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WHISPERS AND ROARS: DECODING THE DILEMMA OF SHARING YOUR HEARING LOSS JOURNEY

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Abstract: Disclosure is the intentional sharing of personal information about oneself. For individuals with disabilities, the decision to disclose can be complex and challenging. This study examines disclosure decisions for deaf or hard of hearing (HoH) individuals, exploring factors that influence the choice to disclose as well as decisions surrounding how they disclose about their disability.

Keywords: Disclosure, Disability, Deaf

Introduction

Disclosure occurs when an individual intentionally shares personal information about himself or herself that reveals something not previously known (Charmaz, 1991; Wheeless, 1978). Disclosure allows for intimacy to develop in an interpersonal relationship (Wheeless, 1978) but also poses certain risks such as negative reactions to disclosure, rejection, vulnerability, and stigma (Caughlin et al., 2008; Charmaz, 1991). For individuals with disabilities or who are attempting to "pass" as ablebodied, the choice to disclose is fraught with additional challenges as individuals in this population attempt to avoid the potential risks of disclosure but often need to disclose to obtain necessary accommodations or to allow for a successful interaction (Charmaz, 1991). This study will examine disclosure decisions for one population of individuals with disabilities, individuals who are deaf or hard of hearing (HoH), by exploring factors that influence the choice to disclose as well as decisions surrounding how they disclose about their disability once they have chosen to.

Disclosure Decisions

There are many decisions involved in the disclosure process for disabled individuals. One such decision includes whether they want to disclose their disability at all. 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) as they attempt to manage the impressions others may have of them (Goffman, 1959). Given that U.S. culture, and much of global culture, sees fully able bodies as the "normal" or "average" body establishing a norm of ablebodiedness, individuals with disabilities are often perceived as less than normal or not fully human (Goodley, 2017). Stone (1995) discusses this "myth of bodily perfection" and the negative implications of this myth as it discourages those with disabilities from disclosing to avoid being seen as "impaired" (p. 413). As Goodley (2017) explains, "an individual becomes disabled when they fail to meet the standards of ableism" (p. 94). Because of this, "disabled people are often cast as broken individuals perhaps not individuals at all" (Goodley, 2017, p. 94). Thus, disclosing about a disability places the individual at risk for stigma (Goffman, 1963).

Not only can disclosure of a disability increase the risk of stigma, it can also harm self-esteem, strain relationships, or be met with judgment and even rejection (Charmaz, 1991; Goffman, 1963; Thompson-Ebanks & Jarman, 2018). Additionally, losing a sense of autonomy over their own bodies and health information presents another disclosure risk. Disclosure about a disability involves the loss of privacy surrounding personal health as disabled individuals (unlike ablebodied individuals) are often asked to "reveal normally private information about their health, bodies, sexuality, or personal habits" because of their disabilities (Braithwaite, 1991, pp. 254–255) or in response to providing "proof" that they have a disability (Matthews & Harrington, 2000; Southall, Jennings, & Gagné, 2011).

When deciding whether to disclose, the risks of disclosure are often weighed against the risks of *not* disclosing such as gaining access to accommodations (socially, physically, or professionally) they need (Blockmans, 2015; Lash & Helme, 2020; Thompson-Ebanks & Jarman, 2018). Najarian (2008) discusses this as she examines "coming out of the disability closet" among deaf college women (p. 118). When faced with the choice to reveal their deafness to receive classroom accommodations (e.g., transcripts, microphones, interpreters) or to not tell anyone to avoid being stigmatized, disabled students often choose not to disclose (Najarian, 2008). Ultimately, disabled individuals often perceive that stigma can negatively affect the learning environment more so than not receiving accommodations (Blockmans, 2015; Hart & Williams, 1995; Najarian, 2008; Thompson-Ebanks & Jarman, 2018). In addition to forgoing accommodations, not disclosing about a disability may lead to forfeiture of potential social support or shared community (Bos, Kanner, Muris, Janssen, & Mayer, 2009). Thus, the decision to disclose has potential impacts across various contexts (i.e., socially, educationally, professionally) as participants attempt to avoid stigma often at the expense of accommodations in these contexts.

Because of stigma prompted by ablebodied norms, many disabled individuals put on a façade of "normality" and choose to closet their disabilities to engage in impression management in attempts to avoid stigma (Davis, 2005; Goffman, 1963; Goodley, 2017; Najarian, 2008). Many disabled individuals attempt to walk a line between gaining access to whatever accommodations they may need and "passing" as ablebodied to avoid stigma (Bitman & John, 2019; Blockmans, 2015; Cureton, 2018; Goffman, 1963; Thompson-Ebanks & Jarman, 2018) and often choose not to disclose their disabilities unless certain reasons demand disclosure (Matthews, 1994). If they do choose to disclose, disabled individuals often also face a "burden of proof," which ultimately requires additional disclosure beyond that of the disability itself as others might question the legitimacy of their disabilities (Lash & Helme, 2020; Matthews & Harrington, 2000) or the need for accommodations (Davis, 2005). As such, the disclosure decision is a complicated one in which disabled individuals often must weigh stigma and potential invasions of privacy against accommodation needs.

Hard of Hearing and Deafness as a Disability

One such population who might attempt to conceal their disability or pass as ablebodied is individuals who are D/deaf or hard of hearing (HoH). Affecting many, hearing loss is one of the most common chronic disabilities in the United States, as approximately one of every eight Americans aged 12 or older experiences some degree of hearing loss (National Institute on Deafness and Other Communication

Disorders, 2020). Given ablebodied standards, society views hearing loss as an "impairment," operating from a medical model of disability (Goodley, 2017) and stigmatizing those who are D/deaf and HoH (Bitman & John, 2019). This stigmatization takes various forms, including others pitying them, viewing them as not worth the time or effort, labeling them as "not normal," and viewing them as less capable or intelligent (Lash & Helme, 2020). To avoid such stigmatization, many D/deaf and HoH individuals conceal their disability or attempt to "pass" as having "normal" hearing (Bitman & John, 2019; Eichengreen, Almog, & Broyer, 2016). Thus, it is important to explore how this disability is managed through communication processes, such as disclosure, particularly as this population attempts to manage stigma.

The HoH and D/deaf population is unique given the variability of identities that exist within this group. Additionally, this population is different from many other types of disabilities given the cultural divide that exists between the various ways in which members of this population might identify. Within this population, the way individuals chose to identify is determined on whether the individual identifies as culturally Deaf. An individual who embraces Deaf culture, identifies as Deaf (capital "D"), whereas an individual who does not identifies as HoH or deaf (lower case "d"; Beckner & Helme, 2018; Skelton & Valentine, 2003). HoH and deaf individuals often do not identify with Deaf culture and attempt to integrate into mainstream society, which often includes embracing mainstream ablebodied norms (Beckner & Helme, 2018; Lash & Helme, 2020). As this study examines the disclosure process surrounding disability, the participants in this study identified as HoH or deaf and operated from more of a medical-model understanding of their disability (framing disability as an individual failing that needs fixed or cured; Goodley, 2017). These participants were more likely to conceal their disability to pass as "normal" or ablebodied and, thus, must make decisions about how and when to disclose (Beckner & Helme, 2018; Hole, 2007; Lash & Helme, 2020). Given the variability in how participants within this population identify, throughout this study the disability itself is referred to as "hearing loss," while all participants are referred to by their individual preferences (most participants identified as "hard of hearing" or "deaf") in an effort to prioritize participant autonomy over identity labels (Goodley, 2017) and privilege participant voices and experiences.

Communication Privacy Management

Communication privacy management theory (CPM) can help inform our discussions of how individuals with disabilities make decisions about disclosing their disabilities and the information surrounding the disabilities (e.g., how they obtained the disabilities, what it means to their lives, what accommodations they need). CPM understands personal information as something that is owned. It examines how and why people disclose private information by using the metaphor of boundaries that separate personal information from public to illustrate the tension between telling and withholding private information (Petronio, 1991, 2002). Boundary permeability helps determine whether private information is shared; the more permeable the boundary, the more easily crossed it is with information more readily shared (Petronio & Durham, 2008). In the context of disability, boundaries surrounding information about the disability, as well as the disability itself, must be managed as disabled individuals decide how permeable those boundaries are.

Boundaries are regulated to cope with or prevent vulnerability and disclosure risks and allow the individual to control private information, such as information about a disability (Petronio, 2002, 2007; Smith & Brunner, 2017). Decisions surrounding boundary regulation are rule-based and how/when information will be shared is determined by two types of criteria: core and catalyst criteria. Core criteria (i.e., cultural expectations, gender tendencies, personality characteristics) tend to be relatively stable, whereas catalyst criteria (i.e., situational conditions, motivational goals, emotional needs, risk/benefit ratio) might cause a change in the privacy rules a person uses in various circumstances (Petronio, 2007). Unique core criteria (e.g., norms surrounding ablebodiedness, identity) and catalyst criteria (e.g., accommodation needs, risk of stigma, social support needs) might drive the decision to disclose about a disability.

CPM has been used to examine the management of a positive social identity at university (see Blockmans, 2015), the core and catalyst criteria that drive self-disclosure of disability in the workplace (see Smith & Brunner, 2017), and disclosure of a disability via social media (see Furr, Carreiro, & McArthur, 2016). Additionally, multiple studies examine parental disclosure about a child with a disability (see Copeland & Lasater, 2018; Hays & Butauski, 2018). However, the use of CPM to examine disability disclosure is still relatively limited. Further examination of the decision criteria (both core and catalyst) that guide decisions to disclose about a disability provides insight into the communication processes that disabled individuals use to manage their disabilities. As such, this study examines the criteria that influence the boundary management process for HoH and deaf individuals as they decide whether to disclose.

RQ1: What criteria are considered as HoH and deaf individuals determine how to regulate or manage the boundary surrounding information about their hearing loss?

Disclosure of a disability involves additional decisions beyond the initial choice of whether to disclose. Once an individual with a disability chooses or is forced to disclose about his or her disability, the individual then must decide *how* to disclose. Caughlin and colleagues (2008) noted that “no single disclosure message type is the most effective” (p. 677). In fact, the appropriate avenue of disclosure is often unique to the individuals, contexts, and relationships involved (DeMatteo et al., 2002). Thus, the disclosure process is a multifaceted one, fraught with various risks and additional decisions on top of the initial disclosure decision. Understanding not only what influences the choice to disclose, but *how* HoH or deaf individuals disclose once they have chosen to do so can help us better understand the ways in which they navigate disclosure. Furthermore, as communication privacy management is a *process* (Bute & Tennley, 2010), it is important to not only examine what drives the decision to disclose but also explore how that decision is enacted through communication.

RQ2: Upon choosing to disclose, how do HoH or deaf individuals disclose about their hearing loss?

Method

This study used qualitative interviews to allow the participants to share their perspectives and provide an avenue for in-depth exploration of their experiences (Lindlof & Taylor, 2002), examining the factors that influenced whether they disclosed as well as how they went about engaging in disclosure. As many investigations concerning disabled individuals are done from an ablebodied researcher’s perspective

(Braithwaite, 1991; Matthews & Harrington, 2000), this approach helped ensure that the voices of the population being studied were captured fully. Furthermore, I have a moderate-severe hearing loss and fit into the population being studied, allowing me, as the researcher, to engage in the discussions *with* the participants as opposed to talking *about* the participants and how *they* view the disclosure process (Beckner & Helme, 2018; Ellis, Kiesinger, & Tillmann-Healy,1997; Lash & Helme, 2020).

Participants

Participants recruited for this study had to be at least 18 years of age and have at least a moderate hearing loss (41–55 decibels of hearing loss), as it is at this degree of hearing loss that people start to have trouble following typical conversation at a normal speech level (American SpeechLanguage-Hearing Association, 2022; Center for Disease Control & Prevention, 2022). Additionally, as the study was examining the disclosure process, the disability needed to be concealable; thus, participants needed to use oral communication (not rely solely on American Sign Language). A total of 30 participants 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 of 30 participants (5%) were college students. Of the 30 participants, 28 were Caucasian/White (93.3%), 1 was Hispanic (3.3%), and 1 was African American (3.3%). Most of the participants reported having a profound hearing loss (*n* = 17; 56.7%), two reported a moderate loss (6.7%), four reported a moderate-severe loss (13.3%), four reported a severe loss (13.3%), and three reported a severe profound loss (10%). Additionally, half of the participants reported having been HoH or deaf since birth (*n* = 15). The others varied in terms of age of onset of the hearing loss (*M* = 9.7; *SD* = 16.549). Finally, most participants did not associate with the Deaf community (*n* = 22; 73.3%), whereas eight reported some level of involvement (26.6%). All participants were assigned a pseudonym to ensure anonymity.

Procedures

Once approved by the institutional review board, recruitment was done by using flyers and through network sampling. Using flyers, advertising for the study was done at local audiologists' offices, the local chapters of the Hearing Loss Association of America, and the Disability Resources Center at a large, public university. Network sampling was done by encouraging interview participants to spread the word about the study to others who might also be willing to participate. Individuals who were interested in participating contacted the researcher by e-mail to set up an interview time and location that was convenient for them. Before all interviews, the participants signed an informed consent document. Interviews ranged in length from 12 to 80 minutes (*M* = 31 minutes; *SD* = 15.08), with the single 12minute interview being an anomaly; the participant simply chose not to share much, despite interviewer follow-up and probing questions.

The one-on-one, in-depth interviews were conducted using an interactive interview style to encourage natural conversation and comfortable disclosure (Ellis et al., 1997). Given that I fit into the population being studied, I was able to interact with the participants in the conversations about choices surrounding the disclosure of their hearing loss, sharing disclosures of my own. This allowed for a reciprocal disclosure process, making the interviewees feel like equal participants in the interactions and more comfortable opening up about challenging or difficult experiences. Like a normal conversation, my having shared in similar experiences prompted many participants to expand on their answers as we discussed those common experiences and their similarities and differences. This created a natural dialogue in the interview and helped eliminate any researcher-participant power dynamics (Beckner & Helme, 2018; Ellis et al., 1997; Lash & Helme, 2020). I worked from a list of questions that acted as a flexible interview protocol to guide conversation and prompt participant narratives about their experiences. The flexible interview protocol included questions that asked about how participants usually disclose about their hearing loss, how they make decisions to disclose (or not), difficulties they have experienced in dealing with disclosure, and the potential risks or costs they perceived to be associated with disclosure. Again, my having experienced life with a hearing loss myself aided in the development of this interview protocol; I was able to use experiences of my own to prompt or develop questions (e.g., “I once had to disclose because of X situation . . . can you tell me about any similar experiences if you have any?”). This also helped eliminate researcher-participant power dynamics and built rapport as I was sharing experiences of my own, making myself equally vulnerable. Furthermore, as I am a part of the marginalized group being interviewed, I was not an outside researcher exploiting disability experience for my own gain (Goodley, 2017).

All of the participant interviews were recorded and then transcribed. These transcriptions were first coded to identify which sections of the interviews answered which research question(s). These sections were then coded, using open coding to allow for major themes or categories of information to arise from the data (Creswell, 2013; Lindlof & Taylor, 2002). With open coding, I was able to identify any major patterns or concepts that were present throughout the interviews across participants, resulting in preliminary themes for each research question. These initial themes were then examined further using axial coding, identifying any overlapping or connected themes and allowing them to be collapsed into more refined categories with deeper meanings (Creswell, 2013; Lindlof & Taylor, 2002).

Two processes were used to ensure the trustworthiness of the data. First, a cocoder read the transcripts and drafted up themes that she recognized. We sat down and compared coding results, discussing any variation, and reaching consensus surrounding the final themes. Second, member checking with two different participants was used to make sure that the themes I had identified accurately portrayed participant experiences. One participant who engaged in member checking valued hearing loss as part of her identity and was more likely to disclose, whereas the other participant was less likely to disclose about her hearing loss. Because of their differences in perception, they related to different themes. However, after explaining to each participant the others’ perceptions, both participants agreed with the themes presented as they felt they helped capture the wide variety of experiences.

Results

Participants identified multiple criteria that influence their choices to disclose as they manage boundaries surrounding their hearing loss (RQ1). Furthermore, on deciding to disclose, participants must decide *how* to disclose their hearing loss and what information to disclose (RQ2). The themes that arose in answer to each of these research questions are discussed below.

Disclosure Criteria (RQ1)

Participants identified two core criteria (i.e., centrality of hearing loss to identity and cultural norms surrounding ablebodiedness) and three catalyst criteria (i.e., the situation/context, interpersonal considerations, and the risks of not disclosing) as they decided how to manage the boundaries surrounding information about their hearing loss.

Core Criteria 1: Centrality of Hearing Loss to Identity.

Several of the participants expressed little or no concern about disclosing their hearing loss—the boundary surrounding information about their hearing loss was fairly permeable or open because hearing loss was an important part of their identities, a core criteria. Tom stated that he just lets people know that he cannot hear: “I don’t try to hide my disability.” Participants who felt it was best to share their hearing loss early in the communication interaction or when they first meet someone seemed to see their hearing loss as an important component of their identities. Denise illustrated this as she explained, “I’m just real comfortable with me. It’s who I am. I’ve been this way all my life.” 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.” However, several participants indicated that it had taken them time to become comfortable with this identity. Both Ted and Jane reflected on how, as they got older, they worried about hiding their hearing loss less and began to accept it as a part of who they are. Jane discussed how 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 as a part of who I am.” Overall, perceiving hearing loss as central to their identities was key for the participants who reported openly disclosing information about their hearing loss, making it a core criteria driving their disclosure decisions.

Core Criteria 2: Cultural Norms of Ablebodiedness

Although participants did discuss the importance of hearing loss to their identities, many participants also (contradicting themselves) discussed another core criteria in that they often choose not to disclose at all, when possible, to pass as “normal” and avoid stigma or difficult and invasive conversations. They explained that their default disclosure decision is to avoid opening up about their hearing loss unless they feel it is absolutely necessary—a core criterion driven by cultural norms of ablebodiedness that stigmatize those with disabilities. 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 share about 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 her underlying rule behind sharing about her hearing loss: “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.” Thus, participants did overwhelmingly attempt to keep boundaries surrounding their hearing loss closed, if possible, a second core criteria (and one that contradicted the first core criteria), often to avoid complications or vulnerabilities driven by cultural norms of ablebodiedness.

Catalyst Criteria 1: The Situation/Context Matters

As they decided how to manage boundaries surrounding their hearing loss, participants discussed the ways in which the situation or context mattered, a catalyst criterion for disclosure decisions. For example, participants distinguished between disclosing to a group versus to one person. Brooke stated, "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 opening up to ask for 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 some courage." Explaining how the situation plays a role, Beth shared a story about a dinner with her husband's coworkers who did not know about her hearing loss:

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 in sharing about her hearing loss, highlighting how each situation is evaluated separately, something participants agreed on.

Catalyst Criteria 2: Interpersonal Considerations

Another type of catalyst criterion influencing participants as they made decisions about boundaries surrounding their hearing loss is the nature of the relationship with the person with whom they are interacting. Many participants emphasized that if it is a person they probably will not see again, they typically do not disclose. James noted this as he talked about how he will avoid sharing his hearing loss with a person he will most likely never see again: "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." Brooke explained the other end of the spectrum: "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." As such, many participants considered the potential for an ongoing relationship with the other person as they considered how to manage boundaries surrounding their hearing loss.

Although the potential for a relationship can be an important factor in the decision to disclose, the participants' perceptions of the other person in the interaction can also play a role in the boundary management process. Ted explained that he is "making a judgment about that person" when he is trying to decide whether to "stop them and let them know about the hearing loss." Nicole emphasized how complex 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 nonjudgmental . . . 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.

Other participants reported examining the social standing or power in the relationship with the other person. If the participants felt confident or in control in the relationship, they were more willing to disclose their hearing loss. However, if the other person in the relationship is a superior, opening up becomes more difficult: “If I have to tell my bosses then I might be a little 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.” Overall, participants discussed several interpersonal catalyst criteria that shaped the management of boundaries surrounding their hearing loss— the potential for a relationship, judgments about the other person, and the power dynamics involved.

Catalyst Criteria 3: Risks of Not Disclosing

In making decisions about how to manage the boundaries surrounding their hearing loss, participants also pointed out considering risks associated with *not* disclosing as a catalyst criterion. Many participants shared about their hearing loss to let the other person know what accommodations or which type of communication behaviors will help (e.g., looking at them, speaking slowly and clearly). Without this, several participants felt as if they would be more likely to misunderstand something. Rebecca stated that she usually shares about her hearing loss 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.” 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.

Nicole explained how she assesses whether her work or schooling would be affected by not opening up. She talked about how she will “analyze the situation and do like a pro/con list” in deciding whether to disclose. Because of the potential for miscommunication, *not* disclosing their hearing loss can be a risk for participants, especially in work or school situations.

Being perceived as snobby, stuck up, or angry are other risks that participants associated with not sharing that they have a hearing loss. When participants do not respond to others or come across as ignoring someone, they often get perceived as being unfriendly. 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.” Furthermore, Adam explained that disclosure helps avoid anger on both fronts. By opening up 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 cannot hear something. Thus, participants were quick to point out that there are risks to *not* sharing about their hearing loss and these risks factor into decisions surrounding boundary management.

Disclosing About the Hearing Loss (RQ2)

When participants *do* choose to open boundaries surrounding their hearing loss, they then must decide *how* to go about doing so. RQ2 examined the communicative process of disclosure to explore how participants enact the choice to open these boundaries. Four themes were identified as participants discussed how they disclose their hearing loss: (1) delaying disclosure, (2) minimizing the hearing loss, (3) using disclosure to educate, and (4) being other-centered.

Delaying Disclosure

Many participants talked about delaying disclosure, often as an impression management strategy, both personally and professionally. For 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. Participants talked about delaying disclosing about their hearing loss until after they got the job and could 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 delayed the disclosure about her hearing loss until her employers could see that she "can do all the things that everyone else can do."

Another major reason participants reported delaying disclosure had to do with wanting to demonstrate effective communication skills before disclosing about the hearing loss. Many participants felt that if they can show proficiency in communicating *before* disclosing about the hearing loss, the other person or 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 also talked about the importance of allowing the other person to get to know her and have a conversation with her before she tells them about her hearing loss. She explained that timing is everything because if she must disclose too early, "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." By using this delay strategy and strategically timing the disclosure, many participants try to overcome potential negative reactions to their hearing loss and influence others' responses to their hearing loss.

Minimizing the Hearing Loss

When participants disclose their hearing loss, many of them reported minimizing or downplaying the severity of their hearing loss. 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." Ted stated, "You use the word deaf and they think that you can't hear anything so I say hard of hearing so it lets them know to get my attention when they are talking to me."

Another way the participants reported minimizing their hearing loss is through joking about the subject when disclosing. Instead of outright telling people that they are hard of hearing, 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." By joking, hinting, or downplaying their hearing loss, many participants discussed minimizing the severity of their hearing loss once they have decided to disclose.

Educating the Other

Another way in which some participants engage in the disclosure process is as a chance to educate or raise awareness on the topic of hearing loss. Many participants talked about being open to questions surrounding their hearing loss as a part of the disclosure process. 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." 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, he or she will either ignore the question or tell the person to leave him or her alone.

Participants also talked about using disclosure to educate others about appropriate or helpful communication behaviors. 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." Natalie reported that she asks 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 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." Overall, participants reported sometimes using the disclosure process to educate others about hearing loss itself as well as helpful communication behaviors to use.

Being Other-Centered

The final way in which participants discussed how they disclose was by addressing their concerns for the *other* person in the interaction. To highlight this, participants talked about apologizing as part of their disclosures, even if they recognized 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?" Other participants also reported using the words "I'm sorry" to preface the disclosure, highlighting their concern 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:

I've got to think about the other person, in their shoes, because they may be intimidated or thinking, "crap, I don't want to say the wrong thing" . . . that sort of thing. So I try to think about the other person.

Natalie also clarified that her disclosure process is often "other-person" centered: "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."

Participants also discussed their feelings of responsibility to take the pressure off the other person in their disclosures. Denise talked about disclosure as "a way of taking responsibility for my hearing loss" 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." Sharing in this idea of taking responsibility, Ashley talked about disclosure about her hearing loss as her job: "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." Through their discussions of how they frame their disclosures as an apology or a chance to take responsibility for their hearing loss, many participants expressed a clear concern for the other person in the interaction.

Discussion

Through boundary management decisions, HoH and deaf individuals attempt to manage the risks of disclosing about a disability. This study examined HoH and deaf individuals, exploring the core and catalyst criteria that shaped the decisions about the management or regulation of boundaries surrounding their hearing loss. Additionally, this study also examined how participants enacted decisions to make the boundary surrounding their hearing loss open by exploring the communication process of disclosure and how the participants typically disclose their hearing loss.

The boundary management process and decision of whether to disclose information about their hearing loss were driven by five major criteria—two core criteria and three catalyst criteria. The core criteria, centrality of hearing loss to identity and cultural norms of ablebodiedness, contradicted one another. Participants simultaneously discussed that their hearing loss was a part of who they are, an identity it was important to be open about, and the need to avoid disclosure to pass as "normal." In this paradox, we see the power of cultural norms for ablebodiedness highlighted. It appears their identities, or how they see themselves, are in constant tension with social norms that stigmatize those with disabilities. This tension between identity and ablebodied cultural norms further complicates the boundary regulation process for HoH and deaf individuals and potentially other disabilities or marginalized identity groups, as the opening of the boundary surrounding their disabilities is a form of coming out about a stigmatized identity (Bos et al., 2009; Corrigan et al., 2010; Najarian, 2008). Furthermore, given that disability identities are stigmatized identities, openly disclosing that identity can prove challenging, as individuals might have to combat internalized stigma in addition to the broader social stigma (Goffman, 1963).

Even participants who personally saw hearing loss as central to their identities demonstrated difficulty in being open about those identities with others. They often discussed disclosure strategies such as delaying disclosure and minimizing their disability. They also emphasized the need to be other-centered in their disclosures, apologizing for their hearing loss as they disclosed, as they saw hearing loss as something that might inconvenience or cause discomfort for the other person, a form of internalized of stigma surrounding hearing loss (Goffman, 1963). The need to apologize highlights the pervasiveness of ablebodied cultural norms as a core catalyst guiding the boundary regulation process as participants felt the need to make the disclosure more "palatable" to nondisabled others, even if they see hearing loss as central to who they are (the other core catalyst).

Participants also discussed disclosure as a way of taking "responsibility" for their hearing loss. They perceive the hearing loss as "their problem" (another phrasing that highlighted potential internalized stigma and ableism), and as such, it is their responsibility to disclose it to avoid any miscommunication. From a nondisabled perspective, the main goal in the communication interaction is to alleviate any potential discomfort experienced by the nondisabled individual, no matter the cost to the individual with the disability (Braithwaite, 1991; Thompson, 1982). Therefore, at some point, the disclosure feels like a responsibility for the participants given the pressures they may feel from a society that values ablebodiedness to make the nondisabled person in the interaction more comfortable, despite the potential cost to the HoH or deaf individual, another form of internalized ableism that privileges the ablebodied identity. As such, the boundary management process again sits in this tension between these two core criteria—sharing who they are while simultaneously "taking responsibility" for that identity as an identity that others might perceive to be a burden, a perception that is influenced by ablebodied cultural norms.

In addition to tensions between the two core criteria, there were tensions between core and catalyst criteria as well. Because of the potential to be defined by their "disabled" identity, a stigmatized identity, many participants stressed being strategic about how, when, to what extent, and to whom they disclose information about their hearing loss—all forms of catalyst criteria they used to guide boundary management decisions. Being proud about one's identity acted as core criteria guiding disclosure decisions and suggests that most HoH and deaf individuals would disclose more openly. However, because of the pervasiveness of stigma surrounding disability, many participants emphasized the need for situational or interpersonal judgment calls, often relying on the necessity of the disclosure. Ultimately, they indicated that each disclosure is unique to the context, situation, and relationship involved (Caughlin et al., 2008; DeMatteo et al., 2002; Southall et al., 2011) and that they relied on catalyst criteria to guide their decisions to disclose. Similarly, participants seemed driven to disclose as a way of taking "responsibility" for their hearing loss (influenced by the core criteria of cultural norms of ablebodiedness) but simultaneously reported being strategic, again relying on catalyst criteria, in their disclosure timing and approaches to avoid being defined by a stigmatized identity. As such, not only does contradiction occur between the core criteria that guide the boundary management process for HoH or deaf individuals but also between core and catalyst criteria. Additionally, given the tension between the core criteria identified in this study (i.e., centrality of hearing loss to identity and ablebodied cultural norms), many participants ultimately relied on catalyst criteria to determine boundary management decisions.

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 HoH or deaf participants, as not all HoH or deaf individuals feel the same way about disclosure. The participants in this study were willing to talk about their hearing loss—the interview participation was a process that required disclosure. Thus, HoH or deaf individuals that were not willing to step forward to participate in this study may manage disclosure differently. Furthermore, age of the HoH or deaf individuals as well as the age at which they lost their hearing might influence the disclosure of hearing loss. Older individuals might manage disclosure of hearing loss differently since age and hearing loss often go hand in hand. Furthermore, individuals who were born with a hearing loss might make choices about disclosure differently than individuals who lose their hearing later in life. Finally, whether participants are a part of the Deaf community is an important variable as those with access to a community of others who actively resist stigmatizing labels may feel differently about disclosing their hearing loss.

It is also important to note that although this study focuses on HoH and deaf individuals, other marginalized identities might face similar struggles in boundary management processes as they experience similar tension between identity and broader cultural norms. Other populations with stigmatized identities that require disclosure might experience tensions between the core and/or catalyst criteria guiding their boundary management decisions. Such populations might include other types of disabilities, mental health conditions, sexual orientation, addiction (Goffman, 1963) that might need to navigate disclosure to access accommodations, social support, or healthcare. Given that boundary regulation surrounding stigmatized identities could impact access to healthcare (see Corrigan et al., 2010; Lash & Helme, 2020), educational accommodations (see Blockmans, 2015; Hart & Williams, 1995; Najarian, 2008; Thompson-Ebanks & Jarman, 2018), interpersonal interactions (see Bos et al., 2009; Braithwaite, 1991; Charmaz, 1991; Goffman, 1959), and workplace success (see Smith & Brunner, 2017; Southall et al., 2011), future research should continue to understand how these boundaries are managed as well as ways in which to make the disclosure process easier for those with stigmatized identities.

Individuals with stigmatized identities, such as HoH or deaf individuals, face disclosure decisions regularly as they navigate societal norms that place them at risk for negative reactions from others, rejection, and discrimination (Caughlin et al., 2008; Charmaz, 1991; Goffman, 1963). In navigating these risks, HoH or deaf individuals often chose not to disclose about their disabilities because of cultural norms of ablebodiedness (a core criteria guiding their disclosure decisions), in the process potentially forfeiting accommodations or communication behaviors that might ease interactions. Finding ways to ease the disclosure process for those who are HoH and deaf, and who have other disabilities, could go a long way in helping this population gain access to necessary accommodations and social support. Furthermore, raising awareness and educating others about hearing loss, and disability more broadly, would go a long way in combatting or challenging social stigma and ablebodied norms (Meisenbach, 2010; Smith, 2011), ultimately decreasing the risks of disclosure for this population and increasing societal inclusivity.

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