population – one fifth of the U.S. population is considered disabled (McNeil, 1993). Thus, one fifth of the population is at risk for being stigmatized due to their having a "disability," making stigma a negative communicative evaluation that affects a large number of people.

2

One particular group of individuals with physical disabilities who face stigma is individuals with hearing loss. Hearing loss is not only one of the most common chronic disabilities, but it affects the lives of those who are hard of hearing in profound ways as they attempt to navigate their lives around their disability (Luey, Glass, & Elliott, 1995). Roughly, 1 in 20 Americans suffer from some degree of hearing loss – around 10 million Americans suffer from hearing loss and around 1 million suffer from functional deafness (Ross, 2006). As a majority of individuals experience life with "normal" hearing, deafness or hearing loss has been considered a handicap or disability for decades (Cherney, 1999). This thought leads to the "infirmity model" or "medical model" of viewing deafness as an affliction or impairment that needs to be "cured" or "fixed" in order to make the hard of hearing individual a "normal" human being (Hole, 2007). This medical model of deafness is showcased by the many normalizing policies that are in place – the practice of "oralism" (forcing deaf children to learn to speak and lip-read and prohibiting sign language), the cochlear implant, and mainstreaming deaf students into hearing schools as attempts to establish "normalcy." "In fact, it is not uncommon to hear/read/see individuals who were raised orally but then turn to sign language referred to as 'oral failures'" (Hole, 2007, p. 266).

Despite the medical model of hearing loss present in mainstream society, individuals within the Deaf community attempt to battle the stigma surrounding hearing loss through a cultural model of deafness that establishes hearing loss as a physiological and linguistic difference and not a biological impairment (Hole, 2007). Through this cultural model, Deafness is valued as a culture and not a disability that needs to be "fixed" or "cured" (Cherney, 1999; Levy, 2002). Despite this cultural model of deafness,

the deafness as a disability view is still prevalent among hearing society, as well as the stigmatizing attitudes surrounding deafness that accompany this medical model of hearing loss (Breivik, 2005). Therefore, stigma is an obstacle that individuals with hearing loss often experience.

The need to understand stigma and the effects of stigma on individuals with hearing loss further stems from the range of negative outcomes associated with stigma. Individuals who experience social stigma are prone to prejudice, stereotyping, discrimination, feelings of shame, devalued social identities, lower levels of self-efficacy, and decreased self-esteem (Corrigan, Morris, Larson, Rafacz, Wassel, Michaels, Wilkniss, Batia, & Rusch, 2010; Crocker, Major, & Steele, 1998; Goffman, 1963, Matthews & Harrington, 2000). Further, stigmatized individuals often experience the negative effects of stigma across various contexts in their lives – the interpersonal context (Gagne, Southall, & Jennings, 2009; Goffman, 1963; Matthews & Harrington, 2000; Southall et al., 2010), the health context (World Health Organization, 2001; Southall et al., 2010), and the educational context (Cooney, Jahoda, Gumley, & Knott, 2006; Hart & Williams, 1995; Macleod & Cebula, 2009; Najarian, 2008). Given the effects of stigma across many contexts within the lives of individuals with disabilities, an understanding of stigma within this population is necessary to take steps toward increasing the quality of life for such individuals. Furthermore, through this research, researchers may gain insight into how people cope with and adjust to other stressful events *outside* of stigma (Miller & Major, 2000).

Stigma's Effect on Communication

Both perceived stigma (society's beliefs) and personal stigma (the internalization) of "falling short of normal" or being "less than equal" can have an effect on the communication and relationships of individuals with disabilities. These individuals may feel shame or embarrassment surrounding the stigma, which may elicit behaviors such as avoidance, anger, expressions of hostility, feelings of worthlessness, or depression (Matthews & Harrington, 2000). These responses often have a negative impact on relationships and interactions with others, especially those who are able-bodied and not sympathetic of the stigma. Such negative effects may include hostile confrontations, defensiveness, or even avoidance of communicative interactions when the disabled individual perceives stigma to be present (Matthews & Harrington, 2000).

In an effort to conceptualize stigma from the perspective of the individual who possesses the stigmatized attribute and explain how a stigmatized individual may respond to stigma, a model founded on the theories of stress and coping (Lazarus & Folkman, 1984) was developed – the stigma-induced identity threats model (Crocker et al., 1998; Major & O'Brien, 2005; Southall et al., 2010; Steele, Spencer, & Aronson, 2002). This model provides an overview of how the stigmatized individual both perceives and reacts to stigmatizing events by examining how the individual evaluates the event and its threat to his or her social identity (Southall et al., 2010). If the event is threatening to his or her social identity (based on the interaction with others, observed situational cues, and the personal characteristics of the stigmatized individual), the stigmatized individual may feel the need to respond by failing to disclose, withdrawing from the situation, or by

identity switching (highlighting attributes that are socially acceptable while downplaying those that are not) (Gagne, Southall, & Jennings, 2009; Southall et al., 2010).

Furthermore, in attempts to overcome negative stigma, the stigma-induced identity threats model states that individuals' responses to stigma may include several communicative reactions. Such reactions include compensation for stigma (enhancing social skills or assertiveness in attempts to self-protect), strategically evaluating their social environments (deciding whether to deny, downplay, or disclose the stigmatizing attribute), and relying on multiple social identities (choosing an identity that emphasizes socially acceptable attributes while hiding attributes that are stigmatized) (Shih, 2004). Thus, the navigation of stigma includes many communication strategies on the part of the disabled individual, such as choosing what to disclose about their disability (as well as when and to whom) and choosing which identity to display to others in different situations (Goffman, 1959).

In addition to disabled individuals' communication being influenced by their stigmatized disability, the communication of the able-bodied individuals around them is often affected. Because able-bodied individuals stigmatize and stereotype individuals with disabilities, able-bodied individuals may interact with individuals with disabilities in ways that cause further communication barriers (outside of the basic barrier of stigma itself). "By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances" (Goffman, 1963, p. 5). An individual with a disability may fear stereotyping to the point that he or she fails to get the medical help necessary for the disability. Furthermore, many able-bodied individuals fear talking to

6

individuals with disabilities due to the fear of offending them or uncertainty surrounding how to communicate with them (Braithwaite, 1991; Thompson, 1982). Additionally, able-bodied individuals often display discomfort, anxiety, and even avoidance in their nonverbal communication during interactions with individuals with disabilities (Park, Faulkner, and Schaller, 2003).

When communicating with stigmatized individuals, able-bodied individuals' communication is affected in other ways as well. During an interaction with an individual with disabilities, studies have found that able-bodied individuals display nonverbal "stiffness" (moving around less frequently), higher levels of fidgeting (touching one's face or playing with one's hair), low levels of eye contact (Kleck, 1968), and less frequent smiling (Comer & Piliavin, 1972). Furthermore, able-bodied adults have been found to choose greater physical distances when engaging in interpersonal communication (Heinemann, Pellander, Antje, & Wojtek, 1981; Langer, Fiske, Taylor, & Chanowitz, 1976) and to terminate interactions sooner with an individual with a disability (Kleck, Ono, & Hastorf, 1966).

Another way in which able-bodied individuals alter communication when addressing individuals with disabilities is through the use of patronizing communication. Patronizing communication consists of modified speech used in order to communicate with stigmatized individuals (such as those with a disability) based on stereotypes that indicate such individuals are lacking in communication skills (Hummert & Ryan, 2001). In addition to the negative communication behaviors listed above, other types of patronizing communication illustrated by able-bodied individuals talking to individuals with disabilities include staring, avoiding or modifying opinions on sensitive topics, and

offering or providing assistance that the disabled individual did not need or ask for (Hummert & Ryan, 2001). Many of these forms of patronizing communication can lead to lower self-esteem and less relationship satisfaction on the part of the individual with a disability (Hummert & Ryan, 2001). This becomes problematic as an individual with lower self-esteem and less relational satisfaction may be less likely to ask for help (something that may be critical for an individual with a disability), interact socially in future situations, or make important social support connections (McCroskey, Richmond, Daly, & Falcione, 1977).

Given that stigma can have a negative effect on the both the communication and identity (if the individual internalizes the stigma) stigmatized individual as well as a negative effect on the communication of the able-bodied individual in an interaction, understanding the way stigma interacts with disabled populations is vital (Goffman, 1963; Matthews & Harrington, 2000). One such stigmatized population that needs to be examined is that of the deaf and hard of hearing (Cherney, 1999; Hole, 2007). Due to this stigma, hard of hearing and deaf individuals may face obstacles in communication across many contexts as stigma can affect their lives in profound ways. How do hard of hearing and deaf individuals perceive stigma surrounding hearing loss? How does this perception of stigma influence how they manage or communicate about their hearing loss? This study aims to understand how hard of hearing and deaf individuals perceive the stigma surrounding their hearing loss as well as how this stigma influences disclosure, a specific communication process this study will investigate.

In order to set up the research questions and provide further background information on stigma and disclosure in the context of hearing loss, Chapter 2 of this

study will consist of a literature review examining previous research on disclosure, disclosure dilemmas, disclosure tactics, invisible disabilities, and the costs of disclosure. Chapter 3 will introduce the Communication Privacy Management theory (CPM), a communication theory that explains how and why we choose to share or conceal private information (Petronio, 1991, 2002), such as hearing loss. Given that the research questions are derived from CPM, Chapter 3 will also pose this study's 5 research questions within a discussion of CPM and its potential application to the hard of hearing and deaf populations. Chapter 4 will outline the methods used to conduct this study – the use of interactive interviewing. Further, Chapter 4 will provide information on the participants recruited for this study, the interview process, and the analysis of the completed interviews. The results generated from the analysis of the interviews will be provided in Chapter 5, which will present the identified themes that address each of the research questions. Chapter 6 will provide an in-depth discussion of the results as well as both their theoretical implications and extensions of current literature. Additionally, Chapter 6 will explore the limitations of this study and offer suggestions for future research. Finally, Chapter 7 will provide conclusions and an overarching summary of this study.

CHAPTER TWO: LITERATURE REVIEW

Disclosure and Individuals with Disabilities

One way in which communication intersects with stigma is in the process of disclosure. Disclosure occurs when an individual intentionally shares personal information about himself or herself that reveals something not previously known (Charmaz, 1991; Wheeless, 1978). Such disclosures allow for intimacy to develop in an interpersonal relationship (Wheeless, 1978). Furthermore, disclosure may allow for personal accommodation in disability contexts (e.g. making sure a hard of hearing individual who utilizes lip-reading can see the speaker's lips). However, there are many barriers and costs associated with the disclosure process (Caughlin, Brashers, Ramey, Kosenko, Donovan-Kicken, & Bute, 2008). Thus, the disclosure process for individuals with disabilities, such as hearing loss, is often fraught with internal debates and tough decisions.

To avoid stigmatizing labels and potentially being recognized by traits or attributes outside of his or her disability, an individual with a disability may choose to avoid disclosure (Charmaz, 1991). Avoiding disclosure can allow the individual with the disability to maintain control over sensitive information that may alter interactions with others. Not only will avoiding disclosure possibly allow the individual with a hearing loss to avoid some of the negative outcomes of stigma, but it may also allow the individual a chance to avoid being labeled as disabled (Charmaz, 1991). Furthermore, avoiding disclosure about the hearing loss allows the individual to keep personal health information private (a luxury able-boded individuals are privy to) and maintain control of his or her own body.

Disclosure Dilemmas

There are several dilemmas experienced by individuals with disabilities when deciding whether to disclose their disability. Members of stigmatized groups "face the difficult question of when to disclose their identity and when to closet it" (Hecht, Jackson, & Pitts, 2005, p. 34). One disclosure dilemma involves the tension between the desire to avoid stigmatization and the desire to obtain social support. Given that disclosing about a disability may reveal vulnerabilities, strain relationships, risk rejection and judgment, or discredit the disabled individual (Charmaz, 1991), an individual with disabilities may forego disclosure in an effort to avoid stigmatization and preserve self-esteem. However, in doing so, the individual with disabilities forfeits any potential social support (Bos, Kanner, Muris, Janssen, & Mayer, 2009).

Najarian (2008) discusses yet another dilemma involved with 'coming out of the disability closet' among deaf college women. The women in her study were faced with the choice to reveal their deafness and confront possible stigma in order to receive classroom accommodations they might need (e.g. transcriptions of lectures, microphones, interpreters, etc.) or to not tell anyone in order to avoid being stigmatized as disabled (Najarian, 2008). Najarian (2008) connects this decision process with Goffman's (1959) idea of impression management or "face" management. Goffman (1959) discusses how individuals attempt to manage the impressions others form of them by putting on a "front" or a "performance" and allowing others to see only what you want them to see. Similarly, Hart and Williams (1995) discuss how students with disabilities often engage in impression management and choose not to disclose their disabilities because stigma can negatively affect the classroom and learning environment for the disabled student as

the teacher or peers may not be comfortable communicating with a student with a disability.

Being autonomous as well as having control of their own body and health information presents another disclosure dilemma for individuals with hearing loss. Disclosure about a disability involves the loss of privacy surrounding personal health as individuals with disabilities (unlike able-bodied individuals) are often asked to "reveal normally private information about their health, bodies, sexuality, or personal habits" simply because of their disability (Braithwaite, 1991, pp. 254-255). Additionally, individuals with hearing loss have to deal with both their own emotions and others' reactions (which may not be positive) upon disclosure (Charmaz, 1991). Because of the potential lack of control over physical and emotional health, many individuals with hearing loss may face internal dilemmas surrounding what and how much they should disclose to others about their disability and often choose to avoid disclosure (Charmaz, 1991).

Disclosure Tactics

Charmaz (1991) describes several different ways in which an individual may disclose his or her disability if an individual chooses or is forced to disclose (due to outside circumstances). The first tactic is *protective disclosing* in which an individual strategically attempts to control how, when, who, and what others know about his or her disability (Charmaz, 1991, p. 119). Secondly, an individual with a disability may engage in *spontaneous disclosure* – an unplanned disclosure in response to outside news or information (Charmaz, 1991, p. 119). Third, an individual with a disability may choose to *inform* others of his or her disability by taking an objective standpoint in discussing the

disability in an attempt to decrease the emotional risks of disclosing (Charmaz, 1991, p. 121). Finally, an individual with a disability may utilize *strategic announcing* (especially in the case of invisible disabilities) in order to protect self and maintain power by planning in advance what, when, and to whom he or she discloses (Charmaz, 1991, p. 121).

Despite the several different ways in which individuals may chose to disclose, it is important to note that "no single disclosure message type is the most effective" (Caughlin et al., 2008, p. 677). In fact, the appropriate avenue of disclosure is often unique to the individuals, contexts, and relationships involved in the process (DeMatteo, Harrison, Arneson, Goldie, Lefebvre, Read, & King, 2002). In a study examining stigma and disclosure of mental illness, Bos et al. (2009) found that, while disclosing illness or disability to close others can increase support and decrease stigma, disclosing disability to acquaintances or colleagues provided less support and more stigma. Therefore, the authors argued for "selective disclosure" (a stressor in itself as the individual must choose when to hide and when to disclose their disability) as "indiscriminant disclosure is likely to have negative consequences for individuals' psychological well-being" (Bos et al., 2009, p. 512). Thus, individuals with hearing loss often are not only faced with the issue of navigating their disability on a daily basis, but also must make decisions about how they present their identity by choosing whether to disclose and deciding *how* to disclose if they choose to do so.

Individuals with a disability may not always have the choice of whether they disclose given that outsiders may ask questions surrounding their disabilities (if such disabilities are visible or noticeable). In such cases, individuals may have to make a

decision about the appropriateness of the question when choosing whether they want to disclose (Braithwaite, 1991). Braithwaite (1991) suggested four criteria from which individuals with disabilities determined whether the question requesting disclosure was appropriate or not. First, the individual must determine if the disclosure is appropriate in terms of the relationship that he or she has with the able-bodied individual. Second, the individual with a disability decides whether the disclosure is relevant to the current context or topic of conversation. Third, the individual with a disability considers the motivation behind the individual asking the question about the disability (Are they being nosy or are they showing concern?). Finally, the individual with a disability considers his or her own mood and whether they feel comfortable disclosing (Braithwaite, 1991).

If the individual with a disability feels the question requiring disclosure is inappropriate, he or she may employ several strategies ranging from indirect to direct confrontation for dealing with the question (Braithwaite, 1991). The indirect strategies to dealing with inappropriate questions include changing the subject, avoiding or ignoring the question, or withdrawing physically. More direct strategies that an individual with a disability may employ include the use of sarcastic or rude responses, the use of humor (often sarcastic humor), or simply telling the able-bodied individual who asked the question that it is none of their business (Braithwaite, 1991). Dealing with inappropriate questions is more common for individuals living with visible disabilities, which hearing loss can be if the individual wears hearing aids or uses sign language. However, such questions may not arise if the disability is invisible, which hearing loss often is. Instead, those with invisible disabilities, such as hearing loss, have other challenges to overcome regarding disclosure.

Complicating Disclosure: Invisible Disabilities

Goffman (1963) distinguishes between individuals who have visible stigmatized attributes that can be easily recognized and those who have invisible stigmatized attributes that are not known or recognized by others present. An invisible disability is one that cannot easily be noticed by others unless the disabled individual or an outside source discloses about the disability, such as hearing loss (Matthews & Harrington, 2000). Approximately forty percent of disabilities in the U.S. are those that cannot easily be seen – or are invisible (Asch, 1984).

Potential invisible disabilities include both mental and physical disabilities. Mental disabilities, such as certain learning disabilities that are not easily recognized without disclosure from the disabled individual, are often considered invisible disabilities. Examples of physical invisible disabilities include many chronic illnesses such as heart disease, diabetes, epilepsy, and even hearing loss (Matthews & Harrington, 2000). With U.S. culture placing an emphasis on being "normal", many individuals who have such disabilities are considered "impaired" or labeled even worse, such as those with hearing loss being labeled "deaf and dumb" (Cherney, 1999; Matthews & Harrington, 2000; Stone, 1995).

Given that U.S. culture places emphasis on health and being "normal," the disclosure process for those with invisible disabilities, such as hearing loss, is difficult to navigate. Stone (1995) discusses the "myth of bodily perfection" and the implications this myth causes for those with invisible disabilities. She discusses how the dominant culture's embodiment of this myth places negative connotations on the term "disability" and discourages those with invisible disabilities from disclosing in order to avoid those

negative perceptions. This cultural outlook and pressure to conceal disabilities is also recognized by Matthews and Harrington (2000) and Davis (2005), as both discuss the prevalence of this able-bodied mind-set within U.S. culture and the stigma that accompanies being "disabled" because of this attitude. The issues surrounding invisible disabilities may further complicate the disclosure process.

Due to the possibility of stigma and negative stereotyping surrounding disabilities, many individuals with invisible disabilities choose not to disclose them (Matthews & Harrington, 2000; Nikolaraizi & Makri, 2004). In order to engage in impression management and avoid stigma, many hard of hearing individuals with invisible disabilities put on a façade of "normality" and choose to "closet their disability" (Goffman, 1959; Najarian, 2008). In fact, Matthews (1997) found that, unless certain situational reasons demand disclosure, most people with an invisible disability choose not to disclose the disability. Reasons for avoiding disclosure include fear of being judged, fear of damaging a potential or current relationship, fear that it would cause unwanted sympathy, and fear that the other person would not believe that the individual did indeed have a disability in the first place (due to its invisibility) (Braithwaite, 1991; Matthews, 1994). Furthermore, individuals with disabilities reported delaying disclosure so that able-bodied individuals could see them as a "person first" rather than as a "disabled person" (Braithwaite, 1991).

Problems associated with disability stigma, such as lower self-esteem and internalizing negative attitudes about their own disability (Nikolaraizi & Makri, 2004), also further complicate the disclosure process for individuals with invisible hearing loss as individuals attempt to navigate between stigma surrounding their disability and the

16

need for accommodation. In addition to navigating between disclosure in order to

achieve necessary accommodations while risking stigma and avoiding stigma by

choosing not to disclose, an individual with an invisible disability has to deal with the

inherent *invisibility* of the disability. Due to the *invisibility* of the hearing loss,

individuals may face difficulty in gaining accommodations even if they do chose to

disclose. Not only do such individuals have to approach strangers to inform them that

they have a hearing loss and need accommodations, but they often have to provide

detailed information about their hearing loss or even proof of their disability.

> Those whose disabilities are invisible may also have to convince other
> people that they really are disabled, not seeking some special—unfair—
> advantage: thus, what they must do is meet a burden of proof. They thus
> face a double bind: either they forgo the assistance or accommodation they
> need—and thus suffer the consequences of attempting to do things they
> may not be able to do safely by themselves—or they endure the
> discomfort of subjecting themselves to strangers' interrogations. (Davis,
> 2005, p. 154-155)

Furthermore, many individuals with invisible disabilities are faced with the

challenges associated with misunderstandings surrounding their disability and its affects

on the individual. Others may begin to doubt or question the presence of a disability

when the symptoms exhibited by the individual with an invisible disability seem to be

inconsistent (sometimes the disability seems more prominent than others) (Matthews &

Harrington, 2000). For example, a person with a severe hearing loss who seems to be

able to understand one person very well but claims they can not hear someone else (due

to differences in abilities to hear certain pitches – one person's voice may be deeper than

the other) may face questioning surrounding the extent of their hearing loss. In this same

manner, an individual with a chronic disease who displays acute symptoms one day but

shows little to no symptoms the next day may face skepticism about the seriousness of

his or her disease (Sinnema, 1992). Thus, individuals with an invisible disability, such as

hearing loss, are faced both with the struggle of whether to disclose as well as the

"burden of proof" they may have to provide as proof of the hearing loss if they do chose

to disclose.

Costs of Disclosure

Once an individual with a disability has navigated the dilemmas surrounding

disclosure, such as deciding how much, to whom, in which context, and when to disclose,

that individual may face negative outcomes, or costs, of that disclosure. While openness

and disclosure about a disability, especially those that are invisible, can provide

individuals with disabilities a chance at proper accommodation and the reduction of

communication barriers in everyday interactions, there are inherent costs to disclosing

about a disability (Matthews & Harrington, 2000). Braithwaite (1991) stated that some

of these costs included the risks of stereotype and stigma surrounding the disability

discussed earlier: embarrassment, being misunderstood, unwanted sympathy, possibility

of social avoidance by others, lower self-esteem for the individual with the disability, and

decreased acceptance from other able-bodied individuals. Additionally, further costs to

disclosure include exposing vulnerabilities, straining relationships, loss of privacy and

control of personal health information, and loss of autonomy (Braithwaite, 1991;

Charmaz, 1991).

In navigating disclosure, individuals with a disability, such as hearing loss, often

face a choice between two different types of costs – personal consequences and social

consequences (Cohen Silver, Wortman, & Crofton, 1990). Personal costs of not

disclosing may include not gaining proper accommodations, not allowing for personal

18

adjustment in communication interactions, a lack of potential social support, and not providing the individual with the cathartic experience of sharing his or her feelings or concerns surrounding his or her disability. Social costs involved in disclosing may include alienation or rejection from an otherwise able-bodied social peer network and risk of potential stigmatizing labels. Thus, individuals with disabilities who disclose often risk social consequences of disclosure in order to decrease personal communication costs (Cohen Silver et al., 1990).

Being labeled is a cost individuals with disabilities may face upon disclosure of their disability. Beart, Hardy, and Buchan (2005) argue that individuals whose disability is known to others often experience identity struggles as the "disabled" label or identity is seen as their dominant identity. They state that oftentimes a person's disabled identity "becomes a person's primary identity, over-riding other identities including gender, ethnic origin, sexuality, and religion" individual trumps any discomfort felt by the individual with the disability about disclosing (Beart et al., 2005, p. 49). Reducing the uncertainty of the able-bodied individual through disclosure about the disability does not ensure that the able-bodied individual will *accept* the individual with the disability (Braithwaite, 1991). Furthermore, increasing the comfort level of the able-bodied individual does not necessarily negate the costs and risks the individual with the disability may experience upon disclosure (Braithwaite, 1991). As others fail to recognize more important or prominent identities the individual with disabilities may have, the "disabled" identity seems to become the dominant identity with which the individual is labeled. Since disabilities are often a source of stigma, this label often causes an individual with a hearing loss to be discredited or negatively stereotyped.

Despite the costs to disclosure mentioned here, some researchers argue that disclosing about a disability to an able-bodied individual may actually positively influence the relationship (Braithwaite, 1991). Studies have found that disclosure about a disability may increase the level of comfort in the interaction for the able-bodied individual and that able-bodied individuals may react more positively towards individuals with disabilities upon disclosure about their disability (Goffman, 1963; Thompson, 1982). However, this research suggests that alleviating the discomfort of the able-bodied individual is the main goal in a communicative interaction with an individual with disabilities, despite the cost of disclosure for the disabled individual (Braithwaite, 1991). Further, much of this research is done from an able-bodied perspective (Braithwaite, 1991). Thus, the purpose of this study is to examine the navigation of stigma and disclosure for hard of hearing individuals from the perspective of hard of hearing individuals.

Healthcare and Educational Contexts, Stigma, and Disclosure

There are many contexts in which the navigation of stigma and disclosure become complicated and fraught with barriers for individuals with hearing loss. As discussed earlier, interpersonal communication is a context that is often affected by stigma surrounding disabilities as stigma can affect both the communication of the able-bodied and the stigmatized individual. Another such setting is the healthcare context. During an average patient visit, physicians are expected to not only address any health problems being experienced by their patients, but also to maintain an interpersonal relationship with their patients and help them make treatment and health decisions all while remaining culturally sensitive (Fiscella & Epstein, 2008). The challenges associated with

accomplishing all of this within the average 15-minute visit with each patient are further

complicated when the patient has a disability. A disability, such as a hearing loss,

provides further obstacles in the healthcare setting for both the patient and the provider

and can interfere with the communication processes involved in the patient-provider

interaction. Because of these barriers, individuals with physical disabilities are often less

likely to use primary preventative healthcare services than the general population, despite

the fact that they are at greater risks for secondary conditions (Kroll, Jones, Kehn, &

Neri, 2006).

One of the major barriers individuals with hearing loss (and other disabilities)

may experience in the healthcare setting is stigma. While stigma's negative effects can

include the effects on the communication of both the stigmatized and non-stigmatized

individual as discussed earlier, it can also lead to a "failure to take advantage of social,

economic and healthcare opportunities because of expected stigma and discrimination"

(Deacon, 2006, p. 424). Stigma has been linked to delays in diagnosis and treatment, as

well as failure to embrace preventative behaviors or adhere to medical recommendations

(Southall et al., 2010; Van Brakel, 2006). Additionally, stigma can cause stereotyping of

patients as incompetent or even as responsible, or at fault, for their disability or illness.

Furthermore, stigma can cause prejudice and discrimination that can lead to inappropriate

or incomplete medical care, fewer medical services, and less insurance benefits

(Corrigan, 2004). Complicating factors, such as invisible disabilities, increase stigma's

barriers to healthcare because many with invisible disabilities may attempt to avoid

stigma and its negative effects by hiding their disability and not seeking medical attention

(as doing so often draws attention to the disability) (Corrigan, 2004; Southall et al., 2010).

Stigma has been found to act as a barrier to health communication, health promotion, treatment, and patient support (World Health Organization, 2001). For example, Zazove, Niemann, Gorenflo, Carmack, Mehr, Coyne, and Antonucci (1993) indicated that 59% of the deaf or hard of hearing patients surveyed stated that they understood their physician "sometimes" or "not at all". Instead of asking for clarification and disclosing that they did not understand, many deaf and hard of hearing patients may simply leave the health interaction uncertain of what was said. Later, the same patients often return seeking answers to problems or concerns that were not understood in the first visit (Zazove et al., 1993). Furthermore, stigma may prevent stigmatized individuals, such as those with hearing loss, from complying with recommended treatments or even from seeking out medical services at all (Gary, 2005; Southall et al., 2010). For example, negative stereotypes can cause hard of hearing individuals to avoid audiologist services as well as wearing hearing aids (Southall et al., 2010).

Another context in which hard of hearing individuals may face dilemmas and challenges surrounding their hearing loss is the educational context. Students with disabilities may experience barriers to learning, such as difficulty completing assignments, gaining accommodations, and accessing information in lectures (Macleod & Cebula, 2009; Najarian, 2008). Due to fear of discrimination, many higher education students with disabilities fail to disclose their disability. Thus, teachers and administration are often not aware of the individuals with disabilities in their classrooms and such individuals may miss out on helpful accommodations (lecture transcriptions,

additional test time, interpreters, etc.) (Mcleod & Cebula, 2009; Najarian, 2008). Furthermore, students with disabilities who attend a mainstream school often have a more difficult time than students with disabilities who attend a special education school due to the stigma they experience (e.g. name-calling, demeaning treatment, etc.) from both non-disabled peers and teachers (Cooney, Jahoda, Gumley, & Knott, 2006; Hart & Williams, 1995). Additionally, the stigma experienced in the educational context often extends into the workplace as many students with disabilities do not plan to disclose their disability to their future employer (Macleod & Cebula, 2009).

In managing classroom identities, many students with disabilities may chose not to disclose their disability, in this case hearing loss. The choice not to disclose (at the risk of forfeiting necessary academic accommodations) may be connected to the fact that a majority of teachers are able-bodied and many able-bodied teachers tend to act differently towards a student once they discover the student is disabled in some way (Hart & Williams, 1995). Teachers are often unsure of how they should talk to disabled students, what they should talk about, and whether they can discuss the disability. This uncertainty negatively affects the learning environment for the disabled student as they may feel uncomfortable and may not ask for necessary classroom accommodations (such as subtitles, an interpreter, or transcriptions for the hard of hearing) (Hart & Williams, 1995). Thus, the educational context is another setting in which individuals with hearing loss face challenges surrounding the navigation of stigma and disclosure. Due to the overarching effect stigma can have on the lives of hard of hearing and deaf individuals, this study will examine stigma and disclosure from the perception of these individuals.

CHAPTER THREE: THEORETICAL FRAMEWORK

Communication Privacy Management

As a theoretical framework from which to examine the concepts of stigma and disclosure from the perspective of hard of hearing individuals, this study will utilize Communication Privacy Management Theory. Communication Privacy Management (CPM) is a communication theory that examines how and why people regulate their privacy and disclose private information (Petronio, 1991). CPM focuses heavily on the processes that people use to determine when and how they choose to reveal or conceal private information, such as hearing loss (Petronio, 1991). Petronio's (1991, 2002) understanding of privacy management rests on the idea that a dialectic exists whenever the decision is made to disclose or conceal private information. Thus, CPM will provide a framework for this study in examining how and why hard of hearing individuals choose to conceal or reveal information surrounding their hearing loss.

As a way to understand how people manage private information, CPM uses the metaphor of boundaries. Boundaries are used as a metaphor to illustrate the tension between telling and withholding private information. Using this metaphor, CPM explains that boundaries exist to divide the private sphere (personal information) from the public sphere (Petronio, 1991; 2002). According to CPM, individuals use these boundaries to protect their private information and determine how/when to disclose private information (Petronio, 1991; 2002). Managing boundaries around private information is necessary because disclosing to others involves risks (Petronio, 1991). Boundaries are regulated in order to cope with or prevent such vulnerability and risks (such as stigma and risks associated with stigma) and allow the individual to control private information in an attempt to navigate perceived risks (Petronio, 2002).

A boundary's permeability, how thick or thin the boundary between public and private is, will help determine whether or not private information is shared. A thicker boundary indicates that the boundary between public and private is less likely to be breached and private information is less likely to be shared, while a thinner boundary indicates that the divide between public and private is less concrete and information is more likely to be shared (Petronio & Durham, 2008). Boundaries can be "open," in which private information is shared and revealed freely, or they can be "partially open," in which only select information is shared. Additionally, boundaries, particularly those that are thicker, can be "closed," in which the information is kept infinitely private (Petronio, 2002; Petronio, Reeder, Hecht, & Ros-Mendoza, 1996).

Boundary ownership consists of the rights and responsibilities each person has over the control of information that they own (Petronio & Durham, 2008). When information is co-owned and two or more people are aware of the private information, there is a boundary linkage (Petronio & Durham, 2008). CPM theory understands information (and boundaries) as something that is owned, and each owner must decide whether or not they are willing to have a confidant (i.e. co-owner) to that information. If the co-ownership expectations are violated and information is shared when one party did not want it shared, boundary turbulence has occurred (Petronio & Durham, 2008).

In determining how, when, and to whom to share private information, CPM states that this is a rule based process, not just an individual decision (Petronio, 2007). Using privacy rules, individuals decide how to manage the boundaries surrounding private information. Such privacy rules include gender criteria (what information is appropriate to share based on gender), contextual criteria (what information is appropriate to share

based on the context of the communication), cultural criteria (what information is appropriate based on cultural rules), motivational criteria (what information will achieve communication goals), and risk-benefit criteria (balancing pros and cons of sharing information) (Petronio, 2007). Using the privacy rules to examine context and appropriateness of information sharing in different situations, individuals manage boundaries surrounding private information (Petronio, 2007). Thus, as a whole CPM discusses how we use communication (or lack of communication) and the contextual rules surrounding our communication in certain situations to manage our private information, such as information surrounding a hearing loss.

CPM and stigma in individuals with disabilities. Communication Privacy Management can be applied to the phenomena of stigma in the context of hard of hearing individuals to provide a framework from which disclosure about hearing loss (and the potential risk of stigma) can be examined. Boundary management for individuals with hearing loss could potentially help them manage stigma by allowing them to manage the private information surrounding their hearing loss. Therefore, CPM can help inform our discussions and investigations surrounding how and when individuals with disabilities, especially those that are invisible, choose to disclose their disability and the personal information surrounding the disability (e.g. how they obtained the disability, what it means to their life, what accommodations they need, etc.) (Charmaz, 1991).

RQ1: How do hard of hearing individuals disclose (manage boundaries) about their hearing loss?

By examining the how hard of hearing individuals navigate disclosure and manage boundaries surrounding information about their hearing loss, this study will investigate

boundary permeability, as well as how individuals with hearing loss choose whether such boundaries are thick or thin, closed or open.

Further, CPM could illuminate this study by providing the framework from which to explore the boundary ownership, boundary linkage, and boundary turbulence involved in managing stigma surrounding hearing loss. Additionally, boundary turbulence could shed insight on how a deaf or hard of hearing individual reacts when potentially stigmatizing information gets disclosed for them. Boundary turbulence in this context could occur when someone shares about a hard of hearing individual's hearing loss without his or her consent.

RQ2: How do hard of hearing individuals deal with boundary turbulence?

Managing the private information about hearing loss is one way in which hard of hearing individuals might navigate the perceived costs of disclosure about their hearing loss. As CPM points out, boundary management is a rule-based process. One such rule-based criteria that influences boundary management is risk-benefit criteria (balancing pros and cons of sharing information) (Petronio, 2007). Individuals with hearing loss may balance the pros (accommodations, social support, etc.) and cons (costs) of disclosure when making decisions about boundary management surrounding their hearing loss.

RQ3: What do hard of hearing individuals perceive to be the costs (or "risks" as labeled by CPM) of disclosure?

One commonly cited cost of disclosure surrounding disabilities is stigma. Stigmatized individuals, such as those with hearing loss, can feel worthless, blemished, devalued, or less than human (Crocker et al., 1998; Goffman, 1963). Further, both the

communication of the stigmatized individual (as they internalize these negative effects of stigma) and the communication of the able-bodied individual can be affected by stigma (Braithwaite, 1991; Goffman, 1963; Matthews & Harrington, 2000; Park et al., 2003). Stigma interacts with disclosure since individuals with disabilities often choose not to disclose in order to avoid stigmatizing labels surrounding the disability (Charmaz, 1991).

RQ4: How do hard of hearing individuals perceive stigma of their hearing loss? By capturing the perspective of the hard of hearing participants, this study will examine stigma as a cost to disclosure as well as how individuals with hearing loss respond to stigma surrounding their hearing loss. Participants' response to stigma is another communicative process that can shed light on how they navigate their hearing loss and the perceptions others' have of their hearing loss.

RQ5: How do hard of hearing individuals respond to stigma (a potential risk of disclosure)?

This study aims to understand how hard of hearing individuals perceive and navigate stigma and disclosure surrounding their hearing loss. CPM will provide this study with a theoretical framework from which to examine how the private information about a hearing loss gets managed in order to avoid stigma or any other negative outcomes.

CHAPTER FOUR: METHOD

To investigate how hard of hearing individuals experience and respond to stigma as well as how they disclose their hearing loss, qualitative inquiry provides an avenue for in-depth exploration their experiences surrounding their hearing loss in these contexts. Qualitative interviews allowed me to examine this phenomenon in a way that gives a voice to the participants and explore the phenomenon from the perspective of hard of hearing participants (Lindlof & Taylor, 2002). As many studies examining communication and disabilities are done from an able-bodied researcher's perspective (Matthews & Harrington, 2000), it is imperative to capture this phenomenon from the viewpoint of those that experience it, the hard of hearing. Additionally, as opposed to talking *about* the individuals with a hearing loss and how *they* experience stigma, interviews allow the researcher to talk *with* the participants about their experiences. Given that I am hard of hearing and fit into the population being studied, I was able to engage in a discussion *with* my participants as opposed to examining this phenomenon from the perspective of an able-bodied researcher.

Participants

There were several requirements for participants recruited for this study. The participants had to have at least a moderate hearing loss (41-55 decibels of hearing loss), use oral communication, and be at least 18 years of age. A total of thirty participants who fit these requirements participated in this study. The final age range for participants in this study ranged from 18 to 79 years of age (M = 53; SD = 17.519). Eighteen of the participants were male (60%), 12 were female (40%), and only 2 out of thirty participants (5%) were students. Of the 30 participants, 28 were Caucasian/White (93.3%), one was

Hispanic (3.3%), and one was African American (3.3%). Most of the participants reported having a profound hearing loss (n = 17; 56.7%), while 2 reported a moderate loss (6.7%), 4 reported a moderate-severe loss (13.3%), 4 reported a severe loss (13.3%), and 3 reported a severe-profound loss (10%). Additionally, half of the participants reported having been hard of hearing or deaf since birth (n = 15; 50%). The other participants varied in terms of age of onset of the hearing loss (M = 9.7; SD = 16.549). Finally, a majority of the participants did not associate with the Deaf community (n = 22; 73.3%), while four reported heavy involvement (13.3%) and four reported some involvement (13.3%). All participants were assigned a pseudonym, which are used throughout the results, to insure anonymity. Further, throughout the results, participants are discussed as either hard of hearing or dead, depending on how they identified themselves during the interview.

Procedures

Once approved by the Institutional Review Board, participants were recruited in several ways. Participants were recruited through a combination of advertising and network sampling. Advertising about the study was done at several locations in order to recruit a diverse sample. Advertising was done through the Disabilities Resources Center at a major University. Additionally, advertising was done at local audiologists offices through the use of a flyer and notifying audiologists and therapists with patients that fit the sample requirements. Further, the flyer was distributed to several chapters of the Hearing Loss Association of America. The requirements to participate in the study were that the participant had to be at least 18 years of age and had to have at least a moderate hearing loss (41-55 decibels of hearing loss). Further, these participants were individuals

who communicate orally (as opposed to using ASL) as the population being investigated consisted of individuals with an invisible hearing loss – individuals who are able to hide their hearing loss. Participants who were interested in participating contacted me by email to set up an interview time and location convenient to them. Upon providing informed consent, the interview was conducted.

Due to the one-on-one nature of one-on-one interviewing methodology, interviews were particularly well-suited to this study and understanding the participants' experiences and individual perspectives (Lindlof & Taylor, 2002). The interviews were conducted using an interactive interview style to encourage disclosure and natural conversation (Ellis, Kiesinger, & Tillmann-Healy, 1997). As I am hard of hearing, I fit into the population being studied and have hearing loss in common with the participants. By interacting with the participants and sharing personal disclosures of my own, I, using interactive interviewing, engaged the participants in a reciprocal conversation.   This conversational style made the participants feel more comfortable and willing to open up about personal experiences in a way they might not have done with an able-bodied researcher.

The interactive interview is designed to eliminate hierarchical differences between researcher and participant and allow for natural dialogue (rather than an interrogation) (Ellis et al., 1997). Due to the interactive and conversational flow that is encouraged in interactive interviewing, set procedures and steps were eliminated given that they would interfere with the emerging dialogue between researcher and participant (Ellis et al., 1997). Thus, I worked from a list of questions (a flexible interview protocol) to guide the conversation and prompt narratives from the hard of hearing participants

surrounding their navigation of stigma and disclosure. This flexible interview protocol (see APPENDIX) allowed for conversation to flow naturally and for participants to share stories and experiences as they arise.

Given that I am part of the population being examined in this study, my role as a member of this population interacted with my role as a researcher. In qualitative research, the researcher is central to the collection and interpretation of the data collected (Finlay, 2002). Given that I could relate with many of my participants' experiences, my "insider status" influenced this study in several ways. First of all, I do not identify as culturally deaf. Thus, I would be less likely to relate to participants who reported internalizing Deaf cultural values. Due to this lack of connection here, I may have been less likely to probe or engage in reciprocal disclosure with these participants. However, because I do relate with many of the participants in my sample (a majority did not identify as culturally Deaf), interactive interviewing allowed me to engage in a conversation with my participants as they shared their experiences, many which resonated with experiences of my own. This reciprocal sharing process can make participants more willing to open up about difficult experiences that they may not have been willing to share with an able-bodied researcher (Ellis et al., 1997). Further, since I am not able-bodied, the participants were able to feel a sense of equality given that I share in their "disability". Because of this sense of "being like us", participants may have been more willing to respond to my recruitment advertisements and spread the word to other potential participants. As a whole, being a part of the hard of hearing population allowed me to engage in interactive interviewing and helped facilitate in-depth discussion

due to my ability to participate in reciprocal disclosure with the participants to prompt further details.

The qualitative interview questions addressed both stigma and disclosure surrounding hearing loss. In order to elicit responses surrounding how they manage boundaries and disclosure surrounding their hearing loss, the participants were asked about how they usually disclose. Participants were also asked about how they typically make the decision to disclose as well as difficulties they have encountered in dealing with disclosure of their hearing loss. Boundary turbulence was addressed through questions surrounding how the participant perceived it when others disclosed about their hearing loss for them. Participants were also asked about what they perceive to be the risks or costs associated with disclosing about their hearing loss. Stigma, one cost associated with disclosure, was addressed through questions surrounding whether participants have experienced a change in behavior or stereotyping once they disclose their hearing loss. Questions about how they respond to such stigma were also asked. Participants were asked probing questions following each answer to elaborate and prompt narratives.

The interactive interview style provided the flexible interview protocol necessary to allow for participants to engage in conversation about their experiences as well as narrative storytelling processes to expand on answers to interview questions. In addition to the qualitative interview questions, participants were asked to fill out a brief quantitative survey to collect demographic information. The interview itself was recorded and later transcribed for coding purposes. After completion of the interview, the participant was encouraged to let others who qualify for the study know about the study and provide them with my contact information (network sample). Through the

recruitment measures (both network sampling and advertising), a total of 30 participants were recruited and interviewed. A majority of the participants (n=17) were recruited through advertising through the Hearing Loss Association of America. The other 13 participants were recruited through network sampling. The participants were asked to pick a location convenient to them for the interview. All participants, except for one, were interviewed in person. One interview was conducted via Skype as it was the most convenient for the participant. Of the in-person interviews, 17 participants were interviewed in their home, 4 were interviewed at their place of work, and 8 were interviewed in a restaurant. Interviews ranged in length from 12 to 80 minutes (M = 31 minutes; SD = 15.08).

Analysis of the Interviews

Following interview and transcription processes, I reviewed the transcriptions and engaged in an initial thematic coding of the transcripts, using Communication Privacy Management as a theoretical framework. Using CPM and the research questions (which were developed based on CPM), the transcriptions were first coded by identifying sections of the interviews that answered each research question (addressed each part of CPM). Using CPM, I broke apart sections of each interview and organized the sections based on which research question (component of CPM) the addressed.

From there, I used open coding to examine the interview sections that fit each research question (each research question was coded separately). Open coding is an initial coding process that allows for major themes or categories of information to arise from the data itself, as the coding is unrestricted (categories have not yet been defined) (Creswell, 2013; Lindlof & Taylor, 2002). This open coding allowed me to identify any

major patterns that occurred within the participants' answers to each research question. Using open coding, I looked at the interview sections that addressed each individual research question (component of CPM) individually. For example, I looked only at sections of the transcript that answered how the participants managed the boundaries surrounding their hearing loss (RQ1) when I was coding for that particular research question. Within each of these research question sections of data, I began analyzing the participants' responses by identifying the major ideas or concepts that were getting repeated by multiple participants throughout the interviews. This resulted in multiple preliminary themes or chunks of data for each research question.

After completing the open coding, I used axial coding within each research question section to narrow down the preliminary themes and identify any subthemes present in the data. Axial coding results in collapsed categories with deeper meanings by making connections between the themes or categories identified in open coding and allows for subthemes to be identified (Creswell, 2013; Lindlof & Taylor, 2002). Using axial coding, I was able to examine the preliminary themes to see where they overlapped, could be refined, or could be combined. After refining the preliminary themes, axial coding allowed me to narrow down my themes into the clearly defined themes presented in the results. In order to stick as closely to the participants' discussions of their experiences as I could, many of the themes identified in the results are worded based on common phrases or word choices made by the participants.

Thirty participants were interviewed for this study. Creswell (2013) suggests anywhere between 5 and 30 participants in order to reach theoretical saturation. There were a wide variety of participants (age, hearing loss level, age at which they lost their

hearing, etc.) and the final identified themes spoke to this variety. While some participants identified with certain themes more than other themes, this variety allowed for a wider view of this population and captured their diverse experiences surrounding hearing loss. Despite this variety, theoretical saturation was reached during the coding process as new data (additional interviews) no longer added to the identified themes (Lindlof & Taylor, 2002). While participants were diverse in terms of demographics, many of their perceptions and experiences surrounding stigma and disclosure of their hearing loss mirrored one another.

In order to ensure the trustworthiness of the data, a co-coder, a fellow doctoral candidate, engaged in the same coding processes. Since I am a member of the population being studied, an outsider's perspective helps to grant objectivity to the study and ensure that my interpretations of the data were based on the participants' descriptions. Given that the co-coder was not a member of the population being studied, she provided this outside perspective. After the co-coder read through the transcripts and drafted up the themes that she recognized, the co-coder and I compared their coding results. The co-coder and I discussed any variation in our identified themes and reached consensus surrounding the final themes. Many of the variations had to do with how we grouped things together a little differently or identified additional themes that, after discussion, could be merged with others. Through this co-coder discussion and comparison, the final themes were solidified and agreed upon.

Member checking was also used to verify that the conclusions I drew accurately portrayed the participants' experiences (Lindlof & Taylor, 2002). Two participants were presented with the themes that I identified in order to engage in member checking. One

participant that engaged in member checking valued hearing loss as part of her identity

and was more likely to disclose while the other participant was less likely to disclose

about her hearing loss. Due to their difference in perceptions, they related to different

themes. The participant that embraced her hearing loss identified with themes that the

other participant did not, and vice versa. However after explaining to each participant the

others' perceptions both of the participants agreed with the themes presented in the final

results as they felt they helped capture the wide variety of experiences surrounding

hearing loss. Further, these participants were interested in the others' perspectives as it

allowed them to see hearing loss from a different standpoint. Through the use of a co-

coder and member checking, the trustworthiness of the data was ensured.

CHAPTER FIVE: RESULTS

Upon analyzing the interview transcriptions, several distinct themes arose within each of the research questions posed. The following sections will discuss the themes identified in terms of how the participants talked about managing boundaries (RQ1) and boundary turbulence (RQ2) surrounding information about their hearing loss, as well as the costs or stigma associated with hearing loss (RQ3 and 4) and how they deal with that stigma (RQ5). The quotes that are provided to illustrate the identified themes have not been altered – they are in the participants' words.

Managing Boundaries (RQ1)

There were several themes that developed as the hard of hearing and deaf participants discussed how they disclose their hearing loss and manage boundaries surrounding information about their hearing loss. Some of the participants expressed a complete openness (thin boundary) surrounding their hearing loss, as hearing loss was considered a central part of their identity, while others talked about the disclosure process as a judgment call (thicker boundary). Participants also discussed the risks of *not* disclosing, the idea of delaying disclosure, minimizing their hearing loss, and using disclosure as an education opportunity. Finally, participants also expressed concern for the other person in the interaction as a major component in the decision process of whether or not they choose to disclose.

Hearing loss is part of my identity. Several of the participants expressed no concern about the disclosure process or managing of the boundaries surrounding their hearing loss. For these participants, the boundaries surrounding information about their hearing loss seemed to be relatively thin since they were willing to openly share about

their hearing loss. Tom stated that he just lets people know that he can't hear – "I don't try to hide my disability." Similarly, David stated, "I am not shy about it." Several participants also explained that they do not really even think about the disclosure process concerning their hearing loss anymore because it has become so "normal" for them. When asked how she typically discloses about her hearing loss, Morgan made this clear when she stated, "I guess I don't think about that much because you get so used to it… you've lived like that all your life." Further, a few participants stated that they would not be able to hide the hearing loss even if they wanted to (due to communication problems, visible hearing aids or cochlear implants, and/or a speech impediment). "I don't hide my hearing loss anymore. In fact, not sure I could. It seems that it doesn't take long for someone to realize that I'm not hearing well" (Allison). Additionally, it was because of the potential for communication problems or misunderstanding that some participants felt it "is better to come clean right up front" (Susan).

Participants who felt it was best to share their hearing loss early in the communication interaction or when they first meet someone also seemed to see their hearing loss as an important component to their identity. Denise illustrated this as she explained, "I'm just real comfortable with me. I've been this way all my life and it is something that I know that I have to do." Echoing this sentiment, Ron stated, "I don't care if you are blind, deaf, one arm… You have to let them know who you are… bottom line." Being able to be proud of their identity or who they are as a person seemed important to the participants who disclosed up front. Not only does sharing about their hearing loss help with eliminating communication problems, but it also allows these participants to share who they are as an individual.

Despite being upfront about their hearing loss now, the participants who demonstrated this open disclosure policy also explained that they were not always so open about who they are – this was something that they became more comfortable with over time. Don explained,

> As you get older, you grow with it and you become more mature about it… there's a saying that as you get older, you don't care what anybody thinks about you… just so you are happy with your life. That's all that matters. When I was younger, it mattered. I kept it to myself because I was afraid what they would think of me.

He went on to explain that with age, he has become more comfortable with his hearing loss and has accepted it as part of his identity, which has made it much easier to disclose. Jane also talked about trying to hide her hearing loss when she was younger and how she has learned to accept her hearing loss as she has gotten older. For her, accepting her hearing loss as part of her identity and being open about it has been beneficial to her overall happiness – "I changed my attitude and I've been much happier that way, not hiding my deafness."

It's a judgment call. While some participants did express a willingness to be completely open about information surrounding their hearing loss, other participants described the disclosure process as more of a "judgment call." When asked if he normally discloses about his hearing loss, John stated, "I tend to shy away from it. I'm choosy, I don't just open up to anybody." For some, the judgment is based on how many people are present for the disclosure as they explained the difference between disclosing to a group versus disclosing to one person. Brooke stated, "I suppose in a group situation it would be more difficult. If you are one on one, it is much easier. I don't know if I would be comfortable sharing that in front of a group." Expanding on this, Natalie

emphasized the difficulty associated with disclosing to a group and asking for any

accommodations for hearing loss: "People don't understand how brave someone is to

stand in front of a group and tell them that I need you to do this for me. It takes… it

takes some courage."

Another factor in the judgment call for several participants is the nature of the

relationship between them and whomever they are disclosing to. Many participants

emphasized that if it is a person they probably will not see again, they typically do not

disclose – it needs to be a person that they are going to have an ongoing relationship with.

Brooke explained this when she talked about whom she chooses to disclose to:

> Well… if I really like that person and want to continue a friendship with
> that person, then I want them to know who I am… this is who I am and I
> come with a hearing loss. But if it is somebody that I won't be spending a
> lot of time with, then I don't really care.

James felt similarly as he talked about times when he avoids disclosing:

> Or the times where people say something and you kind of smile and nod
> because it is like… I don't know who you are and we are never going to
> see each other again in our lives so I'll just smile and say yeah…
> whatever. Yeah, there's no point in getting into a whole thing… my life
> story with this person I'm never going to see again.

As shown here, many participants talked about making this judgment based on

whether or not they would ever see the person again. In navigating this judgment,

Natalie discussed dealing with this and understanding that as a hard of hearing person

"you just miss things" so you have to "accept that pick and choose when to tell people".

Other participants reported making this judgment based on their social standing or power

in the relationship. If the participants feel confident or in control in the relationship, they

are more willing to disclose their hearing loss. However, if the other person in the

relationship is a superior, the disclosure becomes more difficult – "if I have to tell my

bosses then I might be a little more shy about it. It depends on where I stand socially.

Like how superior I am" (Beth). Some of this relationship power dynamic boils down to

how comfortable the participant is in the relationship. Natalie explained this: "I think a

level of safety is involved. Trust and safety when it comes to who I'm comfortable

telling."

While the relationship can be an important factor when making the disclosure

judgment, the actual other person in the interaction can play a role in whether or not the

participants choose to share their hearing loss. Don explained that he's "making a

judgment about that person" when he is trying to decide whether or not to "stop them and

let them know about the hearing loss." Nicole emphasized how complex and stressful

this process can be:

> I think the first thing is determining how somebody is going to react…
> assessing their personality and whether or not they are understanding, or
> comforting, or non-judgmental… that's important. So knowing somebody
> well enough to make that decision about disclosing… knowing somebody
> well enough to be able to assess those types of things.

Another factor that plays a role in making the judgment of whether or not to

disclose is the situation in which the interaction takes place. When explaining how the

situation plays a role in that judgment call, Beth shared a story about getting dinner with

her husband's coworkers who did not know that she was hard of hearing:

> I just didn't feel comfortable enough telling them, but I had a very hard
> time at dinner… I hardly spoke a word because… you know, there was
> only 3-4 of us, but still… they were talking fast, not looking at me when
> they were talking, and we were trying to eat and look, and I hardly heard a
> word of the conversation, but I wasn't comfortable enough to tell them,
> hey I'm hearing impaired, look at me because I just met them for the first
> time at a business dinner so that moment was very awkward.

In that instance, Beth did not feel comfortable, given the situation and people involved, in disclosing about her hearing loss.

Participants also assess their goals in a given situation as they decide whether or not they should disclose their hearing loss. Matt talked about considering whether he is "going to be talking to them for that long" or if misunderstanding information from that situation later was "going to be detrimental to a goal". Nicole explained how she assesses whether her work or schooling would be affected by not disclosing. She talked about how she will "analyze the situation and do like a pro/con list" in deciding whether to disclose – "It really depends on if it is something that is a means to an end". Many participants explained that they will decide to disclose if they feel that they may miss out on something important or if the disclosure will get them necessary accommodations, especially in the workplace or classroom.

Another consideration when making judgments about whether to disclose is the word choice used when disclosing about hearing loss. Brooke said that she often discloses that she has a "hearing loss" as opposed to a "hearing impairment" because people seem to be more comfortable with the former. Don also talked about being careful with his word choices when he discloses about his hearing loss: "you use the word deaf and they think that you can't hear anything so I say hearing impaired so it lets them know to get my attention when they are talking to me." Instead of saying that he is deaf (which he is given that he has a profound hearing loss), he will downplay the hearing loss in order to let other people know that he is capable of communicating.

As a whole, the disclosure process for many participants was characterized by the many judgments they have to make in deciding whether to share their hearing loss. Many

43

participants explained that their basic underlying method was to avoid disclosing unless they felt it was necessary. When talking about disclosing about her hearing loss, Amy stated, "if I don't have to, I'm not going to bother. It's not that I try to avoid it… I mean obviously I would love to avoid it. I'm more focused on understanding… if I understand, then I will avoid it." Similarly, James does not disclose his hearing loss "unless it comes up", Beth "tries not to make it a thing unless I actually have to tell them", and Karen only discloses "when I have to". Mary summed up the underlying judgment behind disclosing for her: "If it doesn't really come up as a problem, then I don't see a need for disclosing it. It's not to be deceptive, but there is no point in disclosing. It doesn't figure into the equation." As a whole, the participants consider many things when trying to make the judgment call surrounding whether they should disclose their hearing loss – the relationship, the person, the situation, the information at risk, and the overall need to disclose.

Risks of not disclosing. When talking about the judgment call that disclosure required, many participants also pointed out the risks or costs associated with *not* disclosing about the hearing loss. Many participants use disclosure to let the other person know what accommodations or which type of communication behaviors will help them understand (such as looking at them, speaking slowly and clearly, etc.). Without this disclosure, several participants felt as if they would be more likely to misunderstand something. Rebecca stated that she usually discloses because "It just makes it easier. That way they look at me when they talk to me. If you don't tell them, you won't get the information you need. Or you lose out on the situation." Matt also reported that sometimes disclosure of his hearing loss is vital to successful communication: "If I feel

like it is going to hold me back… them not knowing that I'm going to need them to repeat something or say something over again, then I will tell them immediately, like right off the bat." Because of the potential for miscommunication, *not* disclosing is actually seen as a risk by participants, especially in work or school situations.

Being perceived as snobby, stuck up, or angry are other risks that participants associated with not disclosing. When participants do not respond to others or come across as ignoring someone, they often get perceived as snobby or stuck up. Ashley explained, "Sometimes people think I'm one big stuck up because I'm not responding to them… and I'm not! I just don't hear them." Similarly, both Denise and Rebecca told stories of how other people thought they were snobby until they found out that the participants just simply could not hear. Nancy also discussed this as she stated, "Oh I have learned the hard way… you are much better off telling. I don't want people to think I'm stupid. I don't want them to think I'm ignoring them or I am angry." By disclosing up front about her hearing loss, Nancy tries to eliminate the potential for others to think that she is ignoring them or angry with them. Adam explained that disclosure helps avoid anger on both fronts. By disclosing about his hearing loss at work and asking for patience, he is able to help prevent customers from getting as frustrated with him when he can not hear something. Thus, while disclosure puts the participants at risk for stigma, participants were quick to point out that there are risks to *not* disclosing as well.

Delaying disclosure. A fourth major theme that arose when talking to the participants about the disclosure process was the idea of delaying disclosure. For some participants, this delay in disclosure is to determine whether they can manage without disclosing. Allison explained this as she stated that she will "take some time to see if I'm

45

going to be able to understand before sharing that I need some accommodations… just a period of time to see if I can manage the situation without sharing." For other participants, this delay in disclosure acts more as an impression management strategy. As an example, James explained the anxiety associated with meeting someone new and important: "I get very self-conscious about it. I try to make an impression or something… so I don't want to start with my hearing." Another way in which this delay becomes an important tool for impression management is on the job market. Many participants talked about having delayed or avoided disclosing about their hearing loss until after they get a job and can prove their proficiency. Beth demonstrated this as she explained that she did not want her employers to "think that I was incompetent because of my hearing loss". Because of this, she will delay the disclosure about her hearing loss until her employers can see that she "can do all the things that everyone else can do".

Another major reason participants reported delaying disclosure has to do with being sure to demonstrate effective communication skills and capabilities before disclosing about the hearing loss. Many participants felt that if they can demonstrate proficiency in communicating *before* disclosing about the hearing loss, the other person/people in the interaction will be less likely to evaluate the hearing loss negatively. Morgan explained, "I won't tell them right away because it scares them and then they won't talk to me. So I just communicate with them first to let them know that I can communicate with them, then I'll tell them." Beth even talked about how, because of this delay strategy, she has been able to get mostly positive or neutral reactions to disclosures about her hearing loss:

> Usually I get the ideal reaction because I try and time it right when I tell
> them about it. If I have to tell someone right off the bat that I don't know

very well and they don't know me personally, then I get that whole I can't talk to her anymore because she's deaf and I don't know how to talk to her, you know that whole awkward walk on eggshells thing. But if I give the people time to talk to me and have a full conversation with them and I do just fine and give them time to get to know me, then when I tell them that I have a hearing loss, they are like oh that's cool and they don't make a big deal of it. So it is all a matter of if I give them a chance to get to know me.

By using this delay strategy and timing the disclosure right, many participants try to overcome potential negative reactions to their hearing loss and influence others' responses to their hearing loss disclosure.

  Minimizing the hearing loss. When participants feel that the time has come to disclose their hearing loss, many of them reported minimizing the loss or downplaying the severity of their hearing impairment. Amy (who has a severe hearing loss) flat out stated that, "I try to minimize it. I would just say that I don't hear very well, can you repeat that?" Beth (who has a moderate to severe loss) explained that "I usually say, just so you know, I have a slight hearing loss. I hear just fine, but you may need to repeat yourself or speak a little louder sometimes, but it is nothing." Additionally, participants reported using words like "hearing loss" instead of "hearing impairment" because it seemed less serious (Brooke) or telling people that they were simply "hard of hearing" instead of "deaf" (Don). Further, James discussed how he downplays his hearing loss by referring to his cochlear implant as a hearing aid because he "doesn't want to get that involved."

  Another way participants minimize their hearing loss is through the use of joking about the subject when disclosing it. Instead of outright telling people that they are hard of hearing or deaf, several participants talked about how they will "hint" that they have a hearing loss. Beth explained, "I have joked with them saying my ears suck, sorry.

Maybe they put the two and two together and are like hmm…. She does talk differently and she says her ears suck so maybe she has a hearing loss." Similarly, Nicole explained that if it is in a casual environment, she will disclose her hearing loss by jokingly saying something like "I can't hear shit." By joking, hinting, or downplaying their hearing loss, many participants talked about minimizing the severity of their hearing loss when they decide to disclose.

Education opportunity. Another way in which some participants view the disclosure process is as an education opportunity – a chance to raise awareness or educate others on the topic of hearing loss. Many participants talked about being open to questions surrounding their hearing loss. For example, Adam stated that, "if anybody asks me anything, I initially just tell them whatever I can to the best of my ability." Similarly, Beth, who works with kids and often gets questions about her hearing aids, discussed how she does not mind answering her student's questions: "I used to just kind of dismiss it, but now I will take out my hearing aid and I will show them and tell them that these help me hear." However, these participants also talked about there being a line when it came to the type of questions asked. Adam explained, "I mean there are some questions where I just look at them like really? You're really going to ask that? Why would you ask that?" If the question is deemed appropriate or genuine, most participants reported having no problem answering the question, but if the participant feels the question is irrelevant or inappropriate, they will either ignore the question or tell the person to leave them alone.

Several participants also talked about using disclosure about their hearing loss as a way to help others or be a role model. Adam explained that he does not mind sharing

his story because "If I can help somebody, then it is worth it." Denise stated that the

reason she is comfortable with openly disclosing about her hearing loss is "because I may

help somebody that is struggling with it. I can let them know that they are going to be

just fine… I can sort of be a role model." Similarly, Nancy explained that since she

works with both deaf kids and adults, "I feel like I need to be a role model." Thus,

participants are comfortable disclosing about their hearing loss if they can enlighten or

share knowledge about their hearing loss in a way that will benefit someone else who

may be dealing with a hearing loss, or other disability.

Participants also talked about using disclosure as a way to educate others about

appropriate or helpful communication behaviors that will aid in successful understanding

despite the hearing loss. For example, Ron stated that he often tells people "I read lips so

I need to see your face", and Matt also is sure to ask for people to look at him and to

"repeat things" for him. Natalie reported that she asks for people to "look at me and also

speak slowly and clearly. I may ask you to repeat something or say it in a different way

so you have to be patient." Even when they disclose to educate others on these necessary

helpful communication behaviors, many participants reported that they often also tell

others to treat them as normally as possible. Beth explained this when she said that she

often tells people to "treat me for who I am without the hearing loss. You know,

accommodate me when I need it, but don't treat me any differently." As a whole,

participants reported sometimes using the disclosure process as a way to potentially act as

a role model or to educate others about hearing loss as well as how to talk to someone

with hearing loss.

Concern for the other person. The final way in which participants discussed the disclosure process or managing the boundaries surrounding their hearing loss was by addressing their concern for the *other* person in the interaction. To highlight this, many participants talked about apologizing as part of their disclosure, even if they recognized the fact that they should not have to apologize. Nancy reported, "I kick myself because I often say I'm sorry, I'm deaf, I can't hear you. And I'm like why am I saying I'm sorry?" Similarly, James emphasized how his concern for the other person in the interaction influences his disclosure: "I do what is the worst thing to do… I say I'm sorry, I can't hear well. I probably should do it like that… I'm not supposed to be sorry. But it does help keep people from getting defensive." Many other participants used the words "I'm sorry" to preface the disclosure when they talked about how they typically disclose their hearing loss. In this, the participants are highlighting their concern (most likely subconsciously) for the other person and the possible "inconvenience" or "discomfort" that may be caused by their hearing loss. Mark explained this as he shared his decision process for how to disclose his hearing loss to the other person:

> The decision process behind that I guess is I've got to think about the
> other person, in their shoes, because they may be intimidated… they may
> be, "oh crap, you know, I don't want to say the wrong thing"… that sort of
> thing. So I try to think about the other person.

Another way in which participants talked about their concern for the other person and how it was the driving factor behind their disclosure was through their discussion of preventing the misconception that they are ignoring the other person. Nancy described this: "I don't want them to think I'm ignoring them or I am angry. I've found that the more upfront I am, they accept it better." Similarly, Tim explained that he often discloses in order to let people know that "I'm not ignoring you, I just can't hear you." Natalie

50

also clarified that her disclosure process is often "other-person" centered: "Most of the time, I tell them, it is because what you say is important to me and I want to be able to hear everything you say. That lets them know that what they say is important to you." Thus, participants disclose as a way to let other people know that they are not being ignored and that what they have to say is important, making that disclosure centered on the participants' concerns for the other person in the interaction.

The final way in which participants discussed their concern for the other person as a motivating factor for disclosure was through discussing their feelings of responsibility to disclose their hearing loss. David explained that he often discloses about his hearing loss when he asks someone to repeat something multiple times: "I will finally say, I'm sorry… I just can't understand what you are saying. I don't want to make them feel like they are doing something wrong… it's my problem." Denise talked about disclosure as "a way of taking responsibility for my hearing loss as much as I can" and making sure that the other person realizes that "It's not that you aren't speaking well, it's just that I am hard of hearing." She said that she has to take "responsibility for my hearing loss as much as I can and accepting that just sometimes I'm not going to understand." Sharing in this idea of taking responsibility for the hearing loss, Ashley talked about disclosure about her hearing loss as her job:

> I always tell people. It is my job to help them understand my hearing loss.
> It is my responsibility to bridge the gap between the hearing person and
> my hard of hearing. It is my responsibility to tell them and let them know.

Through their discussions of preventing misunderstandings and taking responsibility for their hearing loss, many participants expressed that it is their concern for the other person in the interaction that often drives them to disclose their hearing loss.

The first research question focused on how participants managed the boundaries surrounding their hearing loss by asking questions about how, when, and why they decide to share about their hearing loss. Some participants reported being fairly open in their disclosure of their hearing loss due to the fact that the hearing loss was an important part of their identity. Other participants talked about the disclosure process as a major judgment call based on the other person, the situation, and the information being discussed. The risks of *not* disclosing were also addressed by participants when they talked about making the decision to disclose. Participants also reported delaying disclosure, minimizing the hearing loss, and using the disclosure process as an education opportunity. Finally, participants also included their concern for the other person in the interaction as a part of the decision process of whether to disclose about their hearing loss.

Boundary Turbulence (RQ2)

The management of boundaries, or disclosure, surrounding information about their hearing loss is not always left to the participants since other people will occasionally share that information for them, resulting in boundary turbulence. As the participants talked about boundary turbulence, three major themes arose – the intentions of the discloser matter, a feeling of a loss of control, and their reactions to turbulence.

Intentions matter. When the participants were asked about boundary turbulence, or other people disclosing for them about their hearing loss, one thing they made clear was that intentions mattered. If the person who disclosed about their hearing loss for them had good intentions (i.e. was trying to be helpful), the participants were less likely to mind the boundary turbulence. To illustrate this, Allison explained that she has had

family members share about her hearing loss in order to facilitate the conversation. She clarified that her family members do this to help her so she does not see boundary turbulence in this situation as a bad thing: "It is not a bad thing and helps the conversation move on". Additionally, Adam explained that "If people do have questions and aren't sure about approaching me like they aren't sure they know me well enough or not, they ask somebody else usually. Yeah, that is perfectly okay." In this, Adam illustrated that he is okay with boundary turbulence as long as the other person's motives are genuine understanding.

On the other hand, participants stated that if the person who discloses for them does not necessarily do so to be helpful, the boundary turbulence is less likely to be seen in a positive light. Amy discussed a time when she was not comfortable with the boundary turbulence because it was done by a person that she did not care for: "That I did not like. That was extremely uncomfortable. This was not a good social situation to begin with. It was not people that I was happy to be with and they took it upon themselves to share that." Participants also explained that if the disclosure is done behind their back or in a way that is malicious in some manner, it is not okay. "I definitely would have a problem if someone was saying things like that kid can't hear anything or that kid is loud all the time, you know if they started saying stuff like that" (Adam). Additionally, participants stated that they do not care for boundary turbulence if there is no *reason* for the disclosure. Matt clarified this: "I don't understand why they have to. I mean, people are going to find out on their own. And you know, it doesn't need… I mean sometimes I don't understand why." In this, Matt indicated his discomfort with boundary turbulence when his hearing loss is disclosed without any purpose.

53

Loss of control. In addition to intentions, another thing participants addressed when talking about boundary turbulence was a feeling of a loss of control. This was talked about in two ways – a loss of control due to physical manifestations of the hearing loss or a loss of control based on others' disclosure for them. Several participants discussed the physical manifestations of their hearing loss (speech impediments, hearing aids, cochlear implants, etc.) as a form of boundary turbulence because these things essentially disclose their hearing loss for them. Beth discussed how her speech usually gives away her hearing loss, something she does not like. She also talked about hiding her hearing aids when she was growing up in an attempt to prevent others from finding out about her hearing loss. Similarly, several participants talked about disliking wearing hearing aids due to their visibility. They explained that it prevents them from being able to hide or make the choice to disclose their hearing loss. In that way, hearing aids can serve as a kind of boundary turbulence – a loss of control surrounding when and where they disclose their hearing loss.

Another way in which participants talked about a loss of control associated with boundary turbulence was in their discussions of others' disclosures for them. Tim explained that his best friend has disclosed his hearing loss for him on multiple occasions: "I wasn't upset or mad at him. Then again, I was like it wasn't really your business. I'm not mad at you, but kind of keep it to yourself." Several other participants indicated that it is not other people's "business" to disclose their hearing loss for them. When asked about others disclosing for him, James talked about getting frustrated sometimes when his wife "overdoes it… sometimes she'll start repeating and it's like, no, I heard." Amy also discussed being "aggravated" when other people decide to disclose

her hearing loss for her. She went on to state, "I will decide when I am comfortable sharing that information." Many participants reported wanting to maintain some control over the boundaries surrounding their hearing loss. To explain the loss of control and power she feels when the boundaries surrounding her hearing loss get managed for her, Natalie told a story of when she was invited to a brunch at a friend's house:

> The friend that invited me knows about my hearing loss. The other women there did not know. I was talking to a lady on one side of the kitchen and I was having no difficulty understanding her. A nice conversation, we were standing there and I was looking at her. My friend came up and stopped her from talking and said, "you need to look at her, she has a hearing loss", talking about me in the third person. Wait a minute, I'm responsible for listening to her, I'm doing fine, thanks. That really was not necessary. To talk about somebody in the third person in their presence, it is just demeaning. I needed to let her know that I'm responsible for this, I can handle this. She said oh, okay. I think she was trying to be nice because I didn't know the other people, but at the same time, that is weird.

In this, Natalie indicated that even though she knew her friend's intentions might have been to be helpful, she did not appreciate the boundary turbulence that occurred. As a whole, participants reported feeling a loss of control when they are no longer in charge of managing the boundaries and the disclosure process surrounding their hearing loss.

Reacting to turbulence. The final theme that arose when talking to the participants about boundary turbulence was how they reacted to turbulence. Reactions varied widely among the participants. Several participants talked about letting it go when someone else discloses for them, even if they did not like that the person disclosed their hearing loss for them. Beth talked about disliking it when a colleague shared her hearing loss for her, but said that she "let it go because at that point, he already told the people he wanted to tell and there wasn't really anything to do." Tim also discussed letting boundary turbulence go when he described an instance when one of his friends disclosed

about his hearing loss for him: "It was in front of the whole class, so I just had to go along with it." The participants who talked about letting it go when boundary turbulence occurred explained that it is usually easier to just let it go than it is to call the other person out and make an even bigger deal about it.

While some participants reported "letting it go" or "going along with it" when their hearing loss gets disclosed for them, others are sure to address the person who caused the boundary turbulence. Natalie explained that she has had conversations with her friends to let them know that she can "handle it" and is "doing fine" and will disclose if she feels it is necessary. Similarly, Tim stated that he had a friend that constantly disclosed for him so he had to address it. He told his friend, "It wasn't really your business. I'm not mad at you, but kind of keep it to yourself." While some participants are verbal in their addressing of boundary turbulence, other participants talked about addressing it in a more subtle way. John has utilized a nonverbal way of letting his father know that he did not like it when he shared his hearing loss for him: "I may give him a look. Let him know that I don't like that." Using nonverbal cues like this, some participants try to subtly get the point across that they do not care for boundary turbulence surrounding their hearing loss.

A final reaction that several participants talked about in terms of dealing with boundary turbulence was being proactive. These participants try to take steps to prevent boundary turbulence from occurring. Nicole explained how she tries to prevent boundary turbulence surrounding her hearing loss by addressing it when she discloses her hearing loss for the first time with that person: "I always say I'd appreciate it if you don't let anybody know." Ashley reported that she tries to prevent boundary turbulence from

happening in a slightly different way. If a friend or family member tries to introduce her

to someone and she senses that they are going to also disclose that she has a hearing loss,

she tries to intervene:

> Sometimes I know… I kind of anticipate what they are going to say and I
> have to get in front of them and say hi… and introduce myself. That
> keeps them from sharing right away that I have a hearing problem. I don't
> want to be identified that way.

Thus, participants reported reacting to boundary turbulence in a variety of ways whether

it is by letting it go, addressing the person who disclosed for them, or attempting to

prevent turbulence altogether.

The second research question in this study is aimed at understanding how the hard

of hearing and deaf participants manage and respond to boundary turbulence surrounding

their hearing loss. When talking about boundary turbulence, participants reported that the

intentions of the other person mattered as the participants evaluate the boundary

turbulence as positive or not. Further, participants explained that boundary turbulence

usually results in them feeling a loss of control surrounding their health information.

Finally, participants reported a variety of reactions to turbulence – from letting it go to

responding proactively to prevent turbulence for occurring.

Costs of Disclosure & Stigma (RQ3 & RQ4)

When managing boundaries surrounding their hearing loss, many participants

talked about what they see as the costs of disclosure as well as how they feel others might

stigmatize their hearing loss (one of the major potential costs of disclosure). Although

these (costs of disclosure and stigma) were originally posed as two separate research

questions, the themes that arose within this section intertwine and overlap. The different

stigmas that the participants pointed out were also cited as costs to disclosing. Given that

57

the participants did not discuss costs of disclosure and stigma as separate and individual

constructs, the themes that arose surrounding these two research questions will be

addressed together. There were five themes that arose when discussing cost of disclosure

and stigma of hearing loss with the participants – feelings of sorry or pity, not feeling

worth others' time, being labeled as 'not normal', the perception that hearing loss limits

capabilities and intelligence, and the idea that hearing loss is different from other

disabilities.

      Feelings of sorry or pity. One of the first types of stigma or costs of disclosure

associated with hearing loss that participants were quick to point out was feelings of sorry

or pity. Participants view these feelings of sorry or pity as a common, but hated, reaction

to their disclosure about hearing loss. Many participants even talked about pity as the

worst response to their disclosure – they hate it when other people say "I'm so sorry" in

response to their sharing about their hearing loss. "I don't like it when some people say,

when I tell them I am deaf, they say oh I'm sorry. I don't like that" (Jane).   Nicole

shared similar feelings when asked what the worst response to her disclosure is:

"Apologizing or saying I'm sorry. Like making me feel like they think it is this huge

burden… that's the worst thing somebody could do." The reason that many participants

found "I'm sorry" as such a horrible reaction is because they feel like the other person

views their hearing loss as a burden or something that limits functioning. The

participants were quick to explain that their hearing loss is definitely not something that

people should be sorry for, as anybody who knows them understands. Susan laughed as

she told a story about her son's teacher calling the house for her: "My son says well she

doesn't use the phone because she can't hear. And the teacher is going oh the poor dear

and Nathan says no… no… she's not poor anything." Feelings of sorry or pity are a common reaction to disclosure according to participants – a reaction that they despise.

Not worth others' time. The perception that a deaf or hard of hearing person is not worth the extra communication time or effort was another stigma or cost of disclosure participants talked about. Karen stated that because "they don't know what to do" in order to communicate with her successfully, a majority of people will not even try: "Unfortunately, in my 60 years of experience, I would say only 25% try or even smile." Adam echoed this sentiment when he explained that, "I have yet to really get any understanding because they are like you know, I am busy, don't waste my time." When talking about trying to order at a fast food place, Nick also touched on this lack of willingness to work with the hard of hearing person: "The person at the counter is in a hurry and doesn't have time to work with the deaf guy." Ron summed up this feeling of being "not worth others' time" when he talked about people in general when they find out about his hearing loss: "Yeah, they don't want to help me out… they don't have the time. They go so fast… they don't know how to cope with it or maybe they don't care." He even went on to say that this stigma is so prevalent that, "I didn't learn anything in high school. They passed me because they didn't know how to cope with me. The easiest thing to do was pass me."

This "not worth others' time" is also communicated to the participants through avoidance and the use of "never mind". Many participants explained that once they disclose their hearing loss, they run the risk of losing future interactions with that person. David explained that many people at his work who know about his hearing loss will avoid talking to him: "they come in and throw things at my desk and walk away. They

59

don't want to start up a conversation because they know I may have a hard time with it."

Similarly, Amy stated, "They perceive that the communication might need more effort so they might avoid it because they don't want to put forth that kind of effort to talk to me."

While avoidance is a popular way to communicate that the participants were not worth the communication effort, so is the lack of willingness to repeat things. Many participants talked about how people who know about their hearing loss will not repeat things for them if they need them repeated multiple times. Adam explained it this way:

> The worst thing I've noticed is repeating stuff. Umm… they decide for you what is important and what is not. And it's like no no no… tell me, let me decide. You don't take that away from me. I don't care… it proves two things. A) I am worth the time for you to repeat something, even if it is worthless. Tell me that and then let me decide… this shows me that you value me more than the 20 seconds of time or the breath and a half that it took to repeat that. B) You still treat me as worthy enough to make that decision for myself. Like oh it is not important… okay, it may not be important to you, but it is important to me that you repeat it.

Karen also talked about her frustration when people will not repeat things for her as she discussed her dislike for the phrase "never mind": "I hate 'never mind'. Oh I hate that word. 'I'll tell you later' and then they don't tell me again… I hate it." In her discussion of the phrase "never mind", Karen explained that it takes the power to decide what is important to hear away from her and also indicates that she is not worth the extra effort to repeat whatever she needs repeated. As a whole, participants feel that this feeling of "not being worth others' time" is a risk of disclosure or a stigma surrounding their hearing loss.

Labeled as 'not normal'. Another stigma or cost of disclosure that participants perceived to be linked with hearing loss is the idea that hard of hearing or deaf people are "not normal". Because of this label of being "not normal", participants explained that

when people know about their hearing loss, the participants are likely to be excluded or seen as outsiders. "That was probably the hardest part… everybody wants to fit in and when you are a little bit of an outsider, you know it" (Beth). James talked about how people will avoid communicating with him in social settings because he is labeled as "different" or "not normal": "That kind of thing was a problem… it caused a lot of anxiety. You don't want to *not* be part of the group, but… nobody is communicating with me." Since some participants want to fit in or be able to assimilate into school or work groups, this potential cost causes them to put off or avoid disclosure. Brooke reported avoiding disclosure, especially when she was younger, in order to prevent being labeled as an outsider: "Yes, I hid it… you wanted to be part of a group." As a whole, the idea that hard of hearing or deaf people are perceived as "not normal" was exemplified by Karen as she talked about how other people view her once they find out about her hearing loss: "They are trying to fix me… I can see people looking at me… looking at my ears, my lips, my mouth… they want to fix me. Don't do that. I'm a human being. Don't do that to me." In this, Karen discussed how others think she needs "fixed" because of her hearing loss – highlighting the fact that people label hard of hearing or deaf people as "not normal".

Participants explained that the label of hearing loss as making them "not normal" is so prevalent that many people are shocked when the participants can communicate normally. Nick shared this experience: "Sometimes when I meet someone, I'm like I'm deaf. And they don't realize it… it shocks them because we are just having a normal conversation." The inability to be "normal" or "communicate normally" is something that the participants explained is often associated with hearing loss. This contrasts

heavily with what participants reported to be the *best* reaction that they can get when

disclosing about their hearing loss – for the other person to act as if they are normal or

just like everyone else. James stated the best way for others to react to his disclosure is to

act like nothing is different: "just say oh okay and that's it. I'm not expecting anything

special. I think I'd be more self-conscious if people had to do something for me." In

this, James highlights that he wants to be communicated with just like everyone else – he

does not want to be labeled as "different" or "not normal". Many other participants

reported this "oh okay" reaction as being ideal. Beth took it a step further and explained

why this is the best reaction: "I just want people to see me for more than just the hearing

loss and treat me the same as anybody else." Despite wanting to be treated normally and

making efforts to be perceived as "normal", many participants explained that being

labeled as "different" or "not normal" is a stigma that could occur if they disclose their

hearing loss (a cost of disclosure).

      Hearing loss limits capabilities and intelligence. A major stigma associated

with hearing loss that participants cited as a cost of disclosure is the perception that

individuals with hearing loss are less capable both physically and intellectually. "I mean

they take my inability to understand something right away as a signal that I'm completely

inept" (Adam). Because of this perception, many participants reported being hesitant to

disclose their hearing loss. Amy talked about delaying or avoiding disclosure because "I

don't want them to think that I am less competent or something like that." The attempt to

avoid this stigma by not disclosing about their hearing loss was especially common when

participants talked about trying to get a job. Many participants reported not telling

potential employers about their hearing loss until after they get the job or until it is

absolutely necessary. Morgan was one such participant. She waited to tell her boss

about her profound hearing loss after she got the job: "I never told him and he hired me

and my first day of work, I went and told him… he about shit his pants. He just stood

there with his mouth open." Morgan felt like if she had told her boss about her hearing

loss during the interview, he would have seen her as incapable and not hired her.

The stigma that hard of hearing or deaf individuals are less capable seems to work

its way into many aspects of the participants lives – even activities that do not require

hearing. Morgan talked about being turned down at an interview for a warehouse job

because of her hearing: "I said what does that have to do with it… it's a warehouse job.

She said we've got forklifts out there. I don't want you getting run over by one. I said

really?! I can see… forklifts are *huge*." On a similar note, Tom talked about how he was

kicked off his high school basketball team because of his hearing loss: "I was like

basketball has nothing to do with my hearing." Nick, an artist, explained how his hearing

was connected to an inability to preform a task that had nothing to do with his hearing –

his hearing loss was connected to the perception that he could not be an artist. Thus, the

perception that hearing loss limits capabilities seems to permeate into all aspects of the

participants' lives, whether the activity requires hearing or not. In discussing this, Natalie

tries to fight back against this perception:

> I think a lot of times people will perceive something like a hearing
> disability… like they might not be capable in the world. I think that's a
> fear that we have… of not being capable. The most important thing for
> folks to understand though is that a lot of times we are just as capable, but a
> lot of times we have to work twice as hard as someone else to get the same
> information correctly.

While hearing loss is perceived to limit physical capabilities, the participants also

discussed how hearing loss is linked to mental limitations as well. Beth stated that the

63

worst response to her disclosing about her hearing loss is: "Probably just to treat me like I'm stupid. I think the biggest thing that bothers me is if they degrade me because of it… if they think I'm not capable of things." This idea of being perceived as less intelligent was also touched on by Nicole as she explained, "I do feel like people are inaccurate in some of the assumptions that they make… they think that our mental capacity is lower just because we can't hear." Brooke also stated, "I feel that a lot of people just think that if you have a hearing loss, you aren't really an intelligent person."

The "deaf and dumb" perception is so pervasive that several participants reported that, upon disclosure of their hearing loss, others have assumed that they attended (or should have attended) special education classes in school. James told a story about his 4th grade teacher "who announced that I should be in a school for the mentally retarded, and I was slowing everybody else down in the class because I had this hearing problem." Several other participants talked about how other people make the incorrect assumption that because the participants are hard of hearing or deaf, they are also mentally retarded or impaired in some way. Denise, a participant with a Master's degree, provided several examples of when this has happened to her:

> I've had very insulting situations where they say, well, did you attend special education classes. I say, no, there's nothing wrong with my brain, it's just my ears. My ears and my brain are separate. They try to group the two together. I even had one of the local hospitals put in my medical file that I was mentally retarded, which I'm not. I had to have a lawyer to get it removed.

In this, Denise highlighted several misconceptions about people with hearing loss – that they need to attend special education schools, that there is something wrong with their brain, and that they are mentally retarded. Thus, the stigma that hard of hearing or deaf

individuals are either physically or mentally limited in some way is a cost of disclosure that many participants addressed.

Different than other disabilities. A final theme that arose when talking to the participants about the potential stigma that they saw as a cost of their disclosure was the perception that hearing loss is different from other disabilities, particularly other physical disabilities. Many participants were quick to point out that hearing loss is a different type of disability, and therefore, the stigma for hearing loss is unlike that of other disabilities. Several reasons that participants felt that hearing loss is unique connect to its inherent invisibility as a disability. For instance, many participants discussed having to provide some sort of proof of their hearing loss as others often express doubt surrounding whether the participants actually have a hearing loss. As she talked about one of the risks of disclosure being disbelief (and thus further explaining), Denise stated, "If I say, I have a disability… people look me up and down… where is it?" Susan talked about how others will think that she has selective hearing as opposed to a hearing loss altogether:

> First of all, they will say, oh, I think she hears what she wants to hear. And that is such bullshit because sometimes I can't hear a lot and then a familiar phrase or words that make sense come through and they're like, oh, she heard that, and I'm like, but I didn't choose to hear that. It's times like that when I think to myself where you should go with this hearing loss thing for a day and see how you feel about it.

Ron has had similar experiences: "They think I select my hearing. I tell them I do have a hearing loss and I wear hearing aids. They think I can hear."

Complicating the doubt that the participants have a hearing loss, participants also talked about the fact that hearing loss and the use of hearing aids in general is misunderstood. Hard of hearing participants explained that, because they do not use sign language, they are not perceived to really have that much of a hearing loss. Participants

65

felt that other people do not understand that the use of sign language is not always connected to the severity of the hearing loss – many participants with severe to profound hearing loss rely on oral communication and reading lips. Morgan, who has a profound loss in both ears, stated, "A lot of people don't understand… they don't think that I am deaf because I can talk and read lips and don't do sign language." Another complicating factor when it comes to this burden of proof associated with disclosing about hearing loss is the misunderstanding of hearing aids. Participants explained that other people often incorrectly assume that hearing aids completely "cure" the hearing loss. Carly explained that she hates it when others "assume it can be corrected with hearing aids. The assumption discounts reality." She went on to say, "I am disappointed when people assume that hearing aids correct a hearing loss the way glasses correct vision." Participants were quick to point out that even if they wore hearing aids or a cochlear implant, there is a difference between *hearing* something and *understanding* something.

Another reason participants expressed that hearing loss differs from other disabilities is the fact that it is often overlooked or not considered (also connected to its invisibility). Adam explained that hearing loss "doesn't get thought about by other people. It isn't like eyesight or something… they don't think about it until it gets put in front of them." Due to the lack of visibility, Denise also emphasized the fact that hearing loss does not get thought about: "I think it is because it is an unseen disability. You get recognition because you are completely deaf and signing, or blind, or have some other physical disability. People don't know about us… it's unseen." Denise discussed this disadvantage further as she explained that a lot of hard of hearing people do not go to big

66

events because "people just don't think about accommodating us." Finally, Rebecca

talked about this as a lack of awareness due to the invisibility of hearing loss:

> They are not used to being around a person with a hearing loss so it is hard
> for them to remember to talk to me in certain ways. You have to
> constantly remind them. If you are in a wheelchair, they can see it.

Another stigma connected to hearing loss that sets it apart from other disabilities

is the connection between hearing loss and aging. Adam explained this when he talked

about disclosing about his hearing loss: "I'd say a lot of people put hearing loss right in

with the elderly. A lot of people are utterly shocked at how young I am… they find out

that I am 22 and I have hearing loss." Similarly, David discussed this connection that

people make between hearing loss and age: "I think that hearing loss is perceived by the

general public as a sign of aging, a sign of lesser abilities, a sign of disability. This

makes me sad." The younger participants in particular were sure to point out the

stereotype connecting hearing loss to age. They feel that this is a stigma that acts as a

cost to their disclosure – people will see them differently or be confused (which required

further disclosure) once they share their hearing loss.

When talking about the differences between hearing loss and other physical

disabilities, participants provided many examples surrounding why they think hearing

loss is unique in terms of stigma or costs of disclosure. Nicole explained that hearing

loss is different than vision loss:

> I feel like people treat me differently and make certain judgments about
> me that would not be associated with something like a vision loss. I wear
> glasses too and I feel like that is pretty normal and accepted and nobody
> says anything or thinks anything about my glasses, but it is different for a
> hearing loss and hearing aids.

In this, Nicole was quick to point out that the stigma surrounding hearing loss is unlike that of other disabilities, in this case vision impairment. Despite the difference in stigma surrounding hearing loss, participants also talked about how hearing loss differs from vision loss in terms of accommodations. Several participants gave examples of when this difference in accommodation was not considered. Joe even talked about disclosing about his hearing loss at a restaurant only to have the waiter bring him a braille menu. James laughed as he shared a similar story about disclosing to a teacher with an accent in order to express his concerns about understanding the accent: "I told that to the teacher and his response was that's okay, I had a blind girl last semester and we did fine. I was like well hey… okay… it's the same thing I guess." Thus, despite the differences in stigma surrounding hearing loss and vision loss (vision loss is also more common place), the perception of accommodations needed is often misunderstood.

Participants went on to talk about other ways that hearing loss is unique from other physical disabilities in general. Mary differentiated hearing loss from other physical disabilities because hearing loss has this extra component of "coming out of the disability closet": "Of all of the disabilities, hearing loss is one that you can hide to a certain degree. Somebody who doesn't have arms or legs or is blind… it is going to be more difficult to hide that disability." In this, the invisibility of the loss forces individuals with hearing loss to engage in disclosure – a process other physical disabilities may not have to engage in. Several participants also mentioned that hearing loss is also addressed differently in legislation and insurance. While many insurance companies cover glasses for vision loss, cochlear implants and hearing aids are often not

covered by insurance. Nicole addressed the stigma surrounding hearing loss from both a

legislative and insurance standpoint:

> There's also stigma that is legislated… hearing loss is treated differently,
> from a policy standpoint than vision impairment or even other disabilities.
> So I feel like that is something that society has created. I do feel like it is
> a more difficult situation to handle than other disabilities because it is
> something that is not common… maybe its not uncommon, but it is
> something that is not recognized. And that is something that I think
> indicates a stigma and a disadvantage… that it is something that is so
> expensive to treat versus other things… insurance doesn't always help
> with hearing loss.

Thus, hearing loss differs from other disabilities in terms of how it is treated both by

insurance companies and legislative policies.

A final way in which participants differentiated hearing loss from other

disabilities was by addressing the cultural complications associated with hearing loss.

There is a community of deaf people that value hearing loss and utilize their own

language (American Sign Language) – the Deaf community. Despite the presence of this

community, several participants talked about how people with hearing loss fall in

between – they are neither deaf nor hearing. As Denise explained that the hard of hearing

individual often gets overlooked or not recognized, she stated, "We get caught in the

middle – we aren't deaf or hearing." Mark also addressed this "caught in the middle"

phenomenon:

> On one hand you have the deaf community and on the other, you have the
> hearing world… It's like… I told my wife I feel like an alien because I
> don't fit in the deaf community, I don't fit in the hearing world… I'm here
> by myself. It's just tough… nobody understands.

In this, Mark highlighted the isolation many hard of hearing individuals may face, as well

as the cultural divide, that makes hearing loss different from other disabilities. Those

who participate in the Deaf community explained the benefits of having a community of

others like them – their culture values hearing loss and allows them to push aside some of the stigmas present in mainstream society. Nick highlighted this:

> Sometimes the hearing people… they just see them as the deaf person. There's so many levels of deafness. You can't just say deaf and leave it there… there are so many different levels. In deaf culture, that person who is completely deaf and signs perfectly, he is highly recognized as a person… he is a leader of his community. But outside of that community, he has a disability and other people may judge him… he's deaf. And the hearing people might say… that poor person, he can't hear. But he does so well in the deaf community. They might think he's retarded in the hearing world, but he's not retarded… these are intelligent people.

Therefore, the cultural community that is available may be helpful to those that assimilate into it. As a whole, participants feel that hearing loss is different from many other physical disabilities because it can be invisible, it often goes unrecognized, it gets treated differently from a policy standpoint, and it has a cultural component.

The third research question in this study was aimed at understanding what the hard of hearing and deaf participants perceive to be the costs of disclosing their hearing loss. Similarly, the fourth research question prompted an investigation of stigma as a cost of disclosure as well as the ways in which individuals who are deaf or hard of hearing perceive their hearing loss to be stigmatized. The themes developed from these two research questions were overlapping as stigma, and the many types identified by the participants, was the main cost of disclosing about their hearing loss. In discussing costs of disclosure and stigma, participants talked about feelings of sorry or pity as one stigma they potentially put themselves at risk for upon disclosure of their hearing loss. Additional stigmas surrounding hearing loss identified by participants included the feeling of not being worth others' time, being labeled as 'not normal', and being seen as

less capable. Finally, participants also talked about how the costs and stigmas associated with hearing loss are different from that of other disabilities.

Responding to Stigma (RQ5)

The final research question examined how the participants respond to stigma surrounding their hearing loss. There were six themes that developed surrounding the participants' response to stigma – avoiding/ignoring, asserting oneself, viewing it as an education opportunity, seeing stigma as the other person's problem, having a positive attitude, and making stigma a positive thing (turning it around to their advantage).

Avoiding/ignoring. When participants perceive stigma to be present or perceive the potential for stigma, they sometimes use ignoring or avoiding as a strategy. If stigma is present, some participants talked about ignoring the stigma altogether. Morgan reported using this as a strategy: "I am usually able to not let it bother me and ignore it. And you have to. It's not going to change. I guess I don't think about it much." Various other participants echoed this sentiment and talked about being so used to stigma surrounding their hearing loss that they have learned to just ignore its presence. Ashley also uses ignoring as a strategy: "I ignore it because it is just not worth it." She went on to explain that you just have to let things go because you will make yourself miserable otherwise.

Similar to ignoring, avoiding is also a strategy participants use to deal with or respond to stigma. Using this strategy, participants try to avoid stigma in several ways – through avoiding disclosure, avoiding stigmatizing people, or avoiding potentially stigmatizing situations. Avoiding disclosure altogether so the other person does not know about their hearing loss is one strategy participants use to avoid stigma. John

explained that, "When I was growing up, I guarded being deaf with my life. I didn't want people to know. I didn't get picked on a whole lot, but I was careful to make sure nobody knew about it." Nicole also talked about trying to avoid disclosure about her hearing loss by hiding her hearing aids:

> I did have the ones that wrapped around your ear and were very visible and I would like pull my hair over them… I would never wear my hair pulled back. I would make sure my hair was down to cover it. It was not something that I wanted people to know.

In this, Nicole avoided disclosure about her hearing loss and any potential for stigma by trying to hide her hearing aids.

Another way participants avoid stigma is by avoiding the people who stigmatize them. Adam talked about people who get tired of working with him or frustrated with him because of his hearing loss. When it reaches that point, he said that he just avoids dealing with them: "I'm just kind of done with them at that point when they get frustrated about that stuff. I'm not going to be around somebody who's always pissed off at me because they have to repeat things twice." Similarly, Morgan explained that if people stigmatize you for your hearing loss, you have to "walk away from them at that point" because otherwise you are "going to make your life miserable." When dealing with stigmatizing people, Ron stated, "If they give me problems, I tell them don't bother… don't talk to me. Forget it." In this, he also tries to avoid stigma by avoiding interactions with the people who stigmatize his hearing loss.

A final way participants attempt to avoid stigma is by avoiding potentially stigmatizing situations. James explained that he can not hear anything in loud restaurants and bars and stated, "I kind of shut down because I can't hear anything. So I prefer not to even go to those places." When Nick was asked if a stigma exists surrounding hearing

loss, he stated, "Yeah, some. But if I can, I avoid it in the fact that if it is a participation group or something, I don't put myself in that group." Thus, he will attempt to avoid stigma by avoiding stigmatizing situations or groups. When talking about avoiding stigmatizing situations, several participants pointed out the downside of this – a feeling of isolation. Allison explained that she is not the person that she could be socially because she avoids big groups. She said that this "makes me feel isolated and lesser." This is echoed by Susan:

> I think maybe the isolation factor is another thing. There are many, many times where I just chose to stay home and read… in college too, I didn't want to go out with groups, especially if it was dark. If we were at a party and people went outside and it was dark, I was just lost in the woods so I just avoided that as much as I could.

In this, Susan illustrated that she often avoids potentially stigmatizing situations, but this strategy can also lead to feelings of isolation. As a whole, participants reported using ignoring and avoiding (disclosure, people, and situations) as one response to stigma.

Asserting oneself. Another response to stigma that participants talked about using was standing up for themselves or asserting themselves in some way. Adam touched on an assertive response to stigma as he stated, "If someone says something that is just rude, I am not afraid to tell them to piss off. And I have told people to piss off before." Beth has also used an assertive response to stigma:

> If people make me feel dumb for it, then I speak up and defend myself. I will be a smart ass and I'll tell them off or I will just say… the fact that you want to make me a degraded person because of my hearing loss actually makes you a bad person.

Using an assertive response, Beth explained that if the person really stigmatizes her, she often tries to turn the situation around and make them feel bad for stigmatizing. Ashley also talked about asserting herself against stigma and the labels associated with hearing

73

loss: "Don't let people label you… don't accept that." Ashley went on to explain that she

often has to remind her boss to evaluate her on her work and not her hearing loss. She

said that she is really clear on that point because, "I've learned that, in the workplace, not

to let my hearing loss be an excuse." Asserting herself in the workplace, Ashley tried to

avoid being labeled as less capable because of her hearing loss.

Education opportunity. Seeing stigmatizing behavior as an education

opportunity was another response that participants reported. Ashley explained that

stigma is typically a result of discomfort or feeling unsure of how to communicate with

her. She tries to overcome that: "I know that I have to be helpful to them… I have to

guide them a little bit." When people respond in a negative way, Morgan also said that

she tries to "let them know that it is okay". She continues talking to them normally to

show that she can have a normal conversation and also lets them know which

communication behaviors would help her understand successfully. Similarly, Beth stated

that she responds to others' stigmatizing reactions by educating them on the appropriate

way to communicate with her: "I want to make sure they know that they can talk to me

normal please. Don't treat me any different than you would anybody else." Karen

directly addressed the use of education to combat stigma: "Don't treat us as the last

person on the earth. We want to be treated fairly. We have to educate them on how to

treat us appropriately." Denise also sees stigmatizing behavior as a chance to educate

others when she talked about her reaction to people who assume, because she is hard of

hearing, that she went to special education classes as a child:

> It gives me an opportunity to educate them. The first time it happened, I
> was really taken back. I said no… why did you think that? The person
> said, well, you have a hearing impairment. I said, so what? There's
> nothing wrong with my brain. Then we went on from there… it allows me

to explain that I went to regular classes, I graduated from college, I have a Master's degree.

As a way to deal with stigma, the participants may try to eliminate or lessen stigma by teaching other people that hard of hearing individuals are just like everyone else and they are capable of many things.

It's not my problem. Participants also addressed or responded to stigma by brushing it off and saying "it's not my problem." Nick stated, "If they have a problem, that's on their part. But I don't have a problem." Similarly, Matt explained, "If you want to feel different about me since I'm hearing impaired, that is your problem not mine. I know how I feel about it." Participants who talked about this were quick to say that they are okay with their hearing loss so it does not matter what other people think. When Mary addressed how she reacts to stigma upon disclosing about her hearing loss, she stated, "That's just information for them to take in… if they can't handle it, then they can't handle it." This is similar to what Tim had to say when he was asked how he responds to stigmatizing behavior surrounding his hearing loss: "I don't really care. If you say, cool, that's fine, that's awesome. But if you say, you're crazy or weird, that's whatever too. I don't care." As a whole, Ashley summed up this theme:

> I've just come to the fact that there is nothing to be embarrassed about hearing loss. I've got it, I've learned to live with it. I am what I am…. People have to accept me for what I am. If they don't like it, that is their problem.

Thus, many participants see stigma and stigmatizing behavior as more of a problem for the other person than it is for them.

Positive attitudes and jokes. One response that participants identified as the best way to respond to stigma is having a positive attitude and being willing to joke about

75

hearing loss. Nancy talked about having a positive attitude surrounding her hearing loss

as she stated, "Yes I am handicapped… I'm deaf… I'm different… but that doesn't have

to mean the end of my life." She went on to say that there are worse things in life than

being deaf. Nancy emphasized the importance of a positive attitude in how it can

actually shape the perceptions of others and maybe even help avoid stigma:

> If you are all like oh… I can't do it, I can't hear, I can't do it. Your whole
> body language and your way of dealing with it, people will respond to
> that… people will get *that* message. It doesn't matter what words you use,
> it doesn't matter what you're talking about. If your body language is
> awww… or so angry… people will remember that 10 times more than
> they are going to remember what you are saying. So I have to prove to
> them that I am fine… that I'm not angry or sad.

Another factor that participants identified as vital to having a positive attitude is

accepting the hearing loss as a part of their identity. Beth discussed how dealing with the

hearing loss has gotten easier as she has grown into her self: "With age, it has gotten a lot

better to deal with. Maybe because I care less about what other people think or because

I'm stronger or because I've totally accepted myself and who I am." Through growing

up and accepting her identity as a hard of hearing person, Beth has been able to develop a

positive and confident attitude surrounding her hearing loss, which allows her to deal

with stigma. Denise highlighted the importance of a positive attitude and acceptance in

dealing with stigma and living with a hearing loss:

> I think it is, for one thing, you have to accept the fact that you do have a
> hearing loss. I think that is the first step to solving the problem. And feel
> good about yourself. Sometimes kindness is not available out there in the
> real world so you have to be able to feel good about yourself so you can
> deal with that and then at the same time take the opportunities to educate
> people. A positive attitude is a must.

When talking about positive attitudes many participants also explained the role

that humor plays in dealing with stigma. Matt discussed using humor to joke about

stigmatizing comments that people may make: "I'll look at a friend and make a joke about the comment." In fact, Matt stated that joking about his hearing loss signified a turning point in friendships/relationships for him: "Actually one of the things that lets me know that we are getting closer is if you feel comfortable making a joke like that and you know that I won't get mad." Nicole also addressed the idea of using humor to cope with potentially stigmatizing or embarrassing situations: "Sometimes the things I think people say are hilarious. So it just makes life a little better when you can laugh about it." Similarly, Jane talked about using humor to make fun of stigmatizing situations: "Oh yes, we use humor a lot. We tell funny stories a lot about what happens to us or what happens to deaf people."

Despite the openness to jokes and humor about their hearing loss, participants were quick to point out that there is a line when it comes to humor – "I like a joke, but a joke and being mean are different things." Mark also made a comment about the boundaries of humor: "Now there is a big difference between humor and being made fun of… that's totally different." This line surrounding humor is blurry and often depends upon the person with the hearing loss. Some participants stated that their evaluations of humor depend on who the person is and how well the participant knows the person, while others said that it depends on the context of the situation. Other participants said that most jokes are okay as long as they can tell that the intentions of the person joking are not malicious.

When used appropriately, participants felt like humor could help deal with stigma, act as a coping mechanism for hearing loss, or make other people feel more comfortable communicating with them. James talked about using humor as a coping mechanism:

77

"Humor helps take away the sting of a lot. It doesn't affect you as much if you can share that… if you can make fun of it." By making fun of things that happen because of his hearing loss, James is able to cope with it a little easier. Mark explained that he typically tries to make others laugh about his hearing loss (to make them more comfortable) by joking about taking advantage of his hearing loss with his wife: "She will say that the best time to talk to me when she is mad at me is when my hearing aids are out… she can cuss at me and she feels better and I can't hear her." Nancy also emphasized the important role that humor can play in easing interactions between her and other people:

> You have to joke. We can't take everything seriously all the time. It also helps others know that I'm not going to attack them. A lot of people are afraid that if I don't understand or if they don't understand, that I'm going to get mad at them or it is going to make them feel stupid. So the more positive I am… it makes them feel like… okay, we can do this.

As a whole, participants think humor and a positive attitude are key responses to stigma because they act as a coping mechanism, allow them to laugh, and help make other people comfortable – the jokes serve as a form of identity management.

Making stigma positive. The last theme that arose when asking participants about how they react or deal with stigma was the idea that stigma does not always have to be a negative thing. Several participants joked about taking advantage of other people's stigmatizing perceptions surrounding hearing loss. For example, Mark joked about using an officer's discomfort communicating with him to get out of a speeding ticket. Beth said that when she attends job interviews, her hearing loss always provides her with an easy answer to questions surrounding challenges she has had to overcome in life. She explained this by talking about interviews for teaching jobs:

> I could use it to my advantage in an interview. I think I would tell my boss, I'm hearing impaired, but I would also say I have grown up with a

hearing loss. I have experienced bullying. I have experienced other ways to communicate… lip reading, sign language. I have found a place in this world regardless of my hearing loss and I might be a little different from everybody else, but it makes me who I am. And I can teach kids that life lesson. I can use what I have experienced to teach them something big. So a lot of interviewers really like to hear that… it is a good seller.

In this example, Beth showcased how her hearing loss has made her a stronger person despite, or perhaps because of, the stigma she has experienced.

Another big way participants talked about stigma as a positive thing is through their discussions of how stigma can be motivating. Adam discussed his frustration with people who assume he is incapable of certain jobs or tasks because of his hearing loss:

I think the glorious question is like are you going to be able to do this job? And I'm just sitting there like you know you can go kiss my ass because yeah, I can do whatever I want, so yeah I can do this job. So someone asks, are you going to be capable as a human being to do this task and its like, yeah. I think that is kind of the one that just really gets me going. I mean even if I don't think I can do it, I'm going to do it anyway just to show that guy.   So someone telling me I can't do something is hard.

Also addressing the motivation that can be provided by stigma, James explained how the challenges associated with his hearing loss have forced him to be more outgoing than he would normally be: "I have to ask somebody what is going on, I can't just assume I know. So it has kind of forced me out there in some ways." Finally, the idea of responding to stigma as a positive thing is summed up by Nicole:

I think that stigma… in terms of me thinking that there is a stigma also motivates me to work harder and to prove people wrong so that is certainly a positive. I definitely don't think that I would have worked as hard as I am now to overcome certain things or to prove certain things otherwise. I almost feel somewhat resilient because I'm able to overcome a lot of things without making excuses for it and that's the worst thing that people could do or that I could do for myself… make it an excuse.

The fifth and final research question was aimed at investigating how participants respond to stigma surrounding their hearing loss. When discussing how they respond to

stigma, participants talked about ignoring or avoiding stigma or stigmatizing individuals or situations. Several participants also reported taking a more direct approach by asserting themselves when stigmatizing behavior occurs or by using the stigmatizing event as an opportunity to educate the other person. Participants also explained that they view the stigma as the other person's problem, not theirs. The use of positive attitudes and jokes was another response participants reported using to cope with or overcome stigma. Finally, participants described reframing stigma as positive by using it as a motivational tool.

As a whole, this study investigated how the hard of hearing and deaf participants manage the boundaries surrounding their hearing loss as well as how they perceive boundary turbulence. This study also examined how the participants viewed stigma surrounding hearing loss, a major cost of disclosure identified by participants. Finally, this study explored how the hard of hearing and deaf participants react to any stigma surrounding their hearing loss that they may experience.

CHAPTER SIX: DISCUSSION

The perceptions of other people can influence communication in many ways. One such perception that may affect communication is stigma – the perception of an individual as not normal, weak, or tainted (Goffman, 1963). Stigmatized individuals are often devalued, seen to have a blemished identity, and are often not accepted (Crocker et al., 1998; Goffman, 1963). Because of the negative effects associated with stigma, stigma affects the communication of both the stigmatized individual as they attempt to navigate or avoid stigma (Goffman, 1959; Matthews & Harrington, 2000; Shih, 2004), as well as the un-stigmatized individual in the interaction (Braithwaite, 1991; Park et al., 2003; Thompson, 1982). Disabled individuals, such as individuals with hearing loss, are a population that is at risk for stigma and its negative effects on communication (Davis, 2005). Disclosure is one communication process that intersects with stigma. Through choices made about disclosure, stigmatized individuals, such as individuals with hearing loss, may attempt to navigate or avoid stigma (Charmaz, 1991; Hecht et al., 2005; Najarian, 2008). Using the Communication Privacy Management (CPM) theory (Petronio, 1991), this study examined hard of hearing and deaf individuals, how they choose to manage boundaries surrounding (disclose) their hearing loss, how they handle boundary turbulence, and how they perceive and respond to stigma surrounding their hearing loss (a potential cost of disclosure).

Managing Boundaries

The first research question posed in this study was aimed at understanding the boundary management process surrounding information about their hearing loss for deaf and hard of hearing individuals. One way in which individuals can potentially avoid

stigma is to manage the boundaries surrounding information about their hearing loss (Braithwaite, 1991). In order to examine this, the participants in this study were asked about disclosure decisions surrounding their hearing loss, what information they were willing to disclose, and what questions they were willing to answer. One theme that arose during the participants' discussions of managing boundaries surrounding their hearing loss was that the hearing loss is part of their identity. Participants talked about how hearing loss has made them the person that they are today and how they have grown comfortable with their hearing loss. These participants reported having "accepted" their hearing loss as a part of who they are and that they have no shame in that identity. Despite feeling this way, many participants who described hearing loss as a part of who they are also talked about managing the boundaries surrounding their hearing loss. They are not willing to be completely open in disclosing about their hearing loss – causing a kind of conflict between their identity and avoiding stigma. For these participants, it seems that the costs and stigma associated with disclosing their hearing loss can outweigh being open about their identity (Braithwaite, 1991).

The participants that this did not seem true for were the Deaf participants, individuals who considered themselves a part of the Deaf community. These individuals appeared more willing to be open about their hearing loss and displayed a sense of pride – no matter what the perceptions of others were. For the Deaf participants, it seemed that the cultural and community outlets available to them help serve as a coping mechanism and even seem to "normalize" hearing loss in some sense (Breivik, 2005, Luey et al., 1995). Since they belong to a group of others like them with hearing loss, these participants see hearing loss as less of a "difference" (Frable et al., 1998; Skelton &

Valentine, 2003). This connects to Bat-Chava's (2000) findings indicating that there are several types of identities associated with deafness or hearing loss – culturally hearing identity, culturally deaf identity, and bicultural identity. Those that are culturally hearing identify with the hearing world and attempt to assimilate into that world, despite the fact that their hearing loss may be stigmatized. Culturally deaf individuals take pride in their hearing loss and associate with others with the Deaf community, allowing them access to a group that could provide social support (Bat-Chava, 2000). Based on the results of this study and previous research (Bat-Chava, 2000; Breivik, 2005), individuals who are culturally deaf and embrace their hearing loss as part of their identity find it easier to disclose about their hearing loss given the social support of a community like them that they have access to.

Given that many hard of hearing children (90%) are born to hearing parents (Grosjean, 2010), the Deaf community is a cultural support system that many deaf or hard of hearing children are not exposed to. Further, many deaf or hard of hearing children born to hearing families are raised orally – they wear hearing aids or cochlear implants, learn to lip read and speak orally, and are mainstreamed in school (Cherney, 1999; Hole, 2007). Because of this, they grow up in a hearing world without the support or even knowledge of anyone else like them and often feel isolated or like an outsider (a feeling several participants talked about when thinking back on their younger years). Exposing these hard of hearing children to a community of others like them may provide them with a support system and encourage them to embrace their identity (Bat-Chava, 2000; Grosjean, 2010; Hole, 2007). This may in turn lead to higher levels of self-esteem for these children, less feelings of isolation, and a willingness to ask for the accommodations

83

that they may need in school and eventually the workplace. This move, however, would require work from both ends of the spectrum – both the hearing world and the Deaf community. Parents and doctors in the hearing world would need to be willing to expose their hard of hearing children/patients to the Deaf community and be open to the experiences afforded to their child/patient through that community. On the other hand, the Deaf community would need to be willing to accept individuals that may gravitate towards oral means of communicating, without frowning on the use of mainstreaming methods if that is what the child chooses. If these two worlds/communities could find a way to work together and maintain an open mind, deaf and hard of hearing children would be provided with a network of social support that could help eliminate feelings of isolation and help them accept their identity (Grosjean, 2010).

While many participants talked about accepting their identity as a hard of hearing person, making judgment calls was another theme that arose when talking to participants about how they manage boundaries surrounding their hearing loss. Participants discussed making judgments about several things in the interaction when deciding whether to disclose their hearing loss: is it a group or interpersonal setting, will I see this person again, what is my social standing in this relationship, do I think the other person will react positively to my disclosure, what are my goals in this situation, and if I do disclose, how do I disclose to this person (word choice)? These judgments all coincide with Charmaz's (1991) discussion of strategic announcing as a disclosure strategy. Using strategic announcements, participants can take control over when, to whom, what, and where they decide to disclose about their hearing loss (Charmaz, 1991). Because of all of these factors, the disclosure process (the how, what, and when to disclose) often varies

from interaction to interaction. No single type of disclosure is perfect as disclosure is often unique to each individual, context, event, and relationship involved in the process (Caughlin et al., 2008; DeMatteo et al., 2002).

While all of these questions were common questions that participants talked about when choosing whether to disclose their hearing loss, the underlying determining factor seemed to be necessity. In making the judgment of whether to disclose, many participants reported that they do not disclose until the hearing loss "comes up" or until they absolutely have to because they are missing important information. Thus, it seems the final judgment call is "do I *need* to disclose for some reason", no matter what the situation is, who the other person is, or the type of relationship involved (Braithwaite, 1991; Matthews, 1997; Najarian, 2008). Based on this result, for many hard of hearing and deaf participants, the boundaries surrounding their hearing loss remain closed unless the hearing loss *needs* to be disclosed – the boundary management process here is determined by the necessity of the disclosure (Petronio, 2002).

When discussing the decisions involved in making the judgment surrounding whether to disclose, the participants pointed out that there are also risks to *not* disclosing their hearing loss. Without disclosure, participants cannot ask for accommodations or helpful communication behavior, and they run the risk of missing important information or being perceived as snobby (Hart & Williams, 1995; Najarian, 2008). Making sure that they understand and obtain essential information is extremely important to most of the participants, especially in terms of school or work. Oftentimes, if participants feel that they are missing out, they will disclose their hearing loss in order to make sure that they can access the information they need (Najarian, 2008). For the participants in these

instances, the risk of missing information is worse than the risk of disclosing or the risk of stigma. Further, many participants talked about disclosing in order to prevent being perceived as rude or snobby because they do not respond to something. It seems here that the stigma associated with being rude or snobby is worse (perhaps because this may be an inaccurate assumption) than the stigma of being hard of hearing (something that is actually true). Further, previous studies have indicated that the disclosure of a disability may increase the comfort level of the able-bodied individual in the interaction and have an overall positive effect on the relationship (Braithwaite, 1991; Goffman, 1963; Thompson, 1982). The disclosure process goes beyond a decision of what is being risked by disclosing to include decisions about what is being risked by *not* disclosing. This weighing of pros and cons illustrates the dialectic nature of CPM (Petronio, 2002). Thus, participants may decide that the risks of *not* disclosing outweigh the risks of disclosing about their hearing loss in certain situations, which may affect boundary management.

Another way many participants reported managing the boundaries surrounding their hearing loss was through *delaying* the disclosure process. Many participants explained that through this disclosure delay, they accomplish several goals that help them overcome stigmatizing behaviors or the negative affects that stigma can have on communication. By delaying the disclosure, participants feel they are able to prove to the other person that they can communicate normally, that they are a human being not defined by their disability alone (Braithwaite, 1991). The participants hope that by delaying the disclosure, once they do disclose their hearing loss, the other person will not start communicating differently. The participants feel that by delaying the disclosure they can help prevent this because they have already been engaging in a successful

interaction with the hard of hearing participant using "normal" communication behaviors, illustrating their capabilities in doing so. This is another form of strategic announcing. By controlling *when* they choose to disclose, participants are attempting to influence the interaction and protect themselves from stigma (Charmaz, 1991).

Further, participants feel that, by delaying the disclosure, they can attempt to overcome being labeled – a stigma identified by many participants. Even if they consider their hearing loss as part of their identity, participants want to avoid being labeled as "not normal" and want to be seen as more than just "the hard of hearing person." This resonates with Braithwaite's (1991) findings stating that disclosure may not happen or may get delayed in order for the disabled individual to be seen as a person first and not defined by their disability. Upon disclosing about their hearing loss, many participants said that sometimes they get labeled as "the deaf person". This label often overshadows other components of their identity. Thus, delaying disclosure is one way in which they manage the boundaries surrounding their hearing loss in an attempt to avoid this stigma and prove that they are an individual with other needs and identities. Thus, *time* plays a role in the boundary management for the hard of hearing and deaf participants in this study (Petronio, 2002).

In managing the boundaries surrounding their hearing loss, the participants also talked about *how* they disclose once they make the decision to disclose. In making this decision, many participants talked about minimizing their hearing loss. Instead of saying that they are deaf (even if they were, profoundly so), participants will state that they have a "hearing loss" or "hearing impairment" because they believe this makes it sound less severe. Participants also reported using words like "little" or a "slight" loss to minimize

the severity of their hearing loss. Further, using phrases like "I can't hear shit" or "my ears suck" are other ways that participants will minimize their hearing loss by using a joking manner to disclose or hint at their hearing loss. Many participants reported doing this in an attempt to prevent any potential stigma.

This minimization downplays the hearing loss to make it seem less like a big deal and hopefully avoid the negative communication responses associated with stigma. Thus, decisions surrounding boundary management go beyond simple choices of how thin or thick the boundaries are. These decisions extend to include *how* to open the boundaries surrounding their hearing loss and *to what extent* they should be opened (how much to reveal) (Petronio, 2002). The extent to which the boundaries are opened speaks to the boundary permeability surrounding information about the participants' hearing loss (Petronio & Durham, 2008). The more permeable the boundaries surrounding information about their hearing loss, the more information participants are willing to share.

In terms of boundary management and *how* they disclose their hearing loss, participants also discussed using disclosure as an education opportunity. Because of this, many participants are willing to answer questions, as long as they were deemed appropriate questions (Braithwaite, 1991), about their hearing loss. The use of "educating others" as a disclosure tactic resonates with Charmaz's (1991) discussion of "informing" (p. 121). According to Charmaz (1991), the use of informing may allow participants to take more of an objective stance towards the illness, or disability, that they are disclosing. Thus, this use of "educating others" to disclose may decrease the emotional risks involved with disclosing by allowing the participants to talk about their

hearing loss in a more objective way (Charmaz, 1991). Participants also use disclosure as a way to educate other people about the appropriate communication behaviors when speaking to someone with a hearing loss. When disclosing about their hearing loss, some participants ask for specific helpful behaviors such as looking at them when speaking and slowing down the speech. In this way, participants are attempting to overcome any discomfort surrounding talking to a hard of hearing person by helping others understand that they only need to make some small changes in their communication behavior.

Participants also reported using disclosure as an education opportunity when they felt as if they could help someone else by providing them with a role model. When participants feel that they can share knowledge about their hearing loss in a helpful manner, they appear more willing to open up the boundaries surrounding information about their hearing loss. In this way, helping others trumps any potential for stigma – once again the participants weigh the costs and benefits to disclosure (Petronio, 2002, 2007). As many hard of hearing children lack connections to others like them (Grosjean, 2010), they might benefit from a deaf or hard of hearing role model. Many participants in this study talked about having no clear connections to others like them growing up as they talked about the isolation associated with this, which was part of the reason why they felt they should act as a role model if the opportunity presented itself. Grosjean (2010) points out the importance of deaf children to gain connections to others like them in order to aid them in their development (2010). Doctors and audiologists may consider providing a "mentor" program or network opportunities for children with hearing loss. This may allow them to connect with a "role model" or another hard of hearing

individual who can provide them with support and knowledge about living with a hearing loss and be able to relate to their experiences in general.

The final way in which participants responded when talking about how they manage the boundaries surrounding their hearing loss, was by talking about their concern for the other person in the interaction (Braithwaite, 1991). Participants reported using the words "I'm sorry" often when first disclosing about their hearing loss. This apology in itself speaks to the fact that the participants are aware of stigma surrounding hearing loss – it indicates their awareness of the fact that their hearing loss could be perceived as an inconvenience or a discomfort to the other person. Several participants even talked about recognizing this fact as they explained that they are trying to stop apologizing when disclosing about their hearing loss. Participants also explained that they will disclose in order to prevent others from feeling ignored (in the case that they do not respond because they did not hear them). Finally, participants discussed disclosure as a way of taking "responsibility" for their hearing loss. They perceive the hearing loss as "their problem", and thus, it was their responsibility to disclose it in order to avoid any miscommunication. Therefore, at some point the disclosure becomes a responsibility for the participants – the opening of that boundary must be done out of concern for the other person in the interaction. This idea connects to Braithwaite's (1991) discussion stating that from an able-bodied perspective (the majority of society), the main goal in the communication interaction is to alleviate any discomfort felt by the able-bodied individual. Living in a mainstream hearing society, the hard of hearing participants may feel influenced by this need to alleviate the discomfort of the able-bodied individual in the interaction and disclose despite the cost of that disclosure (Braithwaite, 1991).

Boundary management decisions then are not only determined by how the hard of hearing participants feel about disclosure, but also by how that boundary management is affecting the *other* person in the interaction.

As a whole, the management of boundaries surrounding their hearing loss for the deaf and hard of hearing participants in this study was a process governed by many decisions (Petronio, 2002). If the participants embraced hearing loss as a major part of their identity, they were more likely to have open or thin boundaries surrounding their hearing loss as they were willing to share about their loss (Petronio, 2002). Because it was a part of their identity, it seemed to make disclosure more of a non-issue. Further, these individuals also often had access to others like them, whether through the deaf community or family with hearing loss, so it seemed to help remove some of the stigma by "normalizing" the hearing loss (Bat-Chava, 2000; Breivik, 2005; Luey et al., 1995). In terms of making the decision to disclose, participants weighed the pros and cons of disclosing (cost-benefit criteria, Petronio, 2002) as they made judgments surrounding how, when, and what to disclose. The hard of hearing participants also reported considering boundary permeability (to what extent to disclose) (Petronio & Durham, 2008). Time was also a big factor in terms of managing boundaries as participants talked about delaying the disclosure in order to ensure that they were seen as a person first and not defined by their disability (Braithwaite, 1991). Disclosure and the management of boundaries surrounding their hearing loss was a process that varied widely as it calls for many decisions and is often unique based on the interaction, the relationships, and the context of the situation (Caughlin et al., 2008; Charmaz, 1991; DeMatteo et al., 2002).

Boundary Turbulence

The second research question posed in this study addresses the idea of boundary turbulence – when the sharing of information about their hearing loss is not the choice of the participant (Petronio, 2002, 2007). When talking about boundary turbulence, the participants highlighted the fact that the intentions of the other person who disclosed for them are important. If the disclosure of the hearing loss is done for them in a way that is positive and the intentions are to help the communication interaction, the participants are less likely to have a problem with it. Thus, boundary turbulence is not necessarily always a negative thing, despite how it is typically conceptualized (Petronio, 2002, 2007). However, if the person who discloses for the participant does so in a way that is not positive or irrelevant to the current interaction, the participants evaluate that boundary turbulence in a negative way. Participants also stated that even if the boundary turbulence occurs in a positive way, if it is not helpful or relevant to the interaction, it is frowned upon. Thus, as a whole, participants are open to boundary turbulence only if it is deemed helpful *by the participant*.

Another way in which participants discussed boundary turbulence was by addressing the lack of control associated with having someone else (or something else) disclose their hearing loss for them (Petronio, 2002, 2007). Several participants talked about their hearing aids or cochlear implants as a form of boundary turbulence. These things make their hearing loss visible and, thus, take away the decision of whether to disclose. Hearing aids do continue to see improvements as they get smaller, and it seems that this continued improvement in the area of invisibility would be helpful to

participants that wish to maintain control over the boundaries surrounding their hearing loss.

In terms of other people disclosing for them, many participants feel that this is associated with a loss of control of the information surrounding their hearing loss. Even when the disclosure is done in a positive way, the participants reported being frustrated when someone else takes that responsibility away from them. For the most part, the disclosure is a choice that participants want the power to make – they feel like it is not anyone else's business. Boundary turbulence is connected to a feeling of a loss of power because it allows other people to share private health information without the consent of the hard of hearing participant – the participant feels as if their ownership of that private information has been violated (Braithwaite, 1991; Petronio, 2007). This is demeaning (as pointed out by several participants) as their health information is no longer private – it is now owned by other people. Further, this creates an unfair power dynamic as the hard of hearing individuals' health information becomes public, while the health information of others remains private (Braithwaite, 1991). Once again, the evaluation of boundary turbulence relies completely on the perception of the hard of hearing participant. Thus, even if the other person perceives that they are trying to be helpful, and even if the disclosure does help the interaction, the hard of hearing participant's perception of that boundary turbulence is the determining factor in how it gets evaluated.

Reactions to turbulence was the final theme that arose from participants' discussions of boundary turbulence. The participants' reactions to turbulence vary widely. Participants reported "letting it go," addressing the person who caused the boundary turbulence, and attempting to be proactive and prevent boundary turbulence

altogether. Letting the boundary turbulence slide is more likely to be a reaction if the

participant feels like there is nothing to gain by addressing the turbulence. If they feel as

if they can make a point, assert themselves, or prevent future turbulence, participants are

more likely to talk to the person responsible for the boundary turbulence. By addressing

the person who caused the boundary turbulence, the participants are advocating for

themselves and educating the other person (letting them know that this was not okay).

The proactive response allows participants to head off any potential future turbulence and

avoid stigma. Plus, like addressing the person who caused the turbulence, proactive

responses put participants in a position of power – they have control over their health

information and the disclosure decision. By taking a proactive response, participants are

able to gain more control as they maintain ownership of their health information

(Braithwaite, 1991; Petronio, 2007).

In looking at boundary turbulence in this population, issues of ownership and

expectations surrounding co-ownership were discussed by many hard of hearing and deaf

participants. Participants discussed a loss of control and power when others disclosed for

them since they viewed their hearing loss as private health information that they should

have ownership over (Braithwaite, 1991; Petronio, 2007). Given that stigma surrounding

disabilities, in this case hearing loss, already has the potential to cause feelings of

worthlessness or being less than human (Goffman, 1963; Matthews & Harrington, 2000),

this lack of power over their health information can make individuals with hearing loss

(and other disabilities) even feel lesser in terms of social positioning. It is important to

note, however, that boundary turbulence was not always seen by the participants as

negative. If the boundary turbulence is helpful to the communicative interaction in the

long run, participants were more likely to view boundary turbulence in a positive way, a surprising result since boundary turbulence is typically conceptualized negatively (Petronio, 2002, 2007).

Costs of Disclosure & Stigma

The costs of disclosure associated with hearing loss as well as the participants' perceptions of stigma (cited as the main cost of disclosure), were examined in research questions 3 and 4. One of the worst ways in which participants reported that other people could act upon disclosure about their hearing loss is by expressing feelings of sorry or pity. The participants do not see their hearing loss as a burden or something that limits their functionality – feelings of pity or sorry imply that the other person does. Thus, participants do not like this response to their disclosure at all. They indicated that feeling sorry or pity for them is a type of stigma surrounding the hearing loss. By replying to the participants' disclosure by saying "oh I'm sorry, you poor dear", others are stigmatizing the hard of hearing participants by suggesting that hearing loss is a 'dis'ability – something that limits them, makes them less than, or is a weakness (Cherney, 1999; Levy, 2002).

Disclosure about their hearing loss also puts participants at risk for another type of stigma that indicates that they are "less than normal" – a feeling that they were not worth others' time (Goffman, 1963). Participants reported that one reason they are hesitant to disclose is because many people will just walk away or decide they are uncomfortable communicating with a hard of hearing or deaf individual (Kleck et al., 1966). Further, participants indicated that others are often unwilling to put forth the extra effort required to communicate with a hard of hearing person. If they are asked to repeat

multiple times, many others tell the participants to "never mind". Participants once again

highlighted the power dynamic created by stigma here. The use of "never mind"

communicates that it does not matter if the participant hears what was going on – his or

her understanding is not worth worrying about. It also caused participants to feel a lack

of control, as they are no longer in charge of deciding for themselves which information

is important. Both avoidance of interactions with the participants as well as the use of

"never mind" are perceived by the participants as a lack of willingness to put forth any

extra communication effort or time. This indicates a stigma as it implies that the hard of

hearing or deaf participants are not worthy of this extra effort – they are inferior in some

way or not worth as much in the eyes of others.

By disclosing about their hearing loss, participants also became prone to being

labeled as "not normal" – another type of stigma they identified (Braithwaite, 1991;

Cherney, 1999; Goffman, 1963; Hole, 2007; Levy, 2002). The disclosure process is seen

by the hard of hearing and deaf participants as an immediate way of labeling themselves

as "different" and it can prevent them from fitting in or being perceived as "normal".

Once again, by disclosing, participants put themselves at risk for feelings of isolation as

they are identified as "different" from the mainstream hearing world (Cherney, 1999;

Hole, 2007). This feeling of being an outsider is further complicated by the fact that

many of the hard of hearing participants in this study also feel as if they are an outsider to

the Deaf community too (since they practice oral communication, they do not fit in with

Deaf cultural values) (Davis, 2007). Thus, these participants lack any real community

from which they can receive social support.

This label of being an "outsider" or being "not normal" is a label many participants identified as a deterrent to the disclosure process (Goffman, 1963). Most participants stated that the ideal reaction they want from the other person is to be treated like nothing has changed. This particular stigma of being labeled as "not normal" contrasted heavily with what the participants *wanted* in terms of communication behavior – being treated as normal. Because of this label of being "not normal", many participants explained that disclosure could cause the opposite of their ideal reaction – others start treating them differently. Therefore, participants will avoid disclosure if they can in order to prevent this stigma and maintain a "normal" communication interaction.

Many participants talked about being treated as "normal" – a phrase used by many participants when asked about what the ideal reaction to their disclosure about hearing loss would be. However, this contrasts with the fact that they do need accommodations in order to communicate effectively. Participants even listed those accommodations: look at me when you talk, speak clearly, do not speak too quickly, etc. Thus, the participants indicated that while they do want these accommodations so they can participate in the conversation, they still want to be treated as "normal", a seemingly contrasting idea. It seems that the participants were asking to have their hearing loss be seen as a matter of fact as opposed to a defining characteristic. They ideally want others to react to their disclosure of their hearing loss in a nonchalant way without making a big deal about it or changing their attitude towards the hard of hearing participant – to treat them as a person first and not as a "disabled person" (Braithwaite, 1991).

The idea that hearing loss limits the capabilities and intelligence of the hard of hearing participants is another stigma they addressed when asked about the risks of

97

disclosure (Cherney, 1999; Matthews & Harrington, 2000). This stigma seems to be very pervasive as it carries over to many aspects of the participants' lives. The participants' abilities are doubted, even if the physical task has nothing to do with hearing, such as art or running track. Because of this, the participants reported being hesitant to disclose, especially in a situation where they may be evaluated in terms of their capabilities, such as a job. The stigma attached to hearing loss carries over into other parts of their lives that are not typically affected by their hearing. Thus, disclosure of their hearing loss puts participants at the risk for an omnipresent stigma, an idea that resonated with Goffman (1963) as he discussed how we can stigmatize in ways outside of or unrelated to the original stigma (yelling at the blind as if they were deaf or incoherent).

This omnipresent stigma not only affects evaluations of the participants' physical capabilities, but their intellectual capabilities as well. Participants touched on the stigma of being "deaf and dumb" as they explained others' perceptions that hearing loss impacts mental capacities as well (Cherney, 1999). Participants were quick to point out that this is not true by explaining that their brain and ears are separate. Despite this, participants reported that disclosure still puts them at risk for being perceived as less intelligent, having gone to special education classes, or even being perceived as mentally retarded. The perception that hard of hearing individuals are less intellectually capable is compounded by the fact that they need things repeated, reworded, and even need a little extra time to process the sounds they hear. Thus, in order to prevent these perceptions from holding them back, many participants reported choosing to avoid disclosure, especially if they feel that the disclosure will put them at risk for being limited in some way (Matthews & Harrington, 2000; Nikolaraizi & Makri, 2004).

Finally, the last issue participants discussed when asked about stigma and costs of disclosure was how hearing loss, and the stigma associated with it, is different from other disabilities. The fact that hearing loss is an invisible disability is one of the prominent reasons participants differentiated hearing loss from other physical disabilities (Matthews & Harrington, 2000). While this invisibility gives hard of hearing individuals the opportunity to avoid disclosure and potential stigma, it also complicates things as they may be faced with the decision between disclosure (and communication accommodations) and avoiding stigma (Goffman, 1959, 1963; Matthews & Harrington, 2000; Najarian, 2008). Further, this invisibility causes its own form of stigma in some ways as it makes hearing loss less noticeable or recognized as a disability. Many events or businesses do not consider accommodating people with hearing loss because it is not a visible or recognized disability. Unlike vision loss, hearing loss is not as commonplace and often gets stigmatized for that reason – while glasses can be a fashion statement (lots of people wear them), the same can not be said for hearing aids.

Because it is invisible, the awareness surrounding hearing loss as a disability and any understanding surrounding hearing loss also gets jeopardized. Thus, hard of hearing individuals may be faced with a burden of proof (they have to prove how bad their hearing loss is), as well as decisions considering the *depth* of disclosure surrounding their hearing loss (Davis, 2005; Matthews & Harrington, 2000). Other people do not often understand that hearing loss affects not only the volume, but also the *clarity* of sound. Because of this, hearing aids do not "cure" hearing loss or give hard of hearing individuals "normal" hearing. Thus, hard of hearing individuals may have to decide if they want to explain all of that information or any other intimate details surrounding their

99

hearing loss. Thus, they may have to make choices about how in-depth they want to get

when disclosing about their hearing loss – how permeable they want to make the

boundary surrounding this private information (Petronio & Durham, 2008).

Hearing loss is also differentiated from other physical disabilities in that it is

treated differently from a policy standpoint, something that perhaps indicates that hearing

loss is not seen as "enough of a disability." Participants pointed out that both insurance

and legislation treat hearing loss differently from other disabilities. For example, the

participants pointed out that, unlike glasses, the costs of their hearing aids and/or cochlear

implants are often not covered by insurance companies. Several participants saw this in

itself as a stigma – one that sets hearing loss apart from other disabilities that get better

coverage. Participants were not sure *why* this was the case, but they explained that this

stigma does exist. It may be connected to the fact that hearing loss is invisible and can go

unrecognized. Several participants did point out that ADA (Americans with Disabilities

Act) was helpful in some ways as it helps them get necessary accommodations and

prevent discrimination. However, even with this legislation present, they explained that

stigma and discrimination surrounding their hearing loss still occur. Overall, participants

perceived many different levels or layers of stigma as they talked about the costs

associated with disclosing about their hearing loss.

As a whole, stigma interacted with CPM in this context on several levels. Hard of

hearing and deaf participants are often faced with the disclosure dilemma of choosing

between the potential stigma they may face upon disclosure and the potential for

accommodations in the classroom, in the doctor's office, or with communication in

general (Davis, 2005; Hart & Williams, 1995; Najarian, 2008; Southall et al., 2010;

Zazove et al., 1993). Further, participants may also forego any opportunity for social support if they do not disclose about their hearing loss and identify with a group of others like them, the Deaf community (Bat-Chava, 2000; Bos et al., 2009). Thus, as CPM illustrates there is a cost-benefit criteria that can govern the decisions surrounding whether to disclosure private information (Petronio, 2002, 2007) and seems to govern many of the disclosure decisions for hard of hearing individuals. Stigma was seen as one of the biggest costs to disclosure as it was the focus of many participants' discussions – a cost that may govern disclosures for many other populations with invisible disabilities (Charmaz, 1991; Matthews & Harrington, 2000).

Responding to Stigma

The last research question posed in this study was aimed at understanding the ways in which hard of hearing individuals respond to stigma. The first way participants reported as a way that they respond to stigma surrounding their hearing loss is by avoiding or ignoring the stigmatizing person or situation. Participants reported avoiding dealing with stigma altogether by either avoiding disclosure of their hearing loss or attempting to simply ignore any potential stigma that does occur (Gagne et al., 2009; Southall et al., 2010). Ignoring stigma or stigmatizing people, however, requires higher levels of self-esteem and comfort with a hard of hearing identity. Thus, this may not be an option for hard of hearing individuals who have recently lost their hearing or who are learning to deal with hearing loss (children) (Grosjean, 2010). Other ways in which participants use avoiding as a means of dealing with stigma is through avoiding stigmatizing people or avoiding potentially stigmatizing situations, such as loud bars or restaurants where their hearing loss may become an issue. Both of these options, while

they may be easier (require less confidence), could contribute to the feelings of isolation experienced by many hard of hearing individuals since they may not be as social or as willing to put themselves out there in order to avoid stigma (Matthews & Harrington, 2000). This could help explain why many children with hearing loss experience feelings of isolation and struggle to "fit in" while growing up.

While participants talked about using avoiding as a strategy, they also discussed a more direct way of dealing with stigma – through asserting themselves. Participants who reported using this option talked about ways in which they have told stigmatizing people to "take a hike". However, similar to ignoring stigma, this option would also take confidence and higher levels of self-esteem. Being assertive despite stigma that indicates inferiority, less control, and less power (Goffman, 1963), would take a self-assured person who is comfortable with their identity. The assertive strategy is a more direct strategy than avoiding or ignoring and, thus, requires the hard of hearing individual to deal with stigma head on.

The presence of stigma upon disclosing about their hearing loss also provided the participants with another education opportunity – another direct approach. Unlike using disclosure itself as an education opportunity (discussed in RQ1), this education opportunity occurs *after* disclosure and only if the hard of hearing individual senses stigmatizing behavior. This response allows the hard of hearing individual to use education as a way of addressing the stigma they perceive to be present. Through educating, participants can fight against stigma by teaching others helpful communication behaviors, to treat them like they are normal, and to not assume that they are less capable. Charmaz (1991) talks about the use of "informing" (similar to educating) as a way to

objectively discuss an illness or disability and help separate emotion from the disclosure. Participants also reported that education as a strategy allows them to raise awareness surrounding hearing loss, something they saw as a benefit to disclosure. Further, because of this growing awareness, participants feel as though the stigma is changing and getting better. Thus, in the future, more organizations and associations aimed at increasing awareness of hearing loss may help combat stigma on a more global plane.

Instead of taking the time and effort to educate stigmatizing others, some participants took another less direct route of dealing with stigma – viewing it as "not my problem". With this approach the participants "reframed" stigma in a way that allowed them to see stigma as the result of someone else's prejudices or biases as opposed to their own "shortcomings". This reframing helped participants step away from stigma in ways that preserved their self-esteem and confidence. This allows hard of hearing and deaf individuals to not take the stigma or stigmatizing behavior personally and, instead, view stigma as a sign of weakness in the *other* person.

Positive attitudes and the use of humor are also very important ways of dealing with stigma identified by the hard of hearing participants in this study. Participants talked about the power of having a positive attitude and accepting their hearing loss as vital components in overcoming the potential negative effects of stigma (i.e. depression, low self-esteem, etc.). This would resonate with the findings of Martin, Puhlik-Doris, Larsen, Gray, and Weir (2002), which found humor to be a coping mechanism for stressful experiences, especially relevant to psychological well-being. Many participants reported that their families were key factors in developing these positive attitudes, even if their parents were hearing. Based on participants' discussions, when raising hard of

hearing children, parents should focus on supportive and positive behaviors that encourage high self-esteem, confidence, and acceptance of self. By developing a positive attitude and high self-esteem, hard of hearing children may be able to deal with stigma in a more positive manner. Participants even noted that this family support seemed to be more influential than whether they attended deaf (had others like them) or mainstream (may have been alone) schools.

The use of humor and jokes were also discussed when talking about having a positive attitude surrounding their hearing loss. Participants cited humor as a way to deal with misunderstandings (laugh about it), stigmatizing comments, and embarrassing situations. Humor makes dealing with the hearing loss and any stigma easier and can provide hard of hearing and deaf individuals with coping mechanism for difficult situations (Martin et al., 2002). Some participants even explained that if a person is comfortable to joke with them about their hearing loss, it indicates that the person is comfortable with them as a hard of hearing person – they have accepted them. Despite the overall positive role that humor plays for the participants, they were quick to point out the difference between joking about hearing loss and making fun of hearing loss. Thus, even when dealing with humor, there is a line. This evaluation of what is appropriate humor is determined by the perceptions of the hard of hearing individual (similar to the evaluations of boundary turbulence).

Finally, the last response to stigma that participants discussed was turning stigma around and making it a positive thing. This perception of stigma allows participants to take control and maintain power in an interaction – to use stigma on their terms. Traditionally, literature has focused on the harmful impacts of stigma (Shih, 2004).

However, stigma can provide stigmatized individuals with motivation if they view it in a way that encourages them to prove the stigma, or other people, wrong, if they can find empowerment in the overcoming of stigma (Shih, 2004). Some participants even talked about how dealing with stigma has made them a stronger person. Hating it when someone labels them or tells them that they cannot do something because of their hearing loss, the participants used these stigmas to push them further. Stigma in this context acted as a driving force as participants wanted to overcome inaccurate perceptions. Thus, participants made the argument that stigma is not always a bad thing – it can serve in positive ways. This reframing of stigma (which is typically conceptualized negatively, Shih, 2004) can provide stigmatized individuals with a coping mechanism or positive driving force – a unique way of overcoming stigma. Thus, as a whole, there is a wide range of responses that participants can have when dealing with stigma, ranging from direct to indirect and varying in levels of positivity.

Directions for Future Research and Limitations

In this study, the use of qualitative interviews allowed for an in-depth examination (Lindlof & Taylor, 2002) of the hard of hearing and deaf population as the participants were able to voice their experiences and perspectives surrounding boundary management, boundary turbulence, stigma, and responding to stigma. The use of interactive interviews further ensured an in-depth exploration of this population because it allowed for reciprocal discussion and eliminated researcher-participant hierarchy (Ellis et al., 1997). Participants were willing to open up and share about their experiences since I was engaging in disclosures of my own, making them feel like they were on equal footing with me.

Since the study was not conducted from an able-bodied researcher's perspective, this helped guarantee that the hard of hearing and deaf participants' voices were captured (Matthews & Harrington, 2000). In order to help ensure objectivity, due to my fitting into the research population, the co-coder for this study was a doctoral candidate who did not fit into this population. This allowed for an individual with another standpoint to look over the data and enhances the trustworthiness of the results. In addition to the co-coder, member checking was also conducted in order to confirm an accurate portrayal of participant experiences. Finally, the variation in the sample allowed a multitude of experiences in order to capture a wider array of perspectives and voices. Through the use of interactive interviews, participants opened up to share about their experiences as a hard of hearing or deaf individual in a hearing world. The results of this study allow for these participants' voices to be heard as they share how they manage the boundaries, boundary turbulence, and stigma surrounding their hearing loss.

Despite its strengths, as with any study, this study has several limitations, some of which call for future research on this topic. The results of this study cannot be applied to all deaf or hard of hearing participants. This lack of generalizability stems from several study concerns. Not all deaf or hard of hearing individuals feel the same way about disclosure. The participants in this study were obviously willing to step forward and talk about their hearing loss – the interview participation was a process in itself that required disclosure. Thus, hard of hearing or deaf individuals that were not willing to step forward to participate in this study may manage the boundaries surrounding hearing loss in different ways. Similarly, these individuals may feel differently about boundary turbulence and stigma and may not respond to stigma in the same ways as the

participants. For instance, the participants here talked about having a positive attitude and making stigma a positive thing. Individuals who were unwilling to step forward may not feel as positive or may not accept their hearing loss as a part of their identity. Thus, this study misses out on those voices and their perceptions. In order to capture a wider variety of voices, future research should consider conducting an anonymous survey surrounding hearing loss and the issues of disclosure and stigma. Perhaps with the survey being anonymous, individuals who do not feel positively about their hearing loss or who do not feel comfortable disclosing would feel safer participating.

Further, this study does not address the wide range of demographic differences present in hard of hearing or deaf individuals. Since several participants discussed having "grown into" their hard of hearing or deaf identity as they have gotten older, future studies should examine age and how it affects comfort disclosing as well as responses to stigma. Many participants did talk about struggling with their hearing loss more when they were younger. Is this associated with a change in culture (hearing loss getting more accepted) or is this a result of the participants becoming comfortable with who they are? This study was not a longitudinal study and, thus, the participants' identities as hard of hearing or deaf were not observed across their lifespans. Additionally, since aging is associated with hearing loss, it could be possible that older individuals do not experience the same stigmas as younger individuals with hearing loss. As a whole, age would be an important demographic variable to examine in more depth when working with this population in future studies. This would provide an interesting avenue for interdisciplinary work in the future. Developmental psychologists could work

with the field of communication to examine how age and developmental stage affect identity and perceptions of ones' hearing loss as the participants get older.

Another demographic variable to consider in future studies is when the individual lost their hearing. Was the hard of hearing individual born with a hearing loss or did they lose it later in life? Further, how long have they had a hearing loss? It is quite possible that individuals who grow up with a hearing loss can more easily accept that hearing loss as a part of their identity. However, individuals who lose their hearing later in life may remember living with normal hearing, which could affect how they manage the boundaries surrounding their hearing loss and how they perceive stigma. Additionally, since participants talked about "growing into" their hearing loss, the length of time someone has had a hearing loss (did they loose it recently) may play a role in their comfort disclosing or perceptions of stigma.

Culture also plays a role in examining the deaf and hard of hearing population. Considering whether participants are a part of the Deaf community is an important variable. Individuals who are part of the Deaf community may feel as though they have more social support and may be more likely to accept their hearing loss as part of their identity since they are surrounded by others similar to them who embrace that identity. These individuals may feel more comfortable with disclosure and may perceive and respond to stigma differently. While a few Deaf participants were included in this study, Deaf individuals who rely solely on American Sign Language (ASL) were not due to the oral interview format. Future research should consider finding ways to include these individuals, whether through survey or through the use of ASL in the interview format (perhaps through the use of an interpreter).

In terms of culture and perceptions of stigma, this study only examined individuals with a hearing loss in the U.S. Other cultures around the world might be more or less willing to communicate with individuals with hearing loss. The stigmas surrounding hearing loss could vary based on global culture. Several participants in the interviews for this study touched on this briefly. One participant mentioned having been to Italy and noticing that hearing aids were more of a fashion statement there. She explained that there seemed to be less of a stigma surrounding hearing loss in Italy. On the other hand, another participant talked about having visited a deaf school in far Eastern Europe. She described the stigma surrounding hearing loss there to be much worse than the stigma she experiences in the U.S. Thus, examining the perceptions of hearing loss, and other disabilities, in different countries around the world is another variable that future research should consider. Certain cultures might be more accepting of individuals with disabilities than others.

Finally, this study did not provide the perspective of the friends or family members of the hard of hearing participants. Friends and family of hard of hearing individuals may notice different disclosure tactics, stigma, or responses to stigma surrounding hearing loss. Further, this study does not examine how families with hard of hearing children feel. What struggles do the families go through when finding out that a child has a hearing loss or another disability? How does the family (particularly a hearing family) communicate about hearing loss with their hard of hearing child? Does this influence influences how he or she internalizes stigma or develops approaches to disclosure? Are there communication strategies these families have used in order to support or help their child with a hearing loss or other disability? What types of coping

mechanisms or social support are helpful for families with children who have recently

been diagnosed with hearing loss or another disability? These are all questions that

future research should consider in order to examine the other side of the story. A

diagnosis of a disability such as hearing loss affects more than just the diagnosed

individual – it often affects the lives of those around them as well.

CHAPTER SEVEN: CONCLUSION

Stigma can affect the lives of stigmatized individuals as well as the communication processes, such as disclosure, in which they engage (Charmaz, 1991; Goffman, 1963; Matthews & Harrington, 2000). This study was aimed at examining hard of hearing individuals, a stigmatized group, and how they disclose or deal with stigma surrounding their hearing loss. Using the Communication Privacy Management Theory (CPM; Petronio, 2002, 2007), this study posed five research questions: how do hard of hearing individuals manage the boundaries surrounding their hearing loss, how do hard of hearing individuals deal with boundary turbulence, what do hard of hearing individuals perceive to be the costs of disclosure, how do hard of hearing individuals perceive stigma, and how do hard of hearing individuals respond to that stigma.

Interactive interviews were conducted in this study as they allowed for a natural conversation to occur during the interview since I have hearing loss in common with my participants (Ellis et al., 1997). These interactive interviews with 30 hard of hearing and deaf participants produced several themes to address each of the research questions. The themes that arose when talking about managing boundaries surrounding hearing loss included a discussion of hearing loss as part of the participants' identities, disclosure as a many-faceted judgment call, the risks of not disclosing, delaying disclosure, minimizing the hearing loss, using disclosure as an education opportunity, and concern for the other person. The second research question asked about managing boundary turbulence to examine how participants perceived it when someone else disclosed about their hearing loss for them. The participants stated that the intentions of the person who caused the

turbulence mattered, turbulence causes a feeling of a lack of control, and their reactions to turbulence varied widely.

Research questions three and four provided overlapping themes and were thus presented together as I discussed the costs of disclosure and the main cost of disclosure identified by participants, stigma. Five themes arose when participants explained the costs of disclosure and their perceptions of stigma: feelings of sorry or pity, not being worth the others' time, being labeled as "not normal", the perception that hearing loss limits physical and mental capabilities, and the fact that hearing loss is different from other disabilities. The final research question addressed how the participants responded to the stigma that they experience surrounding their hearing loss. Participants stated that they responded to stigma by avoiding/ignoring the stigma, asserting themselves, using it as another education opportunity, viewing it as the other person's problem, having a positive attitude, and by making stigma a positive thing.

Following the results, this study provided an in-depth discussion of each of the themes identified by the participants. Boundary management surrounding hearing loss for these participants seemed to extend beyond decisions surrounding whether to disclose to include questions of identity (Bat-Chava, 2000), when to disclose (delaying disclosure; Braithwaite, 1991), how much to disclose (boundary permeability in CPM; Petronio & Durham, 2008), and the pros and cons of disclosing (risk-benefit criteria in CPM; Petronio, 2002). On occasions where disclosure was done for them without their consent (boundary turbulence in CPM occurred; Petronio, 2002, 2007), participants talked how this made them feel. Often, participants evaluated the boundary turbulence based upon how helpful they perceived it – boundary turbulence, despite current conceptualizations

(Petronio, 2002, 2007), can be perceived as positive if the turbulence is helpful. Participants also talked about the inherent lack of control and power associated with their ownership of private health information being violated (Braithwaite, 1991; Petronio, 2007).

Disclosure for individuals with disabilities is often fraught with dilemmas as they have to navigate stigma, often at the expense of accommodations and/or social support (Bos et al., 2009; Hart & Williams, 1995; Najarian, 2008). Thus, one of the major costs to disclosure identified by participants was stigma (Charmaz, 1991; Goffman, 1963; Matthews & Harrington, 2000). Participants discussed that stigma occurred on many levels (participants were pitied, labeled, seen as not normal, and seen as incapable). Therefore, one of the main reasons participants identified hesitating or strategizing about the disclosure was stigma as they weighed the pros of disclosure (social support, accommodations) against these many levels of stigma that they may experience upon disclosure (cost-benefit criteria in CPM; Petronio, 2002, 2007). Participants also discussed their reactions to stigma if it occurred. Reactions to stigma varied based on the individual participant and the stigmatizing event. Participants' reactions ranged from direct to indirect and required various levels of self-esteem and positivity.

In this study, participants reported on stigma surrounding their hearing loss as well as the disclosure, a communication process, decisions they use to help manage this stigma. Given that the hard of hearing and deaf participants were often also attempting to navigate any stigma surrounding their hearing loss (they wanted to be seen as an individual outside of their "disability"), disclosure, or communication privacy management, was complex. As a whole, boundary management, stigma, and dealing

113

with stigma are difficult processes for the hard of hearing participants in this study, processes full of decisions. These processes require many judgment calls and affect the communication of the participants in profound ways as the participants attempt to navigate stigma and live their lives as hard of hearing or deaf individuals in an otherwise hearing world.

Interview Protocol

Demographics:

1. Male/Female
2. Age
3. Student?
4. Race/Ethnicity
5. Hearing Loss Level
6. When hearing loss started
7. How hearing loss started

Questions:

1. As you have already shared with me, you have a hearing loss. When you are talking to other people for the first time, how do you share about your hearing loss?

2. When was the last time you had to share about your hearing loss to someone else?

3. Do you ever share about your hearing loss on purpose? Do you ever completely avoid sharing about your hearing loss (hide your hearing loss)?
   a. Can you give me an example of when you shared about your hearing loss on purpose?
   b. Can you give me an example of when you avoided sharing about your hearing loss (hid the hearing loss)?

4. When was the first time you realized that you had to share about your hearing loss?
   a. Can you tell me about this experience?

5. How do you usually go about sharing about your hearing loss?
   a. Can you tell me a story or give me an example of how you shared?

6. How do you decide how to share about your hearing loss?

7. Are there certain situations or settings that you find to be easier to share your hearing loss?
   a. What settings are those?
   b. Why are those settings easier?

8. Are there certain situations or settings that you find to be harder to share your hearing loss?
   a. What settings are those?
   b. Why are those settings more difficult?

9. What are some difficulties you have when sharing about your hearing loss?

10. What is the hardest thing for you when sharing about your hearing loss?

11. What do you see as the costs or risks of sharing about your hearing loss?

12. What are some difficult stories for you in terms of sharing about your hearing loss?

13. Has anyone ever shared about your hearing loss for you?
    a. How did you handle that situation?
    b. Did you give them permission to do so?
    c. How did you feel about someone else sharing about your hearing loss?

14. How do you want other people to react when you share about your hearing loss?
    a. What is an ideal reaction for you?
    b. Why is that an ideal reaction?
    c. Can you give me an example of when someone reacted this way?
    d. How often do people react this way?

15. What is the worst way for someone to react when you share about your hearing loss?
    a. Why is that the worst way for them to react?
    b. Can you give me an example of when someone reacted this way?
    c. How often do you get this reaction?

16. Has anyone ever treated you differently or stereotyped you once you shared about your hearing loss?
    a. What did they do?
    b. How did you feel about their behavior?
    c. How often does this happen?
    d. How do you handle/respond to this behavior?

* Each answer will be followed with probing questions to get participants to expand on their answers. Further, prompting for narratives (i.e. "tell me about a time when…") will be used to elicit stories that provide examples to elaborate on participant answers.

REFERENCES

Agne, R. R., Thompson, T. L., & Cusella, L. P. (2000). Stigma in the line of face: Self-disclosure of patients' HIV status to health care providers. *Journal of Applied Communication Research, 28*, 235-261.

Asch, A. (1984). The experience of disability: A challenge for psychology. *American Psychologist, 39*, 529-536.

Bat-Chava, Y. (2000). Diversity of deaf identities. *American Annals of the Deaf, 145*(5), 420-428.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 18*, 47-56.

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. New York: Doubleday Dell.

Bos, A. E. R., Kanner, D., Muris, P., Janssen, B. & Mayer, B. (2009). Mental illness stigma and disclosure: Consequences of coming out of the closet. *Issues in Mental Health Nursing, 30*, 509-513.

Braithwaite, D. O. (1991). "Just how much did that wheelchair cost?": Management of privacy boundaries by persons with disabilities. *Western Journal of Speech Communication, 55*, 254-274.

Breivik, J. (2005). Vulnerable but strong: Deaf people challenge established understandings of deafness. *Scandinavian Journal of Public Health, 33*(5), 18-23.

Caughlin, J. P., Brashers, D. E., Ramey, M. E., Kosenko, K. A., Donovan-Kicken, E., & Bute, J. J. (2008). The message design logics of responses to HIV disclosures. *Human Communication Research, 34*, 655-684.

Charmaz, K. (1991). Disclosing illness. In *Good days, bad days: The self in chronic illness and time* (pp. 107-133). New Brunswick, NJ: Rutgers University Press.

Cherney, J. L. (1999). Deaf culture and the cochlear implant debate: Cyborg politics and the identity of people with disabilities. *Argumentation and Advocacy, 36*, 22-34.

Cohen Silver, R., Wortman, C. B., & Crofton, C. (1990). The role of coping in support provision: The self-presentational dilemma of victims of life crises. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 397-426). New York: Wiley.

Comer, R. J., & Piliavin, J. A. (1972). The effects of physical deviance upon face-to-face inter-action: The other side. *Journal of Personality and Social Psychology, 23,* 33-39.

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with learning disabilities attending mainstream and segregated schooling: Perceived stigma, social comparisons and future aspirations. *Journal of Intellectual Disability Research, 50,* 432-445.

Corrigan, P. W., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P., Wilkniss, S., Batia, K., & Rusch, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology, 38*, 259-275.

Corrigan, P. W. (2004). How stigma interferes with mental health care. *American Psychologist, 59*(7), 614-625.

Corrigan, P.W., & Watson, A.C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology-Science and Practice, 9*, 35-53.

Crocker, J., Major, B., & Steele, C. (1998). Social stigma. In D.T. Gilbert, S.T. Fiske & G. Lindzey (Eds.), *The handbook of social psychology* (Vol. 2, 4th ed., pp. 504-553)*.* New York: McGraw-Hill.

d'Agincourt-Canning, L. (2001). Experiences of genetic risk: Disclosure and the gendering of responsibility. *Bioethics, 34*, 655-684.

Davis, L. (2007). Deafness and the riddle of identity. *Chronicle of Higher Education, 53*, 5-8.

Davis, N. A. (2005). Invisible disability. *Ethics, 116*, 153-213.

Deacon, H. (2006). Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. *Journal of Community & Applied Social Psychology, 16*, 418-425.

DeMatteo, D., Harrison, C., Arneson, C., Goldie, R. S., Lefebvre, A., Read, S. E., & King, S. M. (2002). Disclosing HIV/AIDS to children: The paths families take to truthtelling. *Psychology, Health, and Medicine, 7*, 339-356.

Ellis, C., Kiesinger, C. E., & Tillmann-Healy, L. M. (1997). Interactive interviewing: Talking about emotional experience. In R. Hertz (Ed.), *Reflexivity and voice* (pp. 119-149). Thousand Oaks, CA: Sage Publications, Inc.

Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4)*,* 531-545.

Fiscella, K., & Epstein, R. M. (2008). So much to do, so little time: Care for the socially disadvantaged and the 15-minute visit. *Archives of Internal Medicine, 168*, 1843-1852.

Frable, D. E., Platt, L., & Hoey, S. (1998). Concealable stigmas and positive self-perceptions: Feeling better around similar others. *Journal of Personality and Social Psychology, 74*, 909-922.

Gagne, J. P., Southall, K., & Jennings, M. B. (2009). The psychological effects of social stigma: Applications to people with acquired hearing loss. In J. Montano & J.B. Spitzer (Eds.), *Advanced practice in adult audiologic rehabilitation: International perspective* (pp. 63-92). New York: Plural Publishing.

Gary, F. A. (2005). Stigma: Barrier to mental health care among ethnic minorities. *Issues in Mental Health Nursing, 26*, 979-999.

Goffman, E. (1959). *Presentation of self in everyday life*. Garden City, NY: Harper & Row.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon and Schuster.

Grosjean, F. (2010). Bilingualism, biculturalism, and deafness. *International Journal of Bilingual Education and Bilingualism, 13*, 133-145.

Harmer, L. M. (1999). Health care delivery and deaf people: Practice, problems, and recommendations for change. *Journal of Deaf Studies and Deaf Education, 4*(2), 73-110.

Hart, R. D., & Williams, D. E. (1995). Able-bodied instructors and students with physical disabilities: A relationship handicapped by communication. *Communication Education, 44*, 140-154.

Hecht, M. L., Jackson, R. L., & Pitts, M. J. (2005). Culture: Intersections of intergroup and identity theories. In Harwood, J., & Giles, H. (Eds.) *Intergroup communication: Multiple perspectives* (pp. 21-42). New York, NY: Peter Lang Publishing.

Heinemann, H., Pellander, F., Antje, V., & Wojtek, B. (1981). Meeting a deviant person: Subjective norms and affective reactions. *European Journal of Social Psychology, 11,* 1-25.

Hétu, R. (1996). The stigma attached to hearing impairment. *Scandanavian Audiology, 43*, 12-24.

Hole, R. (2007). Narratives of identity: A poststructural analysis of three Deaf women's life stories. *Narrative Inquiry, 17*, 259-278.

Hummert, M. L., & Ryan, E. B. (2001). Patronizing. In W. P. Robinson & H. Giles (Eds.), *The new handbook of language and social psychology* (pp. 253-269). London: Wiley.

Kleck, R. E. (1968). Physical stigma and nonverbal cues emitted in face-to-face interaction. *Human Relations, 21,* 19-28.

Kleck, R. E., Ono, H., & Hastorf, A. H. (1966). The effects of physical deviance upon face-to-face interaction. *Human Relations, 19,* 425-436.

Kroll, T., Jones, G. C., Kehn, M., & Neri, M. T. (2006). Barriers and strategies affecting the utilization of primary preventative services for people with physical disabilities: A qualitative inquiry. *Health and Social Care in the Community, 14*(4), 284-293.

Langer, E. J., Fiske, S., Taylor, S. E., & Chanowitz, B. (1976). Stigma, staring, and discomfort: A novel-stimulus hypothesis. *Journal of Experimental Social Psychology, 5,* 253-259.

Lazarus, R. S., & Folkman, S. (1984.) *Stress, appraisal, and coping.* New York: Springer Pub. Co.

Levy, N. (2002). Reconsidering cochlear implants: The lessons of Martha's Vineyard. *Bioethics, 16*(2), 134-153.

Lindlof, T. R., & Taylor, B. C. (2002). *Qualitative communication research methods* (2nd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Luey, H. S., Glass, L., & Elliott, H. (1995). Hard-of-hearing or Deaf: Issues of ears, language, culture, and identity. *Social Work, 40*(2), 177-181.

Macleod, G., & Cebula, K. R. (2009). Experiences of disabled students in initial teacher education. *Cambridge Journal of Education, 39*, 457-472.

Madaus, J. W., Foley, T. E., McGuire, J. M., & Ruban, L. M. (2010). Employment self-disclosure of postsecondary graduates with learning disabilities: Rates and rationales. *Journal of Learning Disabilities, 35*, 364-369.

Major, B., & O'Brien L. T. (2005). The social psychology of stigma. *Annual Review of Psychology, 56*, 393-421.

Martin, R. A., Puhlik-Doris, P., Larsen, G., Gray, J., & Weir, K. (2002). Individual differences in uses of humor and their relation to psychological well-being:

Development of the humor styles questionnaire. *Journal of Research in Personality, 37*, 48-75.

Matthews, C. K. (1994, February). *To tell or not to tell: The management of privacy boundaries by the invisibly disabled.* Paper presented at the annual meeting of the Western States Communication Association, San Jose, CA.

Matthews, C. K., & Harrington, N. G. (2000). Invisible disability. In D.O. Braithwaite & T. I. Thompson (Eds.), *Handbook of communication and people with disabilities* (pp. 37-48). Mahwah, NJ: Erlbaum.

McCroskey, J. C., Richmond, V. P., Daly, J. A., & Falcione, R. L. (1977). Studies of the relationship between communication apprehension and self-esteem. *Human Communication Research, 3*, 269-277.

McNeil, J. M. (1993). *Americans with disabilities: 1991-92*. Washington, DC: U.S. Government Printing Office.

Miller, C. T., & Major, B. (2000). Coping with stigma and prejudice. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 243-272). New York, NY: Guilford Press.

Najarian, C. G. (2008). Deaf women: Educational experiences and self-identity. *Disability and Society, 23*, 117-128.

Nikolaraizi, M., & Makri, M. (2004). Deaf and hearing individuals' beliefs about the capabilities of deaf people. *American Annals of the Deaf, 149*, 404-414.

Park, J. H., Faulkner, J., & Schaller, M. (2003). Evolved disease-avoidance processes and contemporary anti-social behavior: Prejudicial attitudes and avoidance of people with physical disabilities. *Journal of Nonverbal Behavior, 27*, 65-87.

Petronio, S. (1991). Communication boundary management: A theoretical model of managing disclosure of private information between marital couples. *Communication Theory, 1*(4), 311-335.

Petronio, S. (2002). *Boundaries of privacy: Dialectics of disclosure.* Albany, NY: SUNY Press.

Petronio, S. (2007). Translational research endeavors and the practices of communication privacy management. *Journal of Applied Communication Research, 35*, 218-222.

Petronio, S., & Durham, W.T. (2008). Communication privacy management theory. In L. A. Baxter & D. O. Braithwaite (Eds.), *Engaging theories in interpersonal communication: Multiple perspectives* (pp. 309-322). Thousand Oaks, CA: Sage.

Petronio, S., Reeder, H. M., Hecht, M. L., & Rose-Mendoza, T. M. (1996). Disclosure of sexual abuse by children and adolescents. *Journal of Applied Communication Research, 24,* 181–199.

Ross, M. (2006). How many deaf people are there in the United States? Estimates from the Survey of Income and Program Participation. *Journal of Deaf Studies and Deaf Education, 11*(1), 112-119.

Scheer, J., Kroll, T., Neri, M. T., & Beatty. P. (2003). Access barriers for persons with disabilities. *Journal of Disability Policy Studies, 13*(4), 221-230.

Shih, M. (2004). Positive stigma: Examining resilience and empowerment in overcoming stigma. *Annals of the American Academy of Political and Social Science. Special Issue: Positive Development: Realizing the Potential of Youth, 591*, 175-185.

Sinnema, G. (1992). Youths with chronic illness and disability on their way to social and economic participation: A health-care perspective. *Journal of Adolescent Health, 13*, 369-371.

Skelton, T., & Valentine, G. (2003). 'It feels like being Deaf is normal': An exploration into the complexities of defining D/deafness and young D/deaf people's identities. *The Canadian Geographer, 47*, 451-466.

Southall, K., Gagne, J., & Jennings, M. B. (2010). Stigma: A negative and positive influence on help-seeking for adults with acquired hearing loss. *International Journal of Audiology, 49*, 804-814.

Steele, C. M., Spencer, S. J., & Aronson, J. (2002). Contending with group image: The psychology of stereotype and social identity threat. In M.P. Zanna (Ed.), *Advances in experimental social psychology* (Vol. 34, pp. 379-440). San Diego: Academic Press.

Stone, S. D. (1995). The myth of bodily perfection. *Disability & Society, 10*(4), 413-424.

Thompson, T. L. (1982). Disclosure as a disability-management strategy: A review and conclusions. *Communication Quarterly, 30*, 196-202.

Turner, J., & Oakes, P. (1986). The significance of the social identity concept for social psychology with reference to individualism, interactionism and social influence. *British Journal of Social Psychology, 25*, 237–252.

Van Brakel, W. H. (2006). Measuring health-related stigma – A literature review. *Psychology, Health, & Medicine, 11*(3), 307-334.

Wheeless, L. R. (1978). A follow-up study of the relationship among trust, disclosure, and solidarity. *Human Communication Research, 4*, 143-157.

World Health Organization (2001). *The world health report 2001—Mental Health: New Understanding, New Hope.* Geneva, Switzerland: World Health Organization.

Zazove, P., Niemann, L., Gorenflo, D., Carmack, C., Mehr, D., Coyne, J., & Antonucci, T. (1993). The health status and health care utilization of deaf and hard-of-hearing persons. *Archives of Family Medicine, 2*(7), 745-752.

VITA

Education

Ph.D., Communication, University of Kentucky (May 2014)
    Areas: Health & Interpersonal Communication; Qualitative Methods
    Dissertation: *I can't hear you but I'm not sure I'm going to tell you: Perceptions of stigma and disclosure for individuals who are deaf or hard of hearing*
    Advisor/Committee Chair: Dr. Donald Helme
    Committee: Dr. Elisia Cohen, Dr. Timothy Sellnow, Dr. Allison Scott,
        Dr. Karin Lewis

M.A., Communication, University of Kentucky (August 2011)
    Areas: Interpersonal & Instructional Communication; Qualitative Methods
    Thesis: *Deaf or hearing: A hearing impaired individual's navigation between two worlds*
    Advisor/Committee Chair: Dr. Donald Helme
    Committee: Dr. Elisia Cohen, Dr. Michael Arrington

B.S., Organizational Communication, Ohio University (June 2009)
    Summa Cum Laude
    Related Area in Business and Technology
    Advisor: Dr. Candice Thomas-Maddox

Certificates

Health Communication, University of Kentucky, Awarded Summer 2013

Women's Studies, Ohio University, Awarded Spring 2009

Academic Employment

August 2011 – August 2014	Instructor of Record, University of Kentucky, College of Communication and Information
August 2010 – May 2011	Graduate Teaching Instructor, University of Kentucky, College of Communication and Information
June 2011 – August 2011	Graduate Research Assistant for Dr. Brandi Frisby, University of Kentucky, College of Communication and Information

June 2010 – August 2010	Graduate Research Assistant for Dr. Nicole Blau and Dr. Candice Thomas-Maddox, Ohio University Lancaster, Communication Studies
June 2010 – August 2010	Presentation Consultant & Designer for Columbus Division of Fire and Ohio State Fire Academy
August 2009 – May 2010	Graduate Teaching Assistant, University of Kentucky, College of Communication and Information
March 2009 – June 2009	Undergraduate Research Assistant for Dr. Nicole Blau, Ohio University Lancaster, Communication Studies

Publications

Kaufmann, R., Simpson, S., & **Lash, B. N.** (2014). "We've got a situation here": Portrayal and discussion of sexual behaviors on Jersey Shore. *The Texas Speech Communication Journal, 38*(1),

Lash, B. N. (2013). Research from the heart: Chancing labels and exposing a private identity. *Health Communication, 28*(4), 422-424.

Frisby, B. N., Weber, K. D., & **Lash, B. N.** (In Press). Participation requirements: An instructor strategy to influence student interest and learning. *Communication Quarterly.*

Helme, D. W., & **Lash, B. N.** (In Press). Campaign program strategies. *The Encyclopedia of Health.*

Helme, D. W., & **Lash, B. N.** (In Press). Dual processing models: ELM & HSM. *The Encyclopedia of Health.*

Helme, D. W., & **Lash, B. N.** (In Press). Moderating variables associated with audience effects. *The Encyclopedia of Health.*

Manuscripts Under Review

Frisby, B. N., **Lash, B. N.**, Stafford, L., & Sellnow, D. D. (Under Second Review). First-year students' identity threats and support: Influences on academic performance and retention. *Journal of College Student Development*. Resubmitted January 2014.

Lash, B. N., & Record, R. A. (Under Second Review). Navigating the thin-ideal in an athletic world: Influence of coach communication on female

athletes' body image and health choices. *Health Communication*. Re-submitted March 2014.

Lash, B. N., & Helme, D. W. (Under Review). Deaf or hearing: A hard of hearing individual's navigation between two worlds. *Disabilities Studies Quarterly*. Submitted April 2014.

Manuscripts in Progress

Lash, B. N., Frisby, B. N., Stafford, L., & Sellnow, D. D. (Revising). First-year students' social identity and its influence on student retention.

Lash, B. N. (Revising). I can't hear you but I'm not sure I'm going to tell you: Perceptions of stigma and disclosure for individuals who are deaf or hard of hearing.

Competitive Conference Papers, Panels, & Poster Presentations

Lash, B. N., Record, R. A., & Kiernicki, K. (2014, May). *Navigating the Thin-Ideal in an Athletic World: Influence of Coach Communication on Female Athletes' Body Image and Health Choices.* Paper submitted to National Communication Association annual conference, Chicago, IL.

Frisby, B. N., Lash, B. N., Stafford, L., & Sellnow, D. D. (2014, May). *First-year students' perceptions of face threats and support: Influences on academic performance and retention.* Paper accepted at International Communication Association annual conference, Seattle, WA.

Lash, B. N. (2013, November). *Personal and perceived stigma of hearing loss: Scale development and exploration of the differences between the 'D'eaf and 'd'eaf.* Paper presented at National Communication Association annual conference, Washington D.C.

Lash, B. N., & Helme, D. W. (2013, June). *Deaf or hearing: A hard of hearing individual's navigation between two worlds.* Paper presented at International Communication Association annual conference, London, England.

Sellnow, D., Reynolds, M., Price, R., Frisby, B., & Lash, B. N. (2013, May). *The role of messages to, from, and about "home" and first year college student retention.* Panel at Kentucky Innovations Conference Higher Education in the 21st Century, Lexington, KY.

Lash, B. N. (2013, April). *Personal and perceived stigma of hearing loss: A scale development project.* Paper presented at Southern States Communication Association annual conference, Louisville, KY.

126

Kaufmann, R., Simpson, S., & **Lash, B. N.** (2012, November). *"We've got a situation here": Portrayal and discussion of sexual behaviors on Jersey Shore*. Paper presented at National Communication Association annual conference, Orlando, FL.

Lash, B. N. (2012, September). *Stigma & hearing loss: An examination of the differences between the 'D'eaf and 'd'eaf*. Paper presented at Kentucky Communication Association annual conference, General Butler State Park, Carrollton, KY.

Lash, B. N. (2011, September). *Perceived caring in instructional communication*. Paper presented at Kentucky Communication Association annual conference, Lake Barkley State Resort Park, KY.

Lash, B. N. (2011, March). *Deaf or hearing: A hearing impaired individual's navigation between two worlds.* Top student paper presented at annual Communication Graduate Student Association Symposium, Lexington, KY.

Lash, B. N. (2010, September). *Humor and coping: The use of humor to manage stress in the Columbus Division of Fire*. Paper presented at Kentucky Communication Association annual conference, Jenney Wiley State Resort Park, KY.

Lash, B. N. (2008, May). *Service learning in action: An analysis of the organizational culture of the Columbus Division of Fire.* Poster presented at Eastern Communication Association annual conference, Pittsburg, PA.

Teaching Experience

Instructor of Record, University of Kentucky, 2010 – 2014
    Courses:
        COM181: Public Speaking
            August 2010 – May 2011
            Encouraged students to get involved with campus activities
            Taught students basic components of public speaking
            Bolstered students' confidence and comfort in speaking

        COM252: Introduction to Interpersonal Communication
            January 2011 – August 2014
            Instructed students on the topic of interpersonal comm.
            Taught students APA format and to find scholarly research
            Guided students through writing a literature review
            Encouraged interactive atmosphere and class participation

COM281: Small Group Communication
August 2013 – December 2013
Educated students on the importance of group comm.
Guided in the development of group communication skills
Facilitated students' navigation of several group projects
Managed class event planning project for on-campus event

Teaching Assistant, University of Kentucky, 2009 – 2010
Courses:
COM101: Introduction to Communication
August 2009 – May 2010
Assisted in managing 150+ students per semester
Handled grading, attendance, and emails for 150+ students

Curriculum Development/Involvement

New Course Development, University of Kentucky, 2013 – 2014
Developed new COM course – Comm. with Individuals with Disabilities
Created syllabus with assignments and required reading for new course
Funding pending

Curriculum Assessment, University of Kentucky, January 2014 – April 2014
Involved with assessment of several undergraduate COM courses
Used Graduation Composition and Communication Requirement (GCCR)
Assessed several undergraduate COM courses to ensure meeting of GCCR
Assessments conducted on both course and program levels

Honors

University of Kentucky Communication Graduate Student Symposium Top
Interpersonal Paper, 2011

Ohio Communication Association Undergraduate of the Year, 2009

Ohio University Lancaster, L.E.A.D. Team, Competitive Selection, 2007 – 2008

Departmental Service

Volunteer, Communication Major Information Sessions, University of Kentucky,
September 2013.

Graduate Student Association Member, University of Kentucky, 2009 – present.

Social Co-Chair, Communication Graduate Student Association, University of
Kentucky, 2009 – 2010.

Professional Service

Reviewer, Western Journal of Communication, January 2014.

Reviewer, Kentucky Conference on Health Communication (KCHC), 2014, Lexington, KY.

Volunteer, National Communication Association Conference, 2009, Chicago, IL.

Volunteer, Eastern Communication Association Conference, 2008, Pittsburg, PA.

Professional Affiliations

International Communication Association, 2012 – present

Southern States Communication Association, 2012 – present

Kentucky Communication Association, 2010 – present

National Communication Association, 2009 – present

Eastern Communication Association, 2008 – 2010

Signed: Brittany Nicole Lash