# The Impact of COVID-19 Pandemic Masking on Individuals with Hearing Loss: Metacognition, Mental Health, and Ableism

**A Dissertation Presented for the**
**Doctor of Philosophy**
**Degree**
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**Kristel Scoresby**
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# INTRODUCTION

This dissertation focuses on understanding the relationship of communication barriers and mental health for people who have hearing loss or deafness. Although hearing loss is considered a spectrum, individuals identify their hearing loss differently. This project did not seek to separate out the identities of hearing loss, but rather to look at hearing loss as a whole.

To increase understanding of this topic and to complete requirements for the Doctor of Philosophy in social work, this dissertation is comprised of three different studies. Each chapter represents a study and is organized in the format of individual manuscripts.

Chapter 1 (and paper 1) represent a systematic review that was undertaken to search the available published literature to identify the impact of communication barriers on mental health. Sixteen total articles met the search criteria and were analyzed through a results-based convergent synthesis design. This design first identified findings from the quantitative and qualitative articles, then identified findings from merging together both types of research. Several gaps in the literature were identified in the systematic review. One of the biggest gaps was the lack of research on the communication barriers that the COVID-19 has introduced, masking. Further research is needed to determine the impact of masking on mental health needs of DHH, as well as other communication barriers.

Chapter 2 (and paper 2) was based on a quantitative exploratory cross-sectional study to address these research questions:

1. What is the rate of depression and anxiety for people who are deaf or hard of hearing during the COVID-19 pandemic?

2. What is the relationship between masking, metacognition, and mental health factors?

The findings of this study indicated that masking was a serious barrier to communication and contributed to people with hearing loss feeling depression and/or anxiety, especially for those who had not experienced these mood disorders prior to the pandemic. Additionally, this study found that metacognition, how people with hearing loss thought and felt about their thinking in stressful communication environments, influenced depression and anxiety.

Chapter 3 (and paper 3) addressed the lived experiences of individuals with hearing loss and answered the research question of: What are the perceptions of DHH of communication, masking, and mental health? This qualitative study was based on a heuristic phenomenology inquiry. Findings indicated that people with hearing loss not only perceived masking as a negative barrier, but that the unwillingness of others to accommodate their hearing challenges had an impact on their mental health and participation in society.

# CHAPTER 1

# HOW COMMUNICATION BARRIERS IMPACT THE MENTAL HEALTH OF INDIVIDUALS WITH HEARING LOSS: A SYSTEMATIC REVIEW

## ABSTRACT

Hearing loss, a communication disorder, is a global concern with approximately 20.3% of people around the world having some degree of hearing loss and is associated with chronic communication barriers. These barriers impact the mental health of individuals with hearing loss. This mixed method systematic review seeks to synthesize the communication barriers that contribute to negative mental health outcomes for adults. Databases searched include Pubmed, Cinahl, Scopus, Proquest, and Taylor and Francis. A total of 1215 articles were identified in August 2021. Through a systematic extraction, sixteen articles (ten quantitative, six qualitative) met the inclusion and exclusion criteria. Communication barriers were organized in the socio-ecological framework and included Intrapersonal barriers (e.g. active listening avoidance), Interpersonal barriers (e.g. lack of consideration from communication partner), Environmental barriers (e.g. reduced access to side conversations), and Systemic barriers (e.g. ableism). The mental health outcomes associated with these barriers were psychosocial factors (e.g. lower quality of life), mental health disorders (e.g., depression), and lack of access to integrated care (e.g., lack of sign language fluent providers). To help address these barriers, authors suggest integrating mental health and hearing health care. Clinicians can increase awareness of how chronic communication barriers contributes to poor mental health outcomes of their patients with hearing loss. Increasing mental health literacy can help individuals with hearing loss advocate for a decrease in communication barriers.

Individuals with hearing loss have a higher risk of negative mental health outcomes such as depression, suicidal ideation, substance use, increased stigma, and decreased quality of life (Adigun, 2017; Guthmann & Graham, 2005; Wallhagen, 2010). Hearing loss, a communication disorder, impacts personal and professional interpersonal connections. When there are chronic communication barriers or breakdowns, as often is the case for those with hearing loss, mental health is negatively impacted (Fellinger et al., 2005; Recio-Barbero et al., 2020). Despite research demonstrating the connection between hearing loss communication barriers and mental health, there is a dearth of information on what specific communication barriers impact mental health (Adigun, 2017). This systematic review seeks to search the state of the literature in regards to the specific relationship between communication challenges in hearing loss and mental health factors.

Hearing loss is a worldwide concern with approximately 1.57 billion people (20.3%) of people around the world having some degree of loss (Chadha et al., 2021; Haile et al., 2021). Due to an aging population, those numbers are projected to increase, with 2.45 billion people having hearing loss by the year 2050 (Haile et al., 2021). In the United States, 23% of the population (38 million) is estimated to have hearing loss with prevalence increasing in the older adult population (Goman & Lin, 2016). Considered a communication disorder, hearing loss is an umbrella term for those who are Deaf, deaf, or hard of hearing (e.g., DHH). In all three of these categories, the spectrum of hearing loss can be anywhere from mild to profound loss (Goman & Lin, 2016; Haile et al., 2021). Those who view themselves as hard of hearing or deaf generally experience

hearing loss as a disability or physical medical condition (Chapple, 2019). They often work on increasing their hearing through the medical model with cochlear implants, hearing aids, assistive listening devices, or other accommodations to communicate in the hearing world (Cohen, 2003; Guthmann & Graham, 2005). For those with hearing loss who identify as Deaf, the distinction is not just with grammar (D/d) but also with culture and language. Those in the Deaf community often view deafness as a unique identity that comes with its own language (i.e., sign language) and cultural norms (Beckner & Helme, 2018; Chapple, 2019). When interacting with the hearing world, Deaf individuals often use interpreters and relay operators to communicate (Guthmann & Graham, 2005).

As a communication disorder, hearing loss has a profound impact on the ability to converse in day-to-day interactions with friends, family, coworkers, and others in personal and professional environments (Kushalnagar, 2019). DHH, regardless of how they identify their hearing loss, are often concerned about the communication barriers in these environments (Beckner & Helme, 2018; Haynes, 2014; Sparrow et al., 2020; Tye-Murray et al., 2007). The world is set up to be hearing, with flowing communication in person, on the phone, through radio, internet, television and broadcast speaker systems (Bitman & John, 2019; Gonsalves & Pichora-Fuller, 2008; Zahnert, 2011). Often, very little thought is taken into consideration on how these types of communication systems limit the auditory information that DHH individuals receive or are able to interpret (Rogers et al., 2003).

Previous research demonstrates the link between communication barriers for DHH and multiple disparities such as poor health care outcomes (Dock, 2018; Henn et

al., 2021; Sheppard, 2014), education disadvantages (Alshawabkeh et al., 2021; Dl, 2008), employment problems (Benito et al., 2016; Punch, 2016), and lower socioeconomic status (Emmett & Francis, 2015; Nakahori et al., 2020). These conditions can contribute to poorer mental health outcomes (Guthmann & Graham, 2005). Mental health, also a critical growing worldwide concern, has shown to have a disproportionate impact on those with hearing loss (Guthmann & Graham, 2005; Lawrence et al., 2020).

## METHODOLOGY

In consultation with the subject librarian, audiology and clinical social work researchers, the following search terms were identified:

> ("hearing loss" OR "hearing impairment" OR deaf OR "hearing disability" OR "hard of hearing") AND ("mental health" OR "mental illness" OR "mental disorder" OR "psychiatric illness" OR outcome) AND (barrier OR mask OR "face covering" OR misunderstand) AND (communication OR "lip reading" OR "facial cues" OR "facial expressions")

Multiple databases were searched (i.e., Pubmed, Cinahl, Scopus, Proquest, Taylor and Francis, Science direct, Oxford university press) in August 2021, resulting in a total of 1215 articles. After applying inclusion and exclusion criteria, title, abstract, then full article screening, 16 articles remained (figure 1). Inclusion criteria were: Articles written in English, original peer reviewed research, hearing loss/deafness measures were used (subjective or objective), mental health outcome measures were used (subjective or

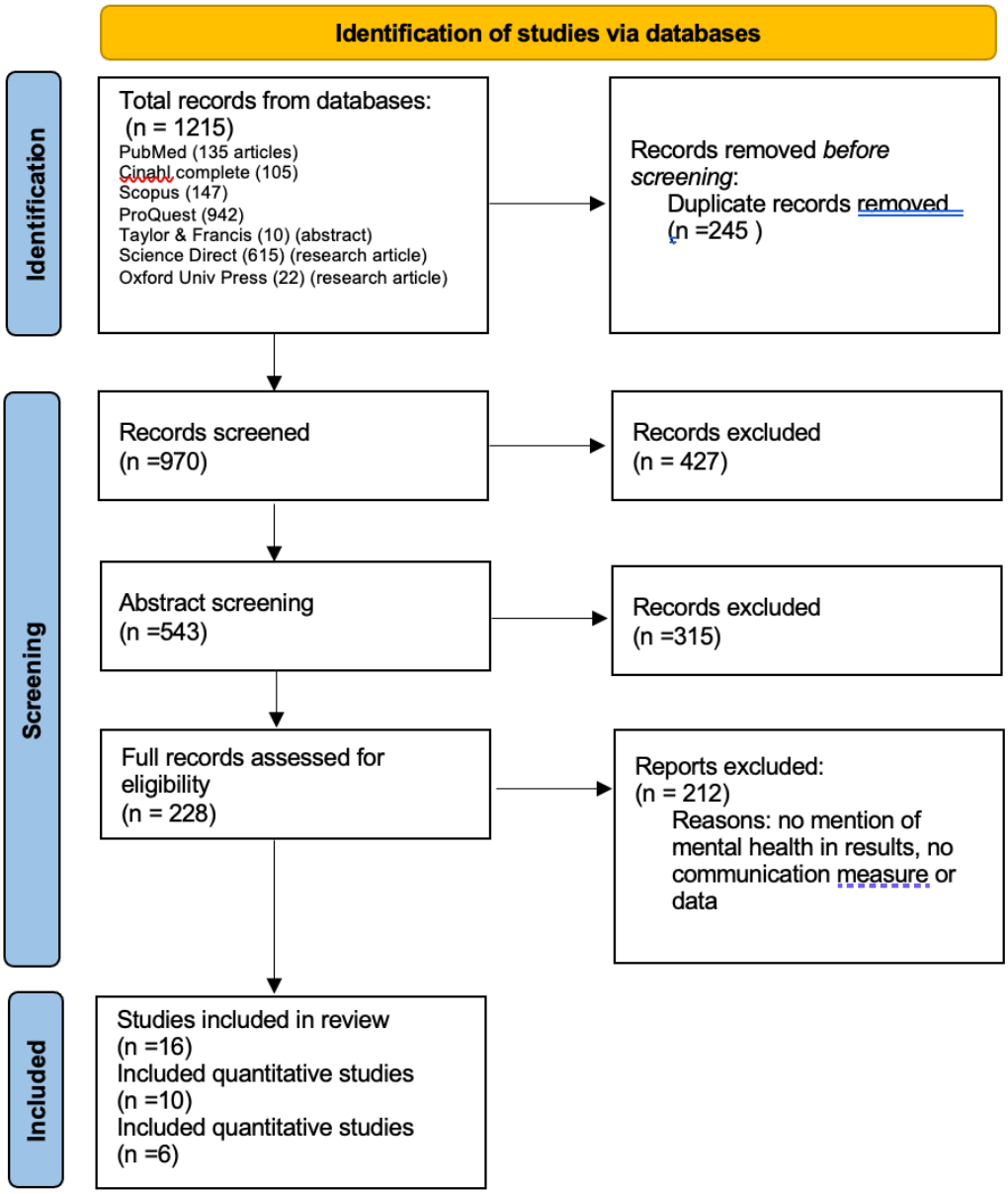



Figure 1: Adapted from: Page MJ, McKenzie, JE, Bossuyt, PM, Boutron, I, Hoffman, TC, Mulrow, CD et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews.

objective), any country. Exclusion criteria: Pediatric/adolescent population, articles that do not address communication.

***Search outcome***

Of the sixteen articles, ten were quantitative and six were qualitative. A mixed methods systematic review was chosen for article extraction. Mixed method systematic reviews are not only appropriate when the research question can be answered by both qualitative and quantitative studies, but should be advocated for as a means to present both types of evidence, as both are needed in practice and policy (Noyes et al., 2019). Two primary synthesis approaches, sequential and convergent, are used most often when a systematic review includes both qualitative and quantitative research (Hong et al., 2017). A sequential design is when one type of evidence informs the other in a sequential order whereas a convergent design is when both types of evidence are analyzed and reported together side by side (Hong et al., 2017; Noyes et al., 2019). This review implements a convergent design, allowing both the quantitative and qualitative findings to be extracted and synthesized throughout the review process (see figure 2) and follows the guidance of Noyes, et al. (2019).

***Quality appraisal***

All studies were assessed with the Mixed Methods Appraisal Tool (MMAT) for use in systematic reviews (Hong et al., 2018). The MMAT does not use an appraisal score, rather it encourages article quality details to be reported. MMAT appraisal details for the studies in this review are available upon request. Overall, many (nine of ten) of

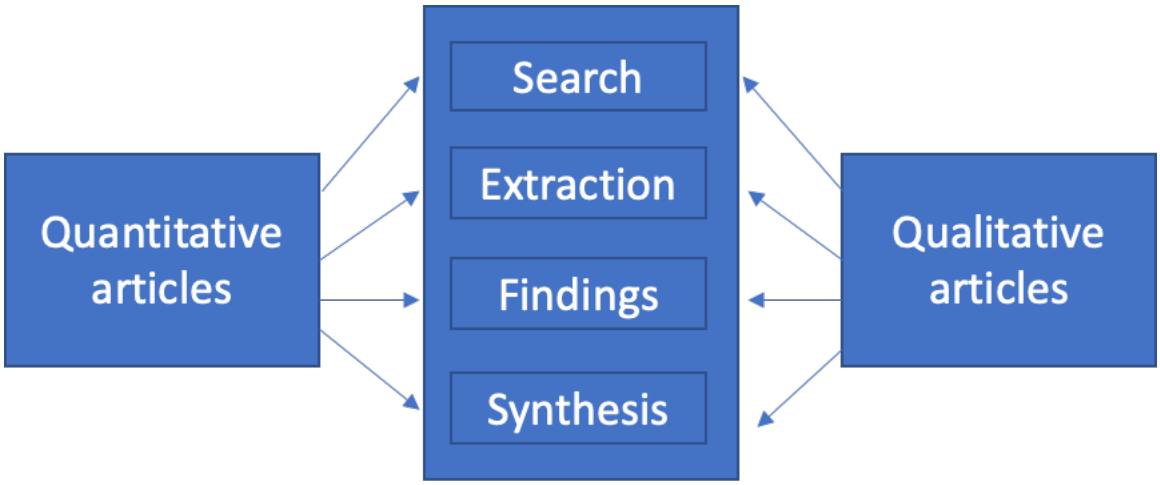



Figure 2: Convergent design

the quantitative articles had a high risk of non-response bias because of not addressing the unique communication needs of their research participants. By not addressing the variety of communication preferences that DHH participants have, researchers are unable to account for those that intentionally declined participation because they could not hear the method of data collection. For example, it is very likely that DHH would not respond to a research invitation in which data was collected over the phone. As DHH often have avoidant social behaviors because of fear of not hearing well, studies should find ways to increase accessibility (Johansson et al., 2019; Monzani et al., 2008) to reduce the risk of non-response bias. There was only one article that used a study with a large sample of DHH individuals intentionally to ensure accurate sampling (Anderson et al., 2018). Two additional articles acknowledged how methodology specifically impacts the response of the DHH population and indicated concern about the appropriateness of their methodology in the discussion or limitation section of three articles (Anderson et al., 2018; Palmer et al., 2016; Woodcock & Pole, 2007). The qualitative articles each addressed the communication preferences of their intended audience. However, the qualitative articles were less likely to have a clear theoretical framework. For example, five of the six qualitative articles did not identify a theory base for their research. Also, two of the six studies did not identify a qualitative methodology. Although study quality varied, each quantitative and qualitative study demonstrated sufficient quality to be included in this review.

### *Data extraction*

In the data extraction phase, a template provided in Noyes et al. (2019) was adapted to fit the inclusion and exclusion criteria of the current study. A spreadsheet, created in Google Sheets, listed extraction categories for qualitative and quantitative studies in different tabs. The completed spreadsheet is included in supplemental file S1. Extracted data included participant characteristics, country of study, operationalization of hearing loss, communication measures and questions and mental health outcome measures.

## RESULTS

### *Study characteristics*

Between the quantitative and qualitative studies, 16 were included in the final synthesis. Study characteristics are in Table 1.1 (in appendix). Sample sizes ranged from N=9 (Sheppard & Badger, 2010) to N=475 (P. Kushalnagar et al., 2018) in an all DHH sample and from N=742 (Palmer et al., 2016) to N=9,079 (Hogan et al., 2009) in the general population. Four studies that sampled Deaf participants who used sign language, eight sampled DHH through oral language (e.g. English), and four sampled both sign and spoken/written language. Four articles studied the elderly population, one looked at college students and all others at the general adult population. Most studies were done in the United States (ten), with two in Australia, and one each in Norway, Canada, Czech Republic, Western Cape and an International setting.

The results are reported in a *Results-based convergent synthesis design* (Hong et al., 2017) which means qualitative and quantitative data are first analyzed separately

(reported in Tables 1.2 and 1.3), and then merged in a third qualitative synthesis (Table 1.4). Tables 1.2-1.4 are in the appendix.

***Quantitative***

Of the ten quantitative studies (see Table 1.2), six measured communication barriers through asking questions about what is heard and not heard, two used communication standardized scales, and two used both audiometrics (hearing tests) and standardized scales. To determine mental health outcomes seven studies used standardized measures and three relied on unstandardized mental health related questions. Some of the studies identified mental health outcomes as mental health disorders whereas some identified mental health outcomes as psychosocial determinants of health. Mental health disorders associated with communication barriers were substance use, depression, and suicidal ideation. Psychosocial determinants of mental health associated with communication barriers were low quality of life, low self-esteem (if oral communication was forced), food insecurity, abuse or perpetration of abuse, loneliness, and mental distress. Some studies indicated that correcting hearing loss with audiological treatment (hearing aids or cochlear implants) became a protective factor for mental health conditions (Gopinath et al., 2011) whereas others indicate that forced oral communication (especially for DHH with a profound hearing loss) exacerbated mental health conditions (Jambor & Elliott, 2005; P. Kushalnagar et al., 2018).

***Qualitative***

Mental health outcomes (Table 1.3) of the six qualitative studies include anxiety, depression, decreased quality of life, lack of self-worth, abuse perpetration, and general

mental health problems. All studies identified communication barriers through coding participant interviews.

***Convergent Synthesis***

Table 1.4 reports the results of the merged analysis between the quantitative and qualitative studies. To analyze and extract the merged data, these five steps were followed:

1) Identification of codes apriori were based on quantitative and qualitative extraction findings.
2) All 16 articles were downloaded into the Dedoose qualitative analysis software system.
3) Concept coding (Saldana, 2021) was done on the abstract, results, and implications sections of all articles in Dedoose using the matrix codes from step 1. During analysis, additional codes emerged and were incorporated into the coding process.
4) Codes were merged into five themes: specific communication barriers, mental health psychosocial factors, mental health interpersonal factors, mental health disorders, and access to integrated care/treatment.
5) A table was created to report main findings and associated illustrative quotes (from qualitative studies) or relevant text (from quantitative studies).

Several unique findings emerged during the convergent synthesis. The concept of "communication barrier" was organized under the socio ecological systems model (Bronfenbrenner, 1977). Intrapersonal communication barriers included communication avoidance and listening fatigue. Interpersonal communication barriers included a lack of consideration from the communication partner and a lack of audible clarity. Systemic communication barriers included ableism and linguistic neglect. Another finding was the lack of accessible mental health treatment options due to a dearth of ASL-fluent mental health professionals, an audiological medical model treatment system, and a lack of information. A third finding is the recommendation from several authors to address the inaccessibility of mental health treatment through creating interdisciplinary partnerships

between audiology and mental health professionals as well as integrating care beyond audiological rehabilitation.

## DISCUSSION

To understand the relationship of hearing loss-related communication barriers on mental health for DHH, this systematic review examined sixteen studies in detail. Results confirm that communication challenges are associated with negative mental health outcomes. However, the lack of considering communication needs of DHH in research studies, the lack of standardized measures to assess communication barriers as well as the lack of theoretical framework for the studies do prevent the ability to draw strong conclusions.

Individuals with hearing loss are diverse and have unique communication needs in research studies. It is critical that researchers are familiar with communication needs of the DHH and are able to create research studies that have these needs in mind (Rhodes & Weiss, 2013; Singleton et al., 2014). For a DHH study to be ethically sound, researchers should conceptualize how communication impacts every aspect of a study from design, informed consent, recruitment to data collection. For example, for participants who use sign language, informed consent and recruitment materials should be offered in sign language, not written English (or the dominant spoken language) (McKee et al., 2013; Singleton et al., 2014). Participants should be asked for their communication preference (e.g. sign language, written English, oral English, in person with real time captioning, etc.) with the researchers understanding that this question alone is not enough to determine the reliability of communication (Young & Hunt,

2011). Research studies that rely on phone call surveys should keep in mind that they are automatically going to lose representation among DHH participants (Anderson et al., 2018).

There are multiple different communication barriers for individuals with hearing loss. Yet, only a small handful of standardized measures were used to identify specific communication barriers in this review. The measures used include: The Hearing Handicap Inventory (HHIE-S) which measures perceptions of communication limitations (Ventry & Weinstein, 1983); Social Disengagement Index (SDI) which measures participation in recreational social activities (Bassuk et al., 1999); and the interRAI-Home Care Assessment (RAI-HC; 37) which measures social and family interactions. Most quantitative studies relied on unvalidated questions about communication. Additional measures to be considered when assessing communication barriers include the Speech Intelligibility Index (Janssen, 1957), Communication Profile for the Hearing Impaired (Demorest & Erdman, 1986), or the Abbreviated Profile of Hearing Aid Benefit (Cox, 1997).

Multiple standardized measures were used to identify mental health outcomes. Findings of the quantitative studies show that DHH are more likely to be heavy drinkers and cannabis users, be depressed, and have a lower quality of life (although this is partially corrected with successful hearing aid use in some participants) than hearing participants. One study looked at multiple different disabilities during the COVID pandemic (Okoro et al., 2021) and found that those with any disability were more likely to report current mental stress, depressive symptoms, substance use and suicidal ideation

as compared to able-bodied individuals. Those with hearing loss were 23.8% more likely to experience depressive symptoms and 23.3% more likely to experience suicidal ideation than those with no hearing loss. In addition, DHH were 20.06% more likely to have initiated or increased substance use during the pandemic than those who do not have hearing loss. As more COVID-related research findings become available, the trend will likely consistently indicate that the higher level of stressors associated with having a disability will negatively impact mental health.

The aspects of communication that impacted mental health status in this review include communication fatigue (Kushalnagar et al., 2014), not feeling included (Kushalnagar et al., 2014) inability to pick up side conversations (Kushalnagar et al., 2018), not hearing conversations, avoidant communication strategies (Williams et al., 2015), lack of shared language (Kushalnagar et al., 2018), and covering (Jambor & Elliott, 2005). Some communication needs are about acceptance of limitations (Kushalnagar et al., 2014) and preparing oneself for the listening environment (Kushalnagar et al., 2014) but they were also systemic communication challenges. These include DHH being expected to educate everyone they try to communicate with and being expected to communicate first in order to help hearing people feel more comfortable (Kushalnagar et al., 2014).

### *Implications*

Multiple studies recommend that mental health providers become culturally aware of DHH needs, increase communication access in treatment and work towards integrating behavioral health with medical and audiological services (Chang et al., 2020;

Gopinath et al., 2012; Jambor & Elliott, 2005; P. Kushalnagar et al., 2014; Steinberg et al., 1998; Williams et al., 2015). Viewing a person with hearing loss as a whole person, with integrated care, can help bridge some of the gaps between barriers and mental health impact. Instead of sending an individual to an ENT for physiological diagnosis, an audiologist for hearing intervention, and a therapist for psychosocial or mental health care, DHH may be better served through coordinated efforts between professionals or even a restructuring of service delivery to receive all of these services in one place. This can address the confusion, the stressors and the lack of access.

Another necessity to bridge the gaps between communication and mental health is to increase education efforts, teaching individuals with hearing loss to advocate for themselves in changing ableist systems that continue to construct listening environments for only hearing people. There are multiple ways, some of them being very simple and cost effective, to increase communication access in a world that has a large percentage of individuals with hearing loss. Education is also essential in increasing awareness of and treating mental health conditions.

This article is being prepared under the conditions of the global COVID pandemic, which has introduced yet another communication barrier for DHH, masking. Further research is needed to determine the impact of masking on the mental health needs of DHH, as well as other communication barriers. Research is also needed on the barriers to integrate services for DHH across professionals.

### *Limitations*

To decrease bias, systematic reviews are often conducted with a research team that provides a checks and balances system. As this manuscript was prepared to fulfill dissertation requirements, all the steps were conducted by a single researcher. Due to this solo project, bias could exist. To overcome this bias, the manuscript is being rigorously reviewed by multiple committee members. In addition, the author's positionality is included below to ensure transparency.

Another limitation of this mixed methods systematic review is there were only quantitative and qualitative studies to review, no mixed method studies that met inclusion criteria. Because mixed methods is a unique methodology, ideally, reviews should include studies that were conducted with a mixed methods design. However, mixed methods studies are a relatively new methodology approach and it is not surprising that the systematic review of the literature did not yield any mixed studies.

## POSITIONALITY

The epistemological and ontological belief systems I operate from are the pragmatic and dialectical pluralism frameworks. I identify as a deaf, but sometimes Deaf individual. I exist some in the hearing world, some in the deaf world, and a little bit in the Deaf world, yet I also exist in none of them. Hearing loss is often described as being "between worlds." That's often where I fit. Most of my family members have hearing loss to some degree, which likely has contributed to multiple mental health complications across my extended family. As a first-generation college student working

on my Ph.D and as a clinical social worker, I hope to stop the negative intergenerational cycles that have so pervasively impacted my family.

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# APPENDIX 1

***Tables***

Table 1.1 Study Characteristics

| **Authors (Year)** | **Type of study/ target pop-ulation** | **Coun-try** | **Participants** | **Communication method of data collection** | **Operation-alization of hearing loss** |
|---|---|---|---|---|---|
| Anderson, M. L., Chang, B. H., & Kini, N., 2018 | Quant-Cross-sectional / General pop-ulation | United States | *N*= 4,139 18-59 years old; 133 (3.3%) DHH; 63% male, 70% non-Hispanic white | Interviews in homes and mobile health clinic | Self-identified |
| Gopinath, B., Schneider, J., Hickson, L., McMahon, C. M., Burlutsky, G., Leeder, S. R., & Mitchell, P. 2012 | Quant-Cohort longit-udinal General pop-ulation | Austra lia | *N*=829 599 (no HL*); 230 (HL) Mean age 64.3 NHL**, 69.8 HL; Male 37.7% NHL, 51.3 HL; lives alone 19.7 NHL, 23.5 HL | In person interview | Audio-metric evaluation |
| Hogan, A., O'Loughlin, K., Miller, P., & Kendig, H. 2009 | Quant-Cross-sectional General pop-ulation | Austra lia | *N*=43,233 *(weighted)* Age 55+ 9079 N (gender not disclosed) | In person interview | Self-identified |
| Jambor, E., & Elliott, M. 2005 | Quant-Cross-sectional DHH | United States | *N*=78 64% female; 46% white; age 19-48; all students | Self-administered (location unknown) | Self-identified |

Table 1.1 continued

| **Authors (Year)** | **Type of study/ target pop-ulation** | **Coun-try** | **Participants** | **Communication method of data collection** | **Operation-alization of hearing loss** |
|---|---|---|---|---|---|
| *Kushalnagar, P., Moreland, C. J., Simons, A., & Holcomb, T.* 2018 | Quant-Cross-sectional Deaf | United States | *N*=475 18-95 years old; primary language ASL (gender not disclosed) | Web based | Self-reported ASL user |
| Okoro, C. A., Strine, T. W., McKnight-Eily, L., Verlenden, J., & Hollis, N. D. 2021 | Quant-Cross-sectional Disabled | United States | *N*=1004 51.7 female; 49.8 age 35-64; 39.5 HS educated; 54.4 employed; 53.8 married/couple | Web based | Self-identified |
| Palmer, A. D., Newsom, J. T., & Rook, K. S. 2016. | Quant-Cohort longi-tudinal General pop-ulation older adults | United States | *N*=742 Mean age 74.91; 62% female; 52% married; 84% white | In person interview | Self-identified or observation of interviewer |
| Williams, K. C., Falkum, E., & Martinsen, E. W. 2015 | Quant-Cross-sectional DHH | Norwa y | *N*=105 Mean age 54.9; 61.3% female; 81% college educated | In person hospital | Previous documented audiometric measures |

Table 1.1 continued

| **Authors (Year)** | **Type of study/ target pop-ulation** | **Coun-try** | **Participants** | **Communication method of data collection** | **Operation-alization of hearing loss** |
|---|---|---|---|---|---|
| Woodcock, K., & Pole, J. D. 2007 | Quant-Cross-sectional General pop-ulation | Canada | *N*=131,535 *weighted* 4% of sample HL*; 4.52% Male; 3.53% female (N=5,256) | Interviews, phone | Questions on what is heard and not heard |
| Yamada, Y., Švejdíková, B., & Kisvetrová, H. 2017 | Quant-Quasi-Exper-imental DHH | Czech Republic | *N*=105 Age 60-90; 49% female | Self-administered in hospital | Audiometric evaluation |
| Chang, P. F., Zhang, F., & Schaaf, A. J. 2020 | Basic quali-tative DHH | International | *N*=52 Aged 18-69; U.S, Germany, UK, Australia; 36 female | Interview over the phone or skype | Self-identified |
| Kushalnagar, P., McKee, M., Smith, S. R., Hopper, M., Kavin, D., & Atcherson, S. R. 2014 | Grounded theory quali-tative DHH | United States | *N*=19 Age of onset of HL- 0 to 5; 63% female; 37% Asian/PI, 37% White; 68% bachelor's or above; 53% English lang; Mean of 6 for self rated functional communication skills (range (0-10); 42% use hearing aid; 42% northeast U.S. | Video conferencing in ASL or English based on participant preferences; administered by research members fluent in ASL and English. 50-60 minutes recorded interview | Self-identified |

Table 1.1 continued

| Authors (Year) | Type of study/ target pop-ulation | Coun-try | Participants | Communication method of data collection | Operation-alization of hearing loss |
|---|---|---|---|---|---|
| Mall, S., & Swartz, L. 2012 | Frame-work approach qual-itative<br><br>DHH | Wester n Cape & Gaute ng | *N*=21<br>5 hearing, 3 Hoh, 13 d/Deaf 9 female, 8 male, 4 unknown gender; 8 working with DHH for over 10 years | Interviews conducted in English; with SASL interpreter if needed for the Deaf | Self-identified |
| Mastrocinq ue, J. M., Cerulli, C., Thew, D., Chin, N. P., & Pollard, R. Q. 2020 | Commun -ity based partici-patory qual-itative<br><br>Deaf | United States | *N*=15<br>14 deaf and 1 HOH; 10 males, 7 White, 4 mixed race; 8 unemployed; 8 some college; all use sign; 13 hearing parents | All in ASL over video meeting (all interviews recorded) | Self-identified |
| Sheppard, K., & Badger, T. 2010 | Hermen-eutic phenom-enology Deaf | United States | *N*=9<br>2 men, 7 women; ages 21-65; born to hearing parents; | All in ASL over video meeting (all interviews recorded) | Self-identified ASL user |
| Steinberg, A. G., Sullivan, V. J., & Loew, R. C. 1998 | Grounde d theory quali-tative Deaf | United States | *N*=54<br>23 men, 31 women; 82% Caucasian; 91% identify as deaf; age of onset of HL before age 6 for 80%; 43% postsecondary education; aged 18-78 | Individual and group interviews conducted in ASL in schools, homes and churches | Self-identified ASL user |

Table 1.2 Quantitative findings

| **Author(s)** | **Communication Measure/Questions** | **MH Outcome Measure** | **Statistical Results** |
|---|---|---|---|
| (Anderson et al., 2018) | Are you deaf or do you have a serious difficulty hearing? (Taken from Disability questionnaire) | First use, lifetime use, regular use of alcohol | DHH respondents had almost 3 times higher rate of heavy drinking than hearing respondents (33% vs. 12%, p = 0.002). Controlled for gender, race, age and education (adjusted OR = 2.5, 95% Confidence Interval [CI] = 1.51 to 4.20, p = 0.0004). |
| (Gopinath et al., 2011) | Hearing handicap inventory for the Elderly- Shortened version (HHIE-S) (Ventry & Weinstein, 1983) | 36-Item Short-Form Survey (SF-36) for well-being (Ware J & Sherbourne, 1992) | DHH had lower mean scores on SF-36 compared to those with no hearing loss at baseline 10 years later (multivariable-adjusted p = 0.03). It is self-perceived hearing handicap in older adults (not measured uncorrected hearing impairment) that was negatively associated with quality of life. However, for those who used hearing aids, they had a significant improvement in quality of life, vitality subscales in the SF-36 |

Table 1.2 continued

| Author(s) | Communication Measure/Questions | MH Outcome Measure | Statistical Results |
|---|---|---|---|
| (Hogan et al., 2009) | 1- Impairment level 2- Disability (if self-selected difficulty with communication or used a HL device) | 12-Item Short-Form Survey (SF-12) Quality of Life (Ware et al., 1996) | For those who indicated presence of communication challenges they had lower quality of life in the physical health and mental health scores. Those 75 or older had 15% lower mental health quality of life scores. 65–74-year-olds had 7% lower mental health scores. Those we were 55-64 HL scored 9% lower than gen pop on mental health quality of life. |
| (Jambor & Elliott, 2005) | Questions about communication method, type of schooling prior to college, degree of HL, age of onset, and group membership 6 item Ellemers scale (Ellemers et al., 1993) | Coping strategies scales created after focus group= withdrawal, covering, bicultural skills with a 4-point response scale. Self-esteem- Rosenberg Self-Esteem scale (Rosenberg, 1965) | Self-esteem and withdrawal were significantly correlated with ethnicity, identity with Deaf Culture, severity of hearing loss (aided), and communication at home. For those that did not sign but were forced to use oral communication may feel further isolated. |

Table 1.2 continued

| Author(s) | Communication Measure/Questions | MH Outcome Measure | Statistical Results |
|---|---|---|---|
| *(Kushalnagar et al., 2018)* | Set of retrospective communication items | Questions taken from US household food security survey and about being previously diagnosed with depression or anxiety disorders. | Retrospectively, Deaf adults who indicated very little understanding of what their parent/caregiver said during their childhood were five times more likely to experience to "often" experience food insecurity as an adult (partial r = 0·15; P < 0·001). |
| (Okoro et al., 2021) | Are you deaf or do you have a serious difficulty hearing? | Disability status; Patient Health Questionnaire-8 (PHQ-8) (Kroenke et al., 2009); frequent mental distress; depression, substance use questions; psychosocial distress questions | Adults who reported having any disability were significantly more likely than adults who reported no disability to have current depressive symptoms, frequent mental distress, suicidal ideation, and COVID-19-related initiated or increased substance use (all p values < .0001).<br><br>For hearing disability compared to hearing, rates of depressive symptoms, mental distress, suicide ideation, increased substance use we all higher. |

Table 1.2 continued

| Author(s) | Communication Measure/Questions | MH Outcome Measure | Statistical Results |
|---|---|---|---|
| (Palmer et al., 2016) | Social disengagement index (Bassuk et al., 1999); relationship characteristics, communication score; Frequency of positive and negative social exchanges (Newsom et al., 2003) | UCLA Loneliness scale (Russell, 1996) | Those with communication disorders had significantly higher loneliness scores than those without communication disorders ($p < 0.001$). |
| (Williams et al., 2015) | Audiometric documentation; Subjective disability perspective; Conversation Tactics Checklist (CONV) (Hallam et al., 2007) | Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983); Fear of Negative Evaluation Scale (FNE) (Watson & Friend, 1969) | Depression symptoms accounted for avoidant communication approaches and fear of being negatively evaluated 41.7%, $F(5, 93) = 13.32$, $p = .000$. |
| (Woodcock & Pole, 2007) | Hearing problem-what is heard and not heard | Questions about depression symptoms | Those with hearing problems are more likely to report higher rates of depression (OR=1.59) |
| (Yamada et al., 2017) | interRAI-Home Care Assessment (RAI-HC37); Pure-tone average audiometric | World Health Organization Quality of Life Assessment- Old Module (WHOQOL-OLD) (Power et al., 2005) | WHOQOL-OLD scores increased for older people who had more social relationships and who used hearing aids for a longer time each day (crude model, $p = 0.046$; adjusted model, $p = 0.024$) |

Table 1.3 Qualitative findings

| Author | Main findings | Relevant themes |
|---|---|---|
| (Chang et al., 2020) | Those who have single-sided deafness (SSD) indicated challenges with less autonomy, increased dependence on others, less communication with family, discrepancy of information in family, and multiple emotional reactions that they were not prepared for. | 1.Family members are a critical component to the quality of health care during and after SSD diagnosis<br><br>2.Disparate, disconnected, and hard to reach medical professionals |
| Illustrative quotes:<br>1."I feel like a totally different person since I have been diagnosed with SSD. My whole life I was so independent and I never asked for help. I was really depressed after I lost my hearing in my left ear because I had to rely on and ask my family to do everything for me. It's gotten better but I still have to ask them to repeat things that other people have said or order for me at restaurants. Even basic house things like picking up the phone? I have to ask them to do that. I feel helpless and not helpful around the house." (p. 533)<br><br>2."Patients with SSD expressed a need for social, emotional, and psychological help. For example, Sasha, who has been SSD for 2 years, P17, expressed her frustration about having to reach out to so many health professionals before having access to psychological help, specifically related to her hearing loss. She expressed the myriad of emotions she experienced post diagnosis and the need for a therapist but the difficulty of getting access to one." (p.534) | | |
| (Kushalnagar et al., 2014) | Characteristics that influence how quality of life (QoL) is viewed among DHH adults are lifestyle factors like advocating for yourself and accepting yourself, and receiving intervention from audiologists as well as communication ability | 1.Health status: self-acceptance, coping with limitation<br><br>2.Intrinsic theme: functional communication skills, navigating barriers, persistence/ resilience<br><br>3.Extrinsic themes: acceptance by others, accessibility, social participation, educating others |

Table 1.3 continued

| Author | Main findings | Relevant themes |
|---|---|---|
| Illustrative quotes:<br><br>1."I accepted myself a long time ago. This was helpful. So, as a hard-of-hearing person, you have to empower yourself to accept yourself regardless of what happens in life. You have to use whatever makes you comfortable to communicate with others to have a good QoL." (p.352)<br><br>2."You can't always hear everything. You need to find a way to ask people to repeat what they said and to search for information before you go in a meeting or appointment. This preparation will help you interact with hearing people better. It is important to research for information well in advance before going in any new situation. You also need to compromise or be flexible. Sometimes it feels like you have to do extra steps before going in such situations. So, yes, I think being hard of hearing does have an impact on QoL. If I did not have access to information, then my quality of life is not optimal, you know.''<br><br>3."If that hearing person is open-minded and curious, you will feel comfortable explaining about deaf issues. If that person seems impatient, I feel like you shouldn't bother explaining. Just find someone else to talk to." (p.354) | | |
| (Mall & Swartz, 2012) | Findings from the members of DHH HIV/AIDS organizations indicate that communication barriers increase risk of HIV/AIDS and mental disorders for DHH individuals | 1.Participants' perceptions of mental health issues in the d/Deaf and hard of hearing community<br><br>2. Intersections in HIV/AIDS and mental health: the role of organizations for people who are d/Deaf and hard of hearing in South Africa |

Table 1.3 continued

| Author | Main findings | Relevant themes |
|---|---|---|
| Illustrative quotes:<br><br>1."It's a bit of a dichotomy or a bit of a strained relationship when one thinks that deafness causes mental health—or again, [that] the lack of relationships, the lack of language, cause mental health issues, and that mental health issues in deafness should really be avoidable. But de- pression, anger, and anxiety—I don't know i would go as far as...condi-tions, you know, such as schizophre-nia and serious clinical conditions, but I do think the prerunners, the precursors, of many of the serious conditions are found in lack of initial love and understanding, love and ac-ceptance (even if it's only perceived by the deaf person), and a lack of communication, a lack of self- worth—all of those issues can lead to the later conditions, and not neces-sarily because of the deafness per se." (p. 496)<br><br>2."Naturally, mental health issues will arise whenever HIV/AIDS is a factor. And that is not hearing-specific phenomenon; it is as much a deaf phenomenon as it is a hearing phenomenon, and the issues are the same. Access to antiretrovirals may not be as easily obtained for the Deaf community, not because they are inherently different, but because they may not be aware that they have the right to access antiretroviral medication or the right to access counseling services, or that any such services even exist. Trained psychiatrists, trained health professionals who are familiar with the Deaf community and how to communicate with the culturally Deaf person, are few and far between. It's a whole new area for the mental health fraternity." (p. 497) | | |
| (Mastrocinque et al., 2020) | Findings indicated that IPV (intimate partner violence) among DHH have unique factors, not associated with general hearing IPV or common interventions. The relationship between types of abuse, injuries, and how systems are accessed were identified. | 1.IGT (intergenerational transmission) of violence<br><br>2.Fund of information<br><br>3.Communication barriers and resulting frustration<br><br>4. Help-seeking |

Table 1.3 continued

| Author | Main findings | Relevant themes |
|---|---|---|
| Illustrative quotes:<br>1.“Really I think that was from my family background . . . I learned most of that behavior from my mom. . . . When I was a kid my mother . . . would abuse me and that’s exactly the behavior I then applied to my ex. I think it’s from kids’ bad experiences. You grow up with it and it sticks with you, you know, and then you transfer it on to someone else and do the same thing. So, I think that hair pulling thing came from my mother.” (p. 12)<br><br>2.I learned everything . . . about relationships from my parents. I saw the things that they did with one another, but I was never privy to their conversations. I saw that my mother cooked for my father, so I cooked for my husband, but I didn’t know how to interact. I knew I had a lot of wants, and I acted out to get what I wanted. I’ve done a lot of research on my own<br>behavior and other people’s behavior in criminal justice, and now I understand what deaf people lack in so many ways because of their language deprivation. (pp. 12-13)<br><br>3.“My mother was impatient because she couldn’t just call my name when I was in another room . . . She wanted to call me but I couldn’t hear her. I didn’t have a hearing aid at that time so of course I couldn’t hear her call me, and she would get mad. She was so impatient. She would take a light, . . . She threw it at me . . .” (p. 13)<br><br>4.“. . . it just costs too much money to involve the police . . . we should work it out in the family.” (p. 14) | | |
| (Sheppard & Badger, 2010) | Communication challenges led to increased depression and lower level of self worth. Each indicated that mental health care is inaccessible. | 1.Early emotional chaos<br><br>2.Feeling depressed<br><br>3.Reaching out<br><br>4.Deaf-belonging |

Table 1.3 continued

| Author | Main findings | Relevant themes |
|---|---|---|
| Illustrative quotes:<br>1."All the participants described early childhood losses, traumas and emotional distress that preceded their depressive symptoms. Narratives were often accompanied by tears, emphatic hand gestures and facial expressions. Many stories were expressed with anger as noted in facial expressions and body language. Most participants turned to their parents for comfort when feeling fear, pain or angst during childhood. Rarely did the parent meet the child's needs because there was no common means of communication. Parents had not learned ASL, were unwilling to learn ASL and most expected the child to learn to lip-read." (Direct quote from the authors as no participant quote available) (p. 785)<br><br>2."All participants experienced typical physical, emotional and cognitive manifestations of depression. Additional descriptions included anger, sadness, loss of interest, indecisiveness, low self-esteem, guilt and feeling depleted. Joan's depression feels like 'a black cloud in my mind'." (Direct quote from the authors as no participant quote available) (p. 786)<br><br>3."All shared their desire for help, but were unsure how to reach out. Health care was described as embarrassing and frustrating. While all prefer to have an interpreter present for most health care, eight expressed that an interpreter was unwelcome when seeking mental health. For example, Sean sought counselling when suicidal, but did not want any interpreter in the community to know because of stigma. The Deaf community is small and close-knit, and interpreters and Deaf adults usually know one another." (Direct quote from the authors as no participant quote available) (p. 786)<br><br>4."Hearing people think, you're Deaf, you're broken –you're used goods, and, you can't have expectations because you're Deaf." (p. 786) | | |
| (Steinberg et al., 1998) | Study participants indicated that mental health problems are caused by external factors such as communication, systemic issues, family dynamics, and how parents raise DHH children. | "Recurrent themes included mistrust of providers, communication difficulty as a primary cause of mh problems, profound concern with communication in therapy, and widespread ignorance about how to obtain services." (p. 982)<br>(Themes not individually reported) |

Table 1.3 continued

| Author | Main findings | Relevant themes |
|---|---|---|
| Illustrative quotes:<br>"That the participants so frequently cited communication difficulty as a primary cause of mental health problems points to its magnitude in the deaf experience. Attribution of mental health problems to communicative isolation or isolation during childhood further reinforces this point." (Themes not individually reported; quote from authors as no participant quotes provided) (p. 984)<br><br>"The participants viewed both mental health institutions and practitioners as authoritarian, restrictive, and prejudiced. Some signed "mental hospital" by using PRISON, STRAIGHT-JACKET, or CRAZY-HOUSE (the capitalized words represent English glosses of the American Sign Language vocabulary used by participants). One woman shrugged, "From a deaf person's point of view, they [jail and mental hospital] are the same." (Themes not individually reported; quote from authors as no participant quotes provided) (p. 983) | | |

Table 1.4 Synthesized findings

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Communication barriers that influenced mental health** | | |
| Intrapersonal/ Individual<br><br>(Listening fatigue, active listening avoidance, unfamiliar context) | "These strategies require expending more efforts than a typical student or employee who is hearing. Constantly putting in 'extra effort' and 'working harder' to gain better access to information risks mental and communication fatigue, which can place a toll on deaf people's health status as well as their academic and/or work productivity." (Kushalnagar, 2014)<br><br>"Even with a slight hearing impairment, an individual would still have to make assumptions to fill in holes, overcome the speech-in-noise barrier to comprehension, and direct attention more elaborately than if their hearing functioned normally. Individuals with unilateral or slight hearing impairment do not necessarily experience the same negative consequences in terms of reduced access to information as those with more severe hearing impairments, but being burdened with the continuous labor of compensation may lead to the same level of fatigue." (Williams, 2007) | Williams, Jambor Mastro-cinque |

Table 1.4 continued

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Communication barriers that influenced mental health (continued)** | | |
| Interpersonal:<br><br>(Lack of consideration from communication partner, limited audibility) | "I think this has a lot to do with the language and the emotions that I experienced while I was growing up. I didn't have the language to tell my parents what I was experiencing, but I was getting picked on and bullied." (Mastrocinque, 2020)<br><br>"Communication barriers often make it difficult for Deaf patients to even discuss their symptoms of depression with nurses and other healthcare providers. Therefore, few Deaf patients receive appropriate treatment for their depression." (Sheppard, 2010) | Kushal-nagar 2018 Jambor, 2005 Mastro-cinque, 2020<br><br>Hogan Palmer Okoro Anderson Sheppard, 2010 |
| Environment/ Community:<br><br>(Poor listening acoustics in environment, reduced access to side conversations or background discussions) | "People gather much information from ambient discussions, for example, a conversation parents are having in another room to solve a conflict, or, information one receives from a television in the background. In situations where a child is deaf, the child is unlikely to learn information not directly communicated to the child, for example, how to peacefully solve a conflict." (Mastrocinque, 2020)<br><br>"Further, deaf people who experienced communication difficulties or reduced access to incidental information (e.g. overhearing conversations; hearing comments on the radio) earlier in life may not have the necessary background knowledge to accurately interpret." (Kushalnagar, 2018) | Hogan<br><br>Kushal-nagar 2018 Mastro-cinque Hogan Palmer Okoro Anderson |

Table 1.4 continued

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Communication barriers that influenced mental health (continued)** | | |
| Systematic barriers<br><br>(Ableism, linguistic neglect, communication intentionally withheld) | "Those who are able to get along well in both the Deaf and the hearing worlds tend to have higher self-esteem. These deaf individuals can take pride in their achievement in the dominant society but can also rely on the support they can get from the community of similar others. This is an important finding since it suggests that the endeavor to integrate deaf people into the majority society is a positive effort, but only if these individuals can keep their ties to the Deaf world for emotional and social support." (Jambor, 2005)<br><br>"Many participants reported the burden of constantly or frequently having to educate others about being deaf." (Kushalnagar, 2014)<br><br>"That the participants so frequently cited communication difficulty as a primary cause of mental health problems points to its magnitude in the deaf experience. Attribution of mental health problems to communicative isolation or isolation during childhood further reinforces this point. To be effective, mental health professionals must not reenact this experience with deaf patients." (Steinberg, 1998) | Kushal-nagar 2018, 2014<br>Mastro-cinque<br>Steinberg |

Table 1.4 continued

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Mental health psychosocial factors** | | |
| (Quality of life, self-esteem, coping, food security) | "As expected, those with a greater hearing loss have higher self-esteem, we suspect because they are less likely to deny their hearing loss and more likely to be accepting of themselves. Instead of trying to remedy their deafness through surgeries and hearing aids, they focus instead on ways to succeed both professionally and personally within their given circumstances. On the other hand, those with some residual hearing may feel torn between two worlds; they are not deaf but they are also not hearing, and their constant search for a clear-cut self-concept may take a toll on their self-esteem." (Jambor)<br><br>"Respondents who used hearing aids reported better health-related quality of life than those who did not. Nonetheless, hearing aid users still reported poorer health-related quality of life to that of the population. Proportionately, hearing aid users scored one third lower than the population on the physical health scale and 13% lower on the mental health scale." (Hogan)<br><br>"Samantha, who has been SSD for 5 years,P15,stated that she went from being able to do everything to being able to do nothing herself, which decreased her sense of autonomy." (Chang) | Kushal-nagar 2014, 2018<br>Yamada<br>Gopinath<br>Hogan<br>Chang<br>Palmer<br>Jambor<br>Okoro |

Table 1.4 continued

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Mental health interpersonal factors** | | |
| (Abuse, family & social relationships) | "He attributed the anger, sadness, embarrassment, confusion, and frustration to how much they do not know about [single sided deafness] and the lack of empathy they had for him because of their lack of knowledge." (Chang)<br><br>"Sexual and physical abuse occurred, and the Deaf individual never knew how to obtain assistance. The Deaf children grew up feeling defective. As adults, the Deaf individuals were stared at or laughed at. Many felt hopeless and attempted suicide as a way to escape." (Shepperd)<br><br>"In the current study, not only was CD a significant predictor of loneliness, it also significantly predicted fewer frequent positive social exchanges. This finding suggests a decline in both the quantity and quality of positive social relationships." (Palmer) | Okoro<br>Mastro-cinque<br>Palmer<br>Kushal-anger 2018 |
| **Mental health disorders** | | |
| (E.g. Depression, suicide ideation, substance use) | "Respondents reporting hearing problems were significantly more likely to report …. depression compared with respondents not reporting hearing problems." (Woodcock, 2007)<br><br>"Adults with any disability were significantly more likely than adults without disability to report current depressive symptoms, frequent mental distress, suicidal ideation, and COVID-19-related initiated or increased substance use." (Okoro, 2021)<br><br>"D/HH respondents were more likely to have been regular cannabis users and heavy alcohol users than hearing respondents. In other words, when D/HH individuals use substances, they tend to be heavy users." (Anderson) | Okoro<br>Sheppard<br>Woodcock<br>Williams<br>Kushal-anger 2014<br>Anderson<br>Mastro-cinque |

Table 1.4 continued

| Theme | Illustrative quote or relevant text | Contributing studies |
|---|---|---|
| **Access to integrated care/treatment** | | |
| (Lack of ASL fluent providers, lack of knowledge, lack of acknowledgement from medical providers) | "While auditory habilitation typically focuses on hearing-specific treatment to reduce impairment (i.e., speech training; cochlear implantation), our findings suggests that the emphasis in managing the deaf patient's treatment plan should be placed on intrinsic context to promote a healthy foundation for the deaf person to be willing to maximize his/her own functional communication skills, navigate through barriers, and persist through challenges while maintaining resilience." (Kushalnagar, 2014)<br><br>Findings demonstrate the need for the programs and services to consider not only factors intrinsic to the deaf individual but also extrinsic factors in enhancing perceived quality of life outcomes among people with a range of functional hearing and language preferences, including American Sign Language." (Kushalnagar, 2014)<br><br>"Our findings also suggest that addressing hearing handicap could be a valuable public health strategy to prevent a decline in health-related QoL among older adults." (Gopinath)<br><br>"Mental health providers should be cognizant of their prevalent negative images within the deaf community. One cannot gain a client's cooperation without an awareness of culturally based fears that the client may bring to the interaction." (Steinberg) | Steinberg, 1998<br>Sheppard, 2010<br>Kushal-nagar, 2014<br>Gaponath, 2012 |

# CHAPTER 2

# THE RELATIONSHIP OF METACOGNITION ON MASKING RELATED DEPRESSION AND ANXIETY FOR INDIVIDUALS WITH HEARING LOSS DURING THE COVID-19 PANDEMIC

## ABSTRACT

Individuals who are d/Deaf or hard of hearing (DHH) faced dual challenges in the COVID-19 pandemic: Understanding and avoiding the virus as well as overcoming the significant increase of communication barriers that masking and social distancing brought. This study explored how masking impacted the mental health of DHH through utilizing a web-based cross-sectional survey during pandemic masking. Of the 190 respondents, 144 participants were included in the descriptive statistics and regression analyses. Results indicate that communicating in masked environments decreased listening comprehension by 25%. Participating in masked conversations increased depression and anxiety scores, especially for individuals that did not experience depression or anxiety prior to the pandemic. Metacognition also had a relationship on the mental health of DHH during the pandemic. As metacognition scores increased, depression and anxiety scores increased.

The COVID-19 pandemic has disrupted multiple aspects of life for nearly everyone across the country and the world, but has been especially difficult for vulnerable populations (Kim & Bostwick, 2020; Patel et al., 2020; Usher et al., 2020). This study identifies and seeks to evaluate the impact of the pandemic on individuals with hearing loss, a population that the pandemic has further marginalized.

The Centers for Disease Control and Prevention (CDC) and other health organizations recommend that individuals stay at least six feet apart and wear masks to prevent illness transmission during the pandemic (Howard et al., 2020; Kai et al., 2020; Xu et al., 2020). Though necessary for physical safety, these regulations add a heavy burden to those who are reliant on facial expressions and lip reading for communication, particularly the deaf and hard of hearing population (**DHH**) (Grote & Izagaren, 2020; Hulzen, R.D. & Fabry, D.A., 2020; Roberson et al., 2012; Schlögl & Jones, 2020). DHH rely heavily on lipreading, visual cues and facial expressions to communicate in their daily lives and have experienced a sharp decline in their ability to navigate personal, social, employment and professional interactions in the pandemic (Grote & Izagaren, 2020; Naylor et al., 2020). In addition, masking interrupts speech signals, causing speech to be less intelligible (Atcherson et al., 2017). The inability to communicate successfully in personal and professional interactions diminishes well-being and mental health, causing DHH to be more vulnerable to mental health distress (Cruice, 2010; Fellinger et al., 2012; Kvam et al., 2007). However, the link between mental health outcomes and masking during the COVID-19 pandemic has yet to be explored.

# LITERATURE REVIEW

## *Anxiety and Depression*

Generalized Anxiety Disorder (GAD) is a mental health disorder characterized by intense and chronic worry, which can severely impact a person's functioning. Symptoms include excessive worry that is difficult to control and occurs more days than not, feeling on edge, difficulty focusing, irritability, muscle tension, and sleep disturbance (American Psychiatric Association, 2013). A systematic review that evaluated GAD prevalence found 19-41% of the DHH sample showed significant anxiety symptoms (Shoham et al., 2019). For comparison, a 2019 national survey identified a prevalence of 8.3% for anxiety disorders among the general population (Twenge & Joiner, 2020).

Major Depressive Disorder (MDD) is a mood disorder that is characterized by multiple symptoms, like feelings of hopelessness, sadness, and a loss of interest in previously enjoyable activities. It can impact daily activities such as sleep, appetite, weight, fatigue, and cognitions (American Psychiatric Association, 2013). Most studies that assess the prevalence of depression with a hearing loss sample draw from an elderly only (>70 years of age) sample. However, one study that included a younger sample (age 12-19) along with a sample of age 70+ found that depression rates for DHH were 11.4% compared to 4.9% for those with normal hearing (Li et al., 2014).

Recent research studies assessing depression and anxiety rates among the general population during the pandemic suggested a tripling for both depression and anxiety prevalence (Ettman et al., 2020; Twenge & Joiner, 2020). However, we do not know

how the pandemic is affecting the depression and anxiety rates of DHH, a population that has historically been more at risk than the general population.

### *Interaction of Hearing Loss and Mental Health*

Several explanations exist to explain the link between hearing loss and mental health. Emotion control and planning is a developmental task that requires access to language and auditory cues, thus lack of exposure to auditory signals can affect the social/emotional development of DHH (Fellinger et al., 2012). When families lack successful communication strategies with deaf and hearing-impaired children, the children are more likely to have an impaired quality of life and less social/emotional resources (Fellinger et al., 2012). The stress of communication can also affect the lens which DHH views their environment. Metacognition theory examines how people think about their thinking, a major determining factor that contributes to mental health outcomes (Nordahl et al., 2019). Metacognition studies that examine DHH samples have found high associations with cognition and mental health disorders (Booth-Butterfield & Booth-Butterfield, 1994; Dehnabi et al., 2017).

### *Communication Barriers*

Previous research rarely identifies which communication barrier impacts mental health negatively. In a previous systematic review conducted by the author to identify the association of communication barriers with hearing loss, findings uncovered multiple communication barriers. These barriers included listening fatigue, listening avoidance, lack of consideration from the hearing partner, poor listening acoustics, reduced access to side conversations, communication abuse, and ableism. These barriers were found to be

associated with higher rates of heavy drinking, use of cannabis, depression, mental stress, and suicidal ideation as well as lower rates of quality of life and self-worth (Scoresby, 2022).

### *Self-Regulatory Executive Function Model (S-REF)*

Strong evidence indicates that psychological distress is caused by how individuals perceive situations (Bailey & Wells, 2015). The self-regulatory executive function model (S-REF) suggests that individuals experience a heightened vulnerability to mental health disorders when they are exposed to stressful situations, particularly as a result of metacognition (Wells & Matthews, 1996). When metacognition (i.e., the beliefs about one's thoughts) are ruminative and negative, it leads to collective responses known as the Cognitive Attentional Syndrome (CAS) (Nordahl et al., 2019; Wells & Matthews, 1996). CAS keeps an individual in an internal threat response, causing them to not see their current stressful situation from a logical or problem-solving perspective. Instead, it causes perpetual worry and decreases cognitive efficiency, as well as impairs a person's ability to self-regulate (Nordahl et al., 2019).

This study seeks to evaluate the impact of the COVID-19 pandemic on individuals with hearing loss. Based on previous literature and empirical observations, the main hypothesis for this study is:

> $H_1$: DHH individuals experience distress when having masked conversations due to their metacognitions.

Following that, the two main research questions in this study are:

1. What are the rates of depression and anxiety for DHH during the COVID-19 pandemic?

2. What is the relationship between masking, metacognition, and mental health factors?

## METHODOLOGY

To address the research questions, a retrospective descriptive exploratory study conducted in 2021 will be used. This study was conducted by a research team of myself, my faculty advisor, and two researchers in the audiology program at UTHSC and was driven by S-REF theory. Utilizing an anonymous web-based survey, we recruited participants from nationwide social media Facebook groups and from the Speech and Hearing Clinic at the University of Tennessee. Recruitment criteria included: 1) being an adult (18 years or older); 2) having any level of hearing loss; and 3) currently experiencing masked communications. The sample size was determined by a G*power analysis, which determined the minimum sample size should be *N*=107. This study was funded by a student-faculty award from the Graduate School at the University of Tennessee.

### *Subjects*

During a recruitment window of eight weeks (February and April 2021), 190 participants responded. Because incentives are helpful when recruiting, especially with hard-to-reach populations, a communication kit was mailed to participants who chose to share their addresses. For those that disclosed their names and addresses, a new survey window opened to allow their contact information to be separated from their survey responses, thus protecting their confidentiality.

### *Sampling strategy*

Exploratory studies often utilize convenience sampling due to time and cost efficiency (Jager et al., 2017). As convenience sampling does not have the same ability to determine sampling error as probability sampling, it cannot be used to generalize the results of a study to the larger population (Stratton, 2021). However, when utilizing a homogenous convenience sampling strategy some of the limitations of non-probability sampling can be minimized (Jager et al., 2017). Sampling from the DHH population can be challenging due to the stigma of having hearing loss, the lack of culturally responsive communication tools in research, and the mistrust of researchers (Dusenbery, et al., 2021). One strategy to address this challenge is to sample from individuals and groups whom the researchers have a relationship with. This strategy allowed the research team to meet and exceed the goal of $N$=107 participants through three different recruitment sources. The study information and link were sent to:

1. Patients of the UTHSC Speech and Language Clinic through email
2. Social media hearing loss related Facebook groups that had granted permission to post
3. Personal and professional contacts of the researchers

### *Survey instrument*

The survey consisted of demographic questions, hearing loss related questions, and several standardized measures, which we detail below. The survey can be found in the appendix.

***Demographic.*** Participants were asked about their race, gender, age, marital status, annual income, employment status, and education level.

***Hearing loss.*** Participants answered questions to self-identify their level of hearing loss, use of hearing aids or cochlear implants, use of sign language, how often they have masked communications and how often they experience masked communication.

***Metacognition.*** To measure the metacognition capacity of the participants, the MCQ-30 (Metacognition Questionnaire-30) was selected because of its relationship with trait anxiety. The MCQ-30 assesses unhelpful metacognitions that can influence trait anxiety (Wells & Cartwright-Hatton, 2004). Participants are asked, using a Likert scale of one (do not agree) to four (agree very much), questions such as "I am constantly aware of my thinking" and "my worrying is dangerous for me." Responses are scored from 30-120. The higher the score indicates the more unhelpful the participant's cognitions are. The MCQ demonstrates good internal consistency with Cronbach's alpha in the range of 0.72 to 0.93 (Wells & Cartwright-Hatton, 2004). The current study has Cronbach's alpha of $\alpha = 0.91$, demonstrating excellent internal consistency.

***Anxiety.*** The STAI-T20 (State Trait Anxiety Inventory) measures anxiety in clinical and research settings (Spielberger, 1983). It specifically looks at trait anxiety, which is situational anxiety. Participants are asked to respond to 20 statements on a Likert scale from one (not at all) to four (very much so). Statements range from "I feel calm" to "I feel jittery." Scores at or above 40 indicate the presence of Generalized Anxiety Disorder. The psychometric properties of the STAI-T are good with internal consistency ranging from 0.86 to 0.95 (Spielberger, et al., 1983). In the current study, Cronbach's alpha was $\alpha = .96$, demonstrating excellent internal consistency.

The GAD-2 (Generalized Anxiety Disorder) screens participants and identifies risk of having generalized anxiety disorder (Plummer et al., 2016). Scores of 3 or higher on this two-question scale deems the participant at risk of GAD. Two questions are asked regarding how often the participant has been bothered in the last two weeks: "feeling nervous, anxious or on edge" and "not being able to stop or control worrying." Responses are on a Likert scale from one (not at all) to four (nearly every day). The GAD-2 has good internal consistency with $\alpha$=0.81 (Staples et al., 2019). For this study, the GAD-2 had a good internal consistency with the Cronbach's alpha of $\alpha$ =0.88.

***Depression.*** The CES-D (Center for Epidemiologic Studies Depression Scale) asks participants how often they have felt depression-related factors in the past week (Radloff, 1977). Using a Likert scale from rarely or none of the time to most or all of the time, participants ranked the frequency of questions such as "I was bothered by things that usually don't bother me" and "I felt lonely." The CES-D indicates a total score of 16 or higher is considered Major Depression Disorder (Santor et al., 1995). Internal consistency of the CES-D has been shown to be excellent with the Cronbach's alpha ranging from 0.85 to 0.90 (Radloff, 1977). In this current study the Cronbach's alpha for the CES-D was excellent with $\alpha$= 0.94.

In addition, the PHQ-2 (Patient Health Questionnaire) screens participants for risk of having major depressive disorder (Löwe et al., 2005; Staples et al., 2019). Scores of three or higher on this two-question scale indicates a higher risk for major depression disorder. Internal consistency for the PHQ-2 is good with Cronbach's alpha demonstrated

in previous studies at .83 (Löwe et al., 2005). In the current study, the internal consistency was $\alpha$ =0.86 demonstrating good internal consistency.

***Communication.*** To measure communication disruptions, the APHAB (Abbreviated Profile of Hearing Aid Benefit) was identified as the most appropriate measure because of its flexibility (Cox & Rivera, 1992). In its original form the APHAB asks participants to rate how well they hear in a variety of situations without a hearing aid and then with a hearing aid. For the purposes of this study, the researchers were able to adapt the questionnaire to how well the participants hear in situations in which people are not masked or in which they are masked. There are four subscales in the APHAB: Ease of Communication (EC), Background Noise (BN), Reverberation (RV), and Aversiveness (AV). As the AV scale was not applicable to masked situations (e.g., "The sound of screeching tires is uncomfortably loud") it was not used in this study. The three subscales that were used have demonstrated previous varying internal consistency. The EC scale and RV scale have shown to have acceptable consistency ($\alpha$= 0.74 and 0.73). The BN scale has shown good internal consistency with alpha of $\alpha$ =0.83 (Cox & Rivera, 1992). For this current study the Cronbach's alpha for the EC, BN and RV subscales are respectively $\alpha$ =0.89, $\alpha$ =0.74, and $\alpha$ =0.82.

***Data Analysis***

Statistical analyses were conducted using SPSS v. 26 and SPSS v. 28. Of the 190 total responses, 154 participants completed initial demographic data. Of those who completed demographic questions only 122 completed at least one subscale. Thirty-two participants appeared to have difficulty with the first measure (APHAB) and either

stopped answering questions or skipped around the survey. Comments made by participants indicate the APHAB was not mobile phone friendly and difficult to see. All *N*=154 participants who completed demographic questions were included in descriptive statistics analysis. Only those respondents who had completed at least one outcome measure subscale (*N*=122) were included in the paired samples t-tests and linear regression analyses.

First, descriptive statistics were performed to identify sociodemographic characteristics, hearing loss characteristics, and hours a day in masked conversations. Next, to further understand the impact of masking, paired samples t-tests were computed between the APHAB conditions of masked and unmasked communication. Finally, multiple hierarchical linear regressions were conducted to examine the association between masking, mental health factors, and metacognition. Three models were computed with each dependent outcome variable (STAI-T, GAD-2, CES-D, PHQ-2). Model 1 assessed masking exposure (IV) and each DV. Model 2 assessed metacognition (IV) and each DV. Model 3 assessed the interaction between masking and metacognition (IV) and each DV.

To identify if the individuals at risk of MDD or GAD during the pandemic were the same individuals who experienced depression or anxiety before the pandemic post-hoc linear regressions were also conducted.

## RESULTS

Descriptive characteristics of the study sample are shown in Table 2.1 (appendix). Of the *N*=154 respondents included in the analyses, 51% (*n*=79) were aged 55 or older,

70% (*n*=108) were female, and 92% (*n*=141) were white. Most had at least a two-year college degree or technical certifications (53.2%, *n*=82) and have part-time or full-time employment (49.2%, *n*=59). Regarding hearing loss, the majority stated they have severe hearing loss (49.4%, *n*=76) and use hearing aids (55.2%, *n*=85). A large majority used spoken language instead of sign language to communicate (85.7%, *n*=132).

To compare listening comprehension between masked and unmasked communication conditions, paired samples t-tests were conducted in SPSS. All three subscales demonstrated statistically significant results when comparing masked to unmasked listening situations. In the EC subscale (i.e., how much effort is involved in listening in fairly quiet environments), participants could hear in unmasked situations at a statistically significant increase of 25% compared to masked situations, $t(123)= 7.096$, $p<.001$. In the BN subscale (i.e., listening in the presence of background noise), participants could hear in unmasked situations at a statistically significant increase of 25% compared to masked situations, $t(122)= 9.322$, $p<.001$. In the RV subscale (i.e., listening in rooms that have reverberation), participants could hear in unmasked situations at a statistically significant increase of 25% compared to masked situations, $t(119)= 7.424$, $p<.001$. These results indicate that participants with hearing loss during the COVID-19 pandemic had 25% less speech and communication understanding when they were in listening situations where others were masked.

***Rates of Depression and Anxiety***

To answer the first research question and determine the rates of depression and anxiety for participants, scores from the PHQ-2, CES-D, GAD-2, and STAI-T were

calculated. A new variable was computed for each to determine the summary of scores. Another variable was then computed to identify threshold scores for each outcome variable. This variable allowed the risk for major depressive disorder and generalized anxiety disorder to be determined. Table 2.1 (appendix) also indicates the results of each depression and anxiety measure for those at or above threshold cut-off scores. For anxiety, 35.2% ($n$=44) scored at clinically significant levels for the GAD-2 and 38% ($n$=46) scored at clinically significant levels for the STAI-T. For depression, 21.4% ($n$=27) scored at clinically significant levels for the PHQ-2 and 44.5% ($n$=53) scored at clinically significant levels for the CES-D.

***Relationship Between Masking, Metacognition, and Mental Health***

To address the second research question and test the relationship between masking, metacognition, and mental health factors, correlations and multiple hierarchical linear regressions were conducted. Independent variables were entered in a sequential order: 1) Hours/day in masked communications, 2) Metacognition measure (MCQ-30), and 3) an interaction variable (mask*MCQ-30). This model was computed four different times, once for each dependent variable (GAD-2, PHQ-2, STAI-T, and CES-D). Table 2.2 (appendix) summarizes the descriptive statistics and analysis results. Regression results show that the MCQ and the STAI-T are positively and significantly correlated with the number of hours the participants experienced in masked communications. The GAD-2 and PHQ-2 were not significantly correlated with the number of hours in masked communications.

Significant regression models were found for CES-D and STAI-T models but not for GAD-2 or PHQ-2. For CES-D and STAI-T the number of hours in masked conversations significantly predicted the dependent variables. Adding in MCQ significantly added to the models. However, the interaction of hours masked and MCQ was not a significant predictor of the dependent variables.

While hours in masked communications did significantly predict higher rates of depression ($R^2$=.061, F(1,97)= 6.271, $p$=.014 and anxiety ($R^2$=.065, F(1,100)=6.915, $p$=.010, metacognition was a much stronger predictor of depression ($R^2$=.375, F(1,96)= 28.807, $p$<.001 and anxiety ($R^2$=.325, F(1,99)= 23.866, $p$<.001.

***Post-hoc Analyses***

To further examine the relationship between masking, metacognition, and mental health factors, hierarchical linear regressions were performed to examine the relationship between pre-COVID self-reported depression and anxiety with during-COVID depression and anxiety (Table 2.3 in appendix). For CES-D there was a significant interaction between masking and experiencing pre-COVID depression. To explore this interaction a separate regression was run for those who experienced depression and for those who did not. For those that did not experience depression pre-COVID, masking was significant, indicating those who spent more time in masked conversations tended to have higher levels of CES-D. For those who experienced pre-COVID depression, masking was not significant, and hours masked had no impact on CES-D. Therefore, those who did not experience depression prior to the pandemic demonstrated increased levels of depression during the pandemic.

The same pattern was true for anxiety. For the STAI-T outcome variable, there was a significant interaction between masking and experiencing pre-COVID anxiety. To explore this interaction a separate regression was run for those who experienced anxiety and for those who did not. For those that did not experience anxiety pre-COVID, masking was significant, indicating those who spent more time in masked conversations tended to have higher levels of STAI-T. For those who experienced pre-COVID anxiety, masking was not significant, and hours masked had no impact on STAI-T. Therefore, those individuals with hearing loss who did not experience anxiety prior to the pandemic showed increased levels of anxiety during the pandemic.

## DISCUSSION

Individuals with hearing loss experience multiple communication barriers in their daily lives that have an impact on their mental health (Fellinger et al., 2005; Recio-Barbero et al., 2020). The COVID-19 pandemic exacerbated these barriers due to masking and social distancing, causing an increase in stress (Kaya et al., 2021). DHH have had the dual challenge of mitigating risk of contracting the virus and accommodating the increase of communication barriers (Garg et al., 2021). This study found that COVID-19 pandemic masking led to a 25% reduction in understanding the speech of others who were masked in a variety of listening situations. This reduction in listening comprehension is associated with high rates of anxiety and depression among the DHH participants in this study.

Multiple studies took place during the COVID-19 pandemic to measure depression and anxiety rates. A systematic review that examined the literature between

December 2019 and June 2020 identified prevalence rates of depression as 20% and anxiety as 35% in the general population (*N*=113, 285) (Lakhan et al., 2020). In a longitudinal study that identified anxiety and depression rates in the general population in six different waves, two waves (5 and 6) in January and April 2021, most closely aligned with the dates of recruitment of DHH individuals in this study. Wave 5 (*N*=7,115) demonstrated rates of depression as 25.5% and anxiety as 23.6%. Wave 6 (*N*=7,204) found rates of depression at 23.8% and anxiety as 22.1% (Hajek et al., 2022). In the current study, rates of depression and anxiety varied based on the measure. Depression rates were 21.4% (*N*=27) as measured by the PHQ-2 and 44.5% as measured by the CES-D. Anxiety rates were 35.2% (*N*=44) as measured by the GAD-2 and 38% (*N*=46) as measured by the STAI-T. Although this study is not a true comparison, due to smaller sample size and not yielding prevalence estimates, the trend demonstrates higher rates of depression and anxiety among participants with hearing loss than in the general hearing public.

Metacognition has been tested during the pandemic in relationship to anxiety from perceived danger and fear (Aydın et al., 2022), cyberchondria (excessive concerns about physical health due to repeated internet searches) (Seyed Hashemi et al., 2020), and health anxiety (Akbari et al., 2021). Each of these studies found increased anxiety and depression from negative metacognitive beliefs (i.e., worrying about worry and lack of control to internal threats). The Cognitive Attentional Syndrome (CAS), when activated by metacognitive beliefs, causes chronic negative thinking, rumination, and a hyperfocus on perceived threats (Bailey & Wells, 2015; Mohammadkhani et al., 2022; Wells &

Matthews, 1996). The activated CAS maintains attention on intrusive thoughts in masked communication, such as “What if I can’t hear?” and can lead to avoidant coping strategies such as thought suppression, disengaging from conversation, or delaying needed tasks that involve communication. This pattern contributes to intolerance, distress, and other negative emotions, which strongly impact depression and anxiety (Aydın et al., 2022; Bailey & Wells, 2015; Mohammadkhani et al., 2022). The current study found that negative metacognitions (perception of the threat of masked communication) had a stronger relationship with both depression and anxiety than the actual condition of being in masked conversations.

The post-hoc analysis identified that those at risk for depression and anxiety were not the DHH individuals that self-identified as experiencing depression or anxiety before the pandemic. Those who had not experienced depression before the pandemic were at risk of depression during the pandemic and those who had not experienced anxiety before the pandemic were at much greater risk of anxiety during the pandemic. This may be explained in a couple of different ways. Those who have extensive experience with hearing loss may have had years of practice to strengthen their mental health resilience (Yang et al., 2021), thus being able to manage the communication threats of the pandemic. DHH individuals have varying levels of hearing loss. It is likely that individuals who were functioning at a high degree with access to facial cues, lip reading, and uninterrupted speech signals, may not have experienced severe barriers until masking, thus creating new challenges that they were not equipped to deal with. Further studies are needed to explore this relationship.

### *Limitations*

There are a few limitations to using this study. One, the APHAB was originally created as a pencil and paper study, not for electronic use. The question and responses are in a side-by-side matrix (see appendix). While completing this measure on a desktop works well, it is not very effective when a mobile device is used to complete it as it's difficult to see the comparison category on a small screen. Thus, a lot of participants stopped taking the survey at this point or they skipped ahead. While the missing data is unfortunate, there were still enough participants with complete data to have the necessary power for statistical analyses.

Another limitation is that the sample was drawn from individuals who are seeking help for their hearing loss, whether in a social media support group or in the speech and hearing clinic. Thus, there is potential risk for bias in the sample, as those who have hearing loss but who do not seek support were not included in the study. However, the study does not seek to generalize the findings to all individuals with hearing loss. This study is limited in its scope due to utilizing convenience sampling methods. Convenience sampling cannot yield prevalence estimates (Jager et al., 2017).

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# APPENDIX 2

***TABLES***

Table 2.1 Sample characteristics

| **Demographic variables** | **%(*n*)** | **Anxiety** | | **Depression** | |
|---|---|---|---|---|---|
| | *N*=154 | GAD-2<br>35.2%<br>(*N*= 44) | STAI-T<br>38%<br>(*N*=46) | PHQ-2<br>21.4%<br>(n=27) | CESD<br>44.5%<br>(n=53) |
| Age | | | | | |
| 18-24 | 5.8 (9) | 13.6 (6) | 10.9 (5) | 18.5 (5) | 11.3 (6) |
| 25-34 | 11.7 (18) | 15.9 (7) | 19.6 (9) | 14.8 (4) | 13.2 (7) |
| 35-44 | 13 (20) | 13.6 (6) | 13.0 (6) | 18.5 (5) | 15.1 (8) |
| 45-54 | 18.2 (28) | 18.1 (8) | 17.4 (8) | 11.1 (3) | 20.1 (11) |
| 55-64 | 17.5 (27) | 25.0 (11) | 21.7 (10) | 22.2 (6) | 18.9 (10) |
| 65-74 | 25.3 (39) | 11.36 (5) | 17.4 (8) | 11.1 (3) | 15.1 (8) |
| 75-84 | 7.8 (12) | 2.3(1) | 0.0 (0) | 3.70 (1) | 5.66 (3) |
| 85 or older | .6 (1) | 0.0 (0) | 0.0 (0) | 0.00 (0) | 0.00 (0) |
| Gender | | | | | |
| Male | 29.2 (45) | 13.6 (6) | 17.4 (8) | 7.4 (2) | 20.1 (11) |
| Female | 70.1 (108) | 84.1 (37) | 80.4 (37) | 88.9 (24) | 77.4 (41) |
| Other | .6 (1) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| Race/ethnicity | | | | | |
| American Indian | .6 (1) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| Asian | 3.9 (6) | 4.55 (2) | 4.34 (2) | 3.70 (1) | 3.78 (2) |
| Black | 1.3 (2) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| Latino/a/x | .6 (1) | 0.00 (0) | 0.0 (0) | 0 | 0.00 (0) |
| White | 91.6 (141) | 86.4 (38) | 87.0 (40) | 21 | 88.7 (47) |
| Multiracial | .6 (1) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| Other | .6 (1) | 0.00 (0) | 0.0 (0) | 3.70 (1) | 0.00 (0) |
| Prefer not answer | .6 (1) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |

Table 2.1 continued

| **Demographic variables** | **%(*n*)** | **Anxiety** | | **Depression** | |
|---|---|---|---|---|---|
| | *N*=154 | GAD-2<br>35.2%<br>(*N*= 44) | STAI-T<br>38%<br>(*N*=46) | PHQ-2<br>21.4%<br>(n=27) | CESD<br>44.5%<br>(n=53) |
| Education | | | | | |
| <High school | .6 (1) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| High school | 7.8 (12) | 16.0 (7) | 19.6 (9) | 22.2 (6) | 17.0 (9) |
| Some college | 15.6 (24) | 16.0 (7) | 19.6 (9) | 14.8 (4) | 18.9(10) |
| Technical certification | 5.2 (8) | 9.10 (4) | 6.52 (3) | 7.4 (2) | 5.66 (3) |
| 2 yr degree | 3.9 (6) | 2.3 (1) | 4.34 (2) | 0.00 (0) | 5.66 (3) |
| 4 year degree | 23.4 (36) | 31.8 (14) | 30.4 (14) | 37.0 (10) | 34.0 (18) |
| Master's degree | 14.9 (23) | 16.0 (7) | 10.9 (5) | 11.1 (3) | 11.3 (6) |
| Doctorate | 5.8 (9) | 2.3 (1) | 2.2 (1) | 0.00 (0) | 3.78 (2) |
| Prefer not answer | .6 (1) | 2.3 (1) | 2.2 (1) | 0.00 (0) | 0.00 (0) |
| Missing | 22.1 (34) | | | | |
| Employment | | | | | |
| Full time | 27.9 (43) | 43.2 (19) | 39.1 (18) | 30.0 (8) | 35.8 (19) |
| Part time | 10.4 (16) | 9.10 (4) | 13.0 (6) | 7.4 (2) | 15.1 (8) |
| Unemployed looking for work | 2.6 (4) | 4.55 (2) | 6.52 (3) | 3.70 (1) | 5.66 (3) |
| Unemployed not looking for work | 2.6 (4) | 6.82 (3) | 4.34 (2) | 7.4 (2) | 3.78 (2) |
| Retired | 24.0 (37) | 13.6 (6) | 13.0 (6) | 14.8 (4) | 17.0 (9) |
| Student | 45. (7) | 9.10 (4) | 8.70 (4) | 14.8 (4) | 7.55 (4) |
| Disabled | 4.5 (7) | 9.10 (4) | 10.9 (5) | 14.8 (4) | 11.3 (6) |
| Prefer not answer | 1.3 (2) | 2.3 (1) | 2.2 (1) | 3.70 (1) | 1.89 (1) |
| Missing | 22.1 (34) | | | | |
| Annual income | | | | | |
| <10,000 | 2.6 (4) | 6.82 (3) | 6.52 (3) | 11.1 (3) | 5.66 (3) |
| 10-39,999 | 14.2 (22) | 16.0 (7) | 17.4 (8) | 30.0 (8) | 22.6 (12) |
| 40-69,999 | 16.8 (26) | 22.7 (10) | 21.7 (10) | 18.5 (5) | 18.9 (10) |
| 70-99,000 | 12.3 (19 | 16.0 (7) | 17.4 (8) | 11.1 (3) | 15.1 (8) |
| 100-149,000 | 10.4 (16) | 11.4 (5) | 10.9 (5) | 7.4 (2) | 11.3 (6) |
| >150,000 | 5.2 (8) | 2.3 (1) | 6.52 (3) | 3.70 (1) | 3.78 (2) |
| Prefer not to answer | 16.2 (25) | 20.1 (9) | 15.2 (7) | 11.1 (3) | 18.9 (10) |
| Missing | 22.1 (34) | | | | |

Table 2.1 continued

| **Demographic variables** | **%(*n*)** | **Anxiety** | | **Depression** | |
|---|---|---|---|---|---|
| | *N*=154 | GAD-2<br>35.2%<br>(*N*= 44) | STAI-T<br>38%<br>(*N*=46) | PHQ-2<br>21.4%<br>(n=27) | CESD<br>44.5%<br>(n=53) |
| Degree of hearing difficulty | | | | | |
| Mild | 7.1 (11) | 9.10 (4) | 4.34 (2) | 3.70 (1) | 5.66 (3) |
| Moderate | 18.8 (29) | 13.6 (6) | 10.9 (5) | 11.1 (3) | 13.2 (7) |
| Moderately-severe | 24 (37) | 27.3 (12) | 28.3 (13) | 22.2 (6) | 22.6 (12) |
| Severe | 49.4 (76) | 50.0 (22) | 56.5 (26) | 63.0 (17) | 58.5 (31) |
| Missing | .6 (1) | | | | |
| Hearing device | | | | | |
| Hearing aid(s) | 55.2 (85) | 50.0 (22) | 58.7 (27) | 51.9 (14) | 56.6 (30) |
| Cochlear imp(s) | 26.6 (41) | 27.3 (12) | 19.6 (9) | 37.0 (10) | 24.5 (13) |
| Bimodal | 9.7 (15) | 6.82 (3) | 8.70 (4) | 0.00 (0) | 7.55 (4) |
| None | 8.4 (13) | 16.0 (7) | 13.0 (6) | 11.1 (3) | 11.3 (6) |
| Sign language | | | | | |
| Yes | 7.8 (12) | 13.6 (6) | 10.9 (5) | 18.5 (5) | 11.3 (6) |
| No | 85.7 (132) | 72.7 (32) | 76.1 (35) | 74.0 (20) | 77.4 (41) |
| Other | 5.8 (9) | 11.4 (5) | 10.9 (5) | 7.4 (2) | 9.43 (5) |
| Missing | .6 (1) | 2.3 (1) | | | |
| Hours day masked conversations | | | | | |
| 0-2 hours | 47.4 (73) | 38.6 (17) | 30.4 (14) | 37.0 (10) | 34.0 (18) |
| 3-5 hours | 20.8 (32) | 29.5 (13) | 34.8 (16) | 33.3 (9) | 34.0 (18) |
| 6-9 hours | 23.4 (36) | 29.5 (13) | 26.1 (12) | 25.9 (7) | 28.3 (15) |
| >10 hours | 5.8 (9) | 2.3 (1) | 6.52 (3) | 3.70 (1) | 3.78 (2) |
| Missing | 4 (2.6) | | | | |

Table 2.2 Masking, metacognition, mental health factors regression

| Dep Var | Model | B | Beta | p | R2 | R2 change | p |
|---|---|---|---|---|---|---|---|
| PHQ2 | Hours | .103 | .062 | .534 | .004 | .004 | .534 |
| | Hours<br>MCQ | .007<br>.063 | .004<br>.535 | .960<br><.001 | .287 | .283 | <.001 |
| | Hours<br>MCQ<br>MCQ*Hours | -.339<br>.045<br>.006 | -.202<br>.384<br>.273 | .580<br>.162<br>.561 | .290 | .002 | <.001 |
| GAD2 | Hours | .214 | .107 | .280 | .011 | .011 | .280 |
| | Hours<br>MCQ | .092<br>.080 | .046<br>.569 | .575<br><.001 | .331 | .320 | <.001 |
| | Hours<br>MCQ<br>MCQ*Hours | .044<br>.078<br>.001 | .022<br>.551<br>.032 | .950<br>.040<br>.945 | .331 | .000 | .945 |
| STAI | Hours | 3.538 | .254 | .010 | .065 | .065 | .010 |
| | Hours<br>MCQ | 2.350<br>2.658 | .191<br>.514 | .024<br><.001 | .325 | .261 | <.001 |
| | Hours<br>MCQ<br>MCQ*Hours | -2.095<br>.260<br>.084 | -.151<br>.266<br>.454 | .675<br>.322<br>.329 | .332 | .007 | .329 |
| CESD | Hours | 3.183 | .246 | .014 | .061 | .061 | .014 |
| | Hours<br>MCQ | 2.203<br>.506 | .171<br>.566 | .039<br><.001 | .375 | .314 | <.001 |
| | Hours<br>MCQ<br>MCQ*Hours | -2.238<br>.281<br>.077 | -.173<br>.315<br>.460 | .619<br>.228<br>.311 | .382 | .007 | .311 |

Table 2.3 Pre-COVID depression and anxiety as predictors for COVID depression and anxiety

| **DV** | **Model** | **B** | **Beta** | **p** | **R2** | **R2 change** | **p** |
|---|---|---|---|---|---|---|---|
| STAI-T with Pre-COVID Anxiety | Hours<br>MCQ | -.155<br>.389 | -.013<br>.478 | .918<br><.001 | .229 | .229 | .001 |
| STAI-T without Pre-COVID Anxiety | Hours<br>MCQ | 5.243<br>.373 | .402<br>.368 | .004<br>.007 | .359 | .359 | <.001 |
| CES-D with Pre-COVID Depression | Hours<br>MCQ | -1.605<br>.497 | -.130<br>.627 | .368<br><.001 | .396 | .396 | <.001 |
| CES-D without Pre-COVID Depression | Hours<br>MCQ | 3.696<br>.461 | .294<br>.502 | .005<br><.001 | .369 | .369 | <.001 |

## *SURVEY*

**Masked Community**

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Start of Block: Consent

**Consent for Research Participation Research Study Title: Facing a Masked Community: Anxiety and Depression Rates for People with Hearing Loss**

Researcher(s):
Kristel Scoresby, LCSW, PhD student, University of Tennessee, Knoxville, kscoresb@vols.utk.ed
Thereasa Abrams, PhD, University of Tennessee, Nashville, tabrams1@utk.edu
Elizabeth Humphreys, Au.D, University of Tennessee Health Science Center Audiology and Speech Pathology, humphre1@uthsc.edu
Patti Johnstone, University of Tennessee Health Science Center Audiology and Speech Pathology, pjohnst1@uthsc.edu

We are asking you to be in this research study because you have a hearing loss and interact with people who are wearing masks due to the COVID-19 pandemic. You must be age 18 or older to participate in the study. The information in this consent form is to help you decide if you want to be in this research study. Please take your time reading this form and contact the researcher(s) to ask questions if there is anything you do not understand.

**Why is the research being done?** The purpose of the research study is to identify how masked communication is affecting people with hearing loss. This study is being conducted by researchers at the University of Tennessee, Knoxville and researchers at the University of Tennessee's Health Science Center. The research team is receiving funding from University of Tennessee, Knoxville.

**What will I do in this study?** If you agree to be in this study, you will complete an anonymous online survey. The survey includes questions about demographic information (like gender and race) and questions about communicating with hearing loss. It should take you about 20-25 minutes to complete. You can skip questions that you do not want to answer.

At the end of the survey, you will be asked if you would like to receive a communication kit (described below) and/or would like to participate in further research. If you select yes, you will be redirected to a different survey which will collect your contact information. Your name and contact information will not be attached to the answers you provided in the research survey.

**Can I say "No"?** Being in this study is up to you. You can stop up until you submit the survey. After you submit the survey, we cannot remove your responses because we will not know which responses came from you.

Either way, your decision won't affect your relationship with researchers, the University of Tennessee or the Health Science Center. If you are receiving services at the Speech and Hearing Clinic, participation in this survey will not affect your services in any way.

**Are there any risks to me?** We don't know of any risks to you from being in the study that are greater than the risks you encounter in everyday life.

**Are there any benefits to me?** We do not expect you to benefit from being in this study. Your participation may help us to learn more about the challenges that masked communication has on the unique

needs of those with hearing loss. We hope the knowledge gained from this study will benefit others in the future.

**What will happen with the information collected for this study?** The survey is anonymous, and no one will be able to link your responses back to you. Your responses to the survey will not be linked to your computer, email address or other electronic identifiers. Information provided in this survey can only be kept as secure as any other online communication.

If you choose to share your name and address so that a communication kit can be mailed to you, your contact information will not be connected to your survey answers. After communication kits have been mailed out, your name and address will be deleted. Information collected for this study will be published and possibly presented at scientific meetings.

**Will I be paid for being in this research study?** Those who participate in this survey and choose to receive compensation, will receive a communication kit in the mail. A communication kit will include an advocacy badge/button you can wear on your shirt or mask, a clear mask for a friend or coworker to wear while speaking with you and an ear saver (helps you wear a mask without interfering with hearing aids or a cochlear implant).

**Who can answer my questions about this research study?** If you have questions or concerns about this study, or have experienced a research related problem or injury, contact the researchers, Kristel Scoresby, kscoresb@vols.uk.edu, 865-974- 2809 or Dr. Thereasa Abrams, tabrams1@utk.edu (615) 782-5191.

For questions or concerns about your rights or to speak with someone other than the research team about the study, please contact:

Institutional Review Board
The University of Tennessee, Knoxville 1534 White Avenue
Blount Hall, Room 408
Knoxville, TN 37996-1529
Phone: 865-974-7697
Email: utkirb@utk.edu

**Statement of Consent** I have read this form, been given the chance to ask questions and have my questions answered. If I have more questions, I have been told who to contact. By clicking the "I Agree" button below, I am agreeing to be in this study. I can print or save a copy of this consent information for future reference. If I do not want to be in this study, I can close my internet browser.

○ Yes, I agree to provide my consent to participate in this research survey and I am 18 years old or older. (1)

○ No, I do not agree to consent or participate in this research survey. (2)

**End of Block: Consent**

**Start of Block: Demographics 1**

Page Break

Q1 What is your age?

- ○ Under 18 (1)
- ○ 18 - 24 (2)
- ○ 25 - 34 (3)
- ○ 35 - 44 (4)
- ○ 45 - 54 (5)
- ○ 55 - 64 (6)
- ○ 65 - 74 (7)
- ○ 75 - 84 (8)
- ○ 85 or older (9)

*Skip To: End of Survey If What is your age? = Under 18*

Q2 What degree of hearing difficulty do you think you have?

- ○ Mild (1)
- ○ Moderate (2)
- ○ Moderately-Severe (3)
- ○ Severe (4)
- ○ I do not know (5)
- ○ I do not have a hearing loss (6)

*Skip To: End of Survey If What degree of hearing difficulty do you think you have? = I do not have a hearing loss*

Q3 How do you identify your gender?

- ○ Male (1)
- ○ Female (2)
- ○ Other (please describe) (3) _____
- ○ Prefer not to answer (4)

Q4 How do you identify your race/ethnicity?

- ○ American Indian or Alaska Native (1)
- ○ Asian (2)
- ○ Black or African American (3)
- ○ Latino/Latina/Latinx (4)
- ○ Native Hawaiian or Pacific Islander (5)
- ○ White (6)
- ○ Multiracial (7)
- ○ Other (please describe) (8) _____
- ○ Prefer not to answer (9)

Page Break

Q5 Do you use a hearing aid, cochlear implant or both?

- ○ Yes. I use a hearing aid (or aids) only (1)
- ○ Yes, I use a cochlear implant (or implants) only (2)
- ○ Yes, I use both a hearing aid and a cochlear implant (3)
- ○ No, I do not use a hearing aid or a cochlear implant (4)

*Skip To: If Do you use a hearing aid, cochlear implant or both? = No, I do not use a hearing aid or a cochlear implant*

*Skip To: If Do you use a hearing aid, cochlear implant or both? = Yes, I use a cochlear implant (or implants) only*

Q6 How long have you used a hearing aid (or aids)?

- ○ Less than 6 weeks (1)
- ○ 6 weeks to 11 months (2)
- ○ 1 to 5 years (3)
- ○ 6 to 10 years (4)
- ○ Over 10 years (5)

Q7 How often do you use your hearing aid (or aids)?

- ○ None (1)
- ○ Less than one hour a day (2)
- ○ 1-4 hours a day (3)
- ○ 4-8 hours a day (4)
- ○ 9 hours or more a day (5)

Q8 How long have you used a cochlear implant (or implants)?

- ○ Less than 6 weeks (1)
- ○ 6 weeks to 11 months (2)
- ○ 1 to 5 years (3)
- ○ 6 to 10 years (4)
- ○ Over 10 years (5)

Q9 How often do you use your cochlear implant (or implants)?

- ○ None (1)
- ○ Less than 1 hour per day (2)
- ○ 1 to 4 hours per day (3)
- ○ 4 to 8 hours per day (4)
- ○ 9 hours or more a day (5)



Q10 At what age did you start to lose your hearing?

_____

Page Break

Q11 How many hours per day, on average, do you talk to people who are wearing masks?

- None (1)
- 0-2 hours a day (2)
- 3-5 hours a day (3)
- 6-9 hours a day (4)
- Over 10 hours a day (5)

Q12 Which type of mask is used most often by those you are speaking with? (Rank the order from 1-4. 1 is most often, 2 is the next most option, 4 is the least used).

_____ A completely covered mask (1)
_____ A mask with a clear window over the mouth (2)
_____ A clear face shield (3)
_____ A clear face shield with a covered mask (4)

Page Break

Q13 When talking with people who are wearing masks, it is.....

- not more difficult to hear (1)
- slightly more difficult to hear. (2)
- moderately more difficult to hear. (3)
- severely more difficult to hear. (4)
- I can't hear anyone wearing a mask. (5)

Q14 When talking with people who are wearing masks, what is your level of distress? Distress is defined as "extreme anxiety, sorrow, or pain."

- ○ no distress (1)
- ○ slight distress (2)
- ○ moderate distress (3)
- ○ severe distress (4)
- ○ unbearable distress (5)

Page Break

Q15 Not including hearing aids or cochlear implant, what type of technology do you use for your hearing loss? (select all that apply)

- ☐ Assistive listening devices/ FM system (1)
- ☐ Speech to text phone apps (2)
- ☐ Captioned telephones or TTY/relay (3)
- ☐ Other (please describe) (4) _____
- ☐ I do not use any of these (5)

Q16 Do you use sign language to communicate?

- ○ Yes (1)
- ○ No (2)
- ○ Other (3) _____

End of Block: Demographics 1

Start of Block: Mental health history

Q17 Before the COVID-19 pandemic, did you....

| | Yes (1) | No (2) | Unsure (3) |
|---|---|---|---|
| experience depression? (1) | ○ | ○ | ○ |
| receive a diagnosis of depression from a professional? (2) | ○ | ○ | ○ |
| receive treatment for depression from a professional? (3) | ○ | ○ | ○ |
| experience anxiety? (4) | ○ | ○ | ○ |
| receive a diagnosis of anxiety from a professional? (5) | ○ | ○ | ○ |
| receive treatment for anxiety from a professional? (6) | ○ | ○ | ○ |

Page Break

End of Block: Mental health history

Start of Block: ABHAB

Q18 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select “C” for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%).
E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| When I am in a crowded grocery store, talking with the cashier, I can follow the conversation. (1) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| I miss a lot of information when I'm listening to a lecture. (2) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| I have difficulty hearing a conversation when I'm with one of my family at home. (3) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |

Q48 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select “C” for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%). E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) |
| I have trouble understanding the dialogue in a movie or at the theater. (1) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| When I am listening to the news on the car radio, and family members are talking, I have trouble hearing the news. (2) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |

Page Break

Q19 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select "C" for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%). E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) |

| | |
|---|---|
| When I'm at the dinner table with several people, and am trying to have a conversation with one person, understanding speech is difficult. (1) | ( ( ( ( ( ( ( ( ( ( ( ( |
| When I am talking with someone across a large empty room, I understand the words. (2) | ( ( ( ( ( ( ( ( ( ( ( ( |
| When I am in a small office, interviewing or answering questions, I have difficulty following the conversations. (3) | ( ( ( ( ( ( ( ( ( ( ( ( |

Q20 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select "C" for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%). E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) |

| | |
|---|---|
| When I am in a theater watching a movie or play, and the people around me are whispering and rustling paper wrappers, I can still make out the dialogue. (1) | ( ( ( ( ( ( ( ( ( ( ( ( |
| When I am having a quiet conversation with a friend, I have difficulty understanding. (2) | ( ( ( ( ( ( ( ( ( ( ( ( |
| When a speaker is addressing a small group, and everyone is listening quietly, I have to strain to understand. (3) | ( ( ( ( ( ( ( ( ( ( ( ( |

Page Break

Q21 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select "C" for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%). E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) | A (99%) (1) | B (87%) (2) | C (75%) (3) | D (50%) (4) | E (25%) (5) | F (12%) (6) | G (1%) (7) |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| When I'm in a quiet conversation with my doctor in an examination room, it is hard to follow the conversation. (1) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| I can understand conversations even when several people are talking, (2) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| It's hard for me to understand what is being said at lectures or church services. (3) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |

Q22 Please select the answers that come closest to your everyday experience. Notice that each choice includes a percentage. You can use this to help you decide on your answer. For example, if a statement is true about 75% of the time, select “C” for that item. If you have not experienced the situation we describe, try to think of a similar situation that you have been in and respond for that situation. If you have no idea, leave that item blank.

A. Always (99%). B. Almost Always (87%). C. Generally (75%). D. Half-the-time (50%).
E. Occasionally (25%). F. Seldom (12%). G. Never (1%)

| | When others are masked | | | | | | | When others are not masked | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A (99 %) (1) | B (87 %) (2) | C (75 %) (3) | D (50 %) (4) | E (25 %) (5) | F (12 %) (6) | G (1 %) (7) | A (99 %) (1) | B (87 %) (2) | C (75 %) (3) | D (50 %) (4) | E (25 %) (5) | F (12 %) (6) | G (1 %) (7) |
| I can communicate with others when we are in a crowd. (1) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| I can follow the words of a sermon when listening to a religious service. (2) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |
| I have to ask people to repeat themselves in one-on-one conversation in a quiet room. (3) | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( | ( |

Page Break

End of Block: ABHAB

Start of Block: CES-D

Q23 Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

| | Rarely or none of the time (less than 1 day) (1) | Some or a little of the time (1-2 days) (2) | Occasionally or a moderate amount of time (3-4 days) (3) | Most or all of the time (5-7 days) (4) |
|---|---|---|---|---|
| 1. I was bothered by things that usually don't bother me. (1) | ○ | ○ | ○ | ○ |
| 2. I did not feel like eating; my appetite was poor. (2) | ○ | ○ | ○ | ○ |
| 3. I felt that I could not shake off the blues even with help from my family or friends. (3) | ○ | ○ | ○ | ○ |
| 4. I felt I was just as good as other people. (4) | ○ | ○ | ○ | ○ |
| 5. I had trouble keeping my mind on what I was doing. (5) | ○ | ○ | ○ | ○ |
| 6. I felt depressed. (6) | ○ | ○ | ○ | ○ |
| 7. I felt that everything I did was an effort. (7) | ○ | ○ | ○ | ○ |
| 8. I felt hopeful about the future. (8) | ○ | ○ | ○ | ○ |
| 9. I thought my life had been a failure. (9) | ○ | ○ | ○ | ○ |
| 10. I felt fearful. (10) | ○ | ○ | ○ | ○ |

Page Break

Q24 Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

| | Rarely or none of the time (less than 1 day) (1) | Some or a little of the time (1-2 days) (2) | Occasionally or a moderate amount of time (3-4 days) (3) | Most or all of the time (5-7 days) (4) |
|---|---|---|---|---|
| 11. My sleep was restless. (1) | ○ | ○ | ○ | ○ |
| 12. I was happy. (2) | ○ | ○ | ○ | ○ |
| 13. I talked less than usual. (3) | ○ | ○ | ○ | ○ |
| 14. I felt lonely. (4) | ○ | ○ | ○ | ○ |
| 15. People were unfriendly. (5) | ○ | ○ | ○ | ○ |
| 16. I enjoyed life. (6) | ○ | ○ | ○ | ○ |
| 17. I had crying spells. (7) | ○ | ○ | ○ | ○ |
| 18. I felt sad. (8) | ○ | ○ | ○ | ○ |
| 19. I felt that people dislike me. (9) | ○ | ○ | ○ | ○ |
| 20. I could not get “going.” (10) | ○ | ○ | ○ | ○ |

Page Break

End of Block: CES-D

Start of Block: STAI-S

Q25 Read each statement and select the appropriate response to indicate how you feel right now, that is, at this very moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

| | 1 (Not at all) (1) | 2 (A little) (2) | 3 (Somewhat) (3) | 4 (Very Much So) (4) |
|---|---|---|---|---|
| 1. I feel calm (1) | ○ | ○ | ○ | ○ |
| 2. I feel secure (2) | ○ | ○ | ○ | ○ |
| 3. I feel tense (3) | ○ | ○ | ○ | ○ |
| 4. I feel strained (4) | ○ | ○ | ○ | ○ |
| 5. I feel at ease (5) | ○ | ○ | ○ | ○ |
| 6. I feel upset (6) | ○ | ○ | ○ | ○ |
| 7. I am presently worrying over possible misfortunes (7) | ○ | ○ | ○ | ○ |
| 8. I feel satisfied (8) | ○ | ○ | ○ | ○ |
| 9. I feel frightened (9) | ○ | ○ | ○ | ○ |
| 10. I feel uncomfortable (10) | ○ | ○ | ○ | ○ |

Page Break

Q26 Read each statement and select the appropriate response to indicate how you feel right now, that is, at this very moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

| | 1 (Not at all) (1) | 2 (A little) (2) | 3 (Somewhat) (3) | 4 (Very Much So) (4) |
|---|---|---|---|---|
| 11. I feel self confident (1) | ○ | ○ | ○ | ○ |
| 12. I feel nervous (2) | ○ | ○ | ○ | ○ |
| 13. I feel jittery (3) | ○ | ○ | ○ | ○ |
| 14. I feel indecisive (4) | ○ | ○ | ○ | ○ |
| 15. I am relaxed (5) | ○ | ○ | ○ | ○ |
| 16. I feel content (6) | ○ | ○ | ○ | ○ |
| 17. I am worried (7) | ○ | ○ | ○ | ○ |
| 18. I feel confused (8) | ○ | ○ | ○ | ○ |
| 19. I feel steady (9) | ○ | ○ | ○ | ○ |
| 20. I feel pleasant (10) | ○ | ○ | ○ | ○ |

Page Break

Q27 Over the last **two weeks**, how often have you been bothered by the following problems?

| |   | | | |
|---|---|---|---|---|
| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
| Feeling nervous, anxious or on edge (1) | ○ | ○ | ○ | ○ |
| Not being able to stop or control worrying (2) | ○ | ○ | ○ | ○ |

Q28 Over the last **two** weeks, how often have you been bothered by the following problems?

| |   | | | |
|---|---|---|---|---|
| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
| Little interest or pleasure in doing things (1) | ○ | ○ | ○ | ○ |
| Feeling down, depressed or hopeless (2) | ○ | ○ | ○ | ○ |

Page Break

**End of Block: STAI-S**

**Start of Block: MCQ-30**

Q29 These questions are concerned with beliefs people have about their thinking. Listed below are a number of beliefs that people have expressed. Please read each item and indicate how much you generally agree with it. Please respond to all the items, there are no right or wrong answers.

| | Do not agree (1) | Agree slightly (2) | Agree moderately (3) | Agree very much (4) |
|---|---|---|---|---|
| Worrying helps me to avoid problems in the future (1) | ○ | ○ | ○ | ○ |
| My worrying is dangerous for me (2) | ○ | ○ | ○ | ○ |
| I think a lot about my thoughts (3) | ○ | ○ | ○ | ○ |
| I could make myself sick with worrying (4) | ○ | ○ | ○ | ○ |
| I am aware of the way my mind works when I am thinking through a problem (5) | ○ | ○ | ○ | ○ |
| If I did not control a worrying thought, and then it happened, it would be my fault (6) | ○ | ○ | ○ | ○ |
| I need to worry in order to remain organized (7) | ○ | ○ | ○ | ○ |
| I have little confidence in my memory for words and names (8) | ○ | ○ | ○ | ○ |
| My worrying thoughts persist, no matter how I try to stop them (9) | ○ | ○ | ○ | ○ |
| Worrying helps me to get things sorted out in my mind (10) | ○ | ○ | ○ | ○ |

Page Break

Q30 These questions are concerned with beliefs people have about their thinking. Listed below are a number of beliefs that people have expressed. Please read each item and indicate how much you generally agree with it. Please respond to all the items, there are no right or wrong answers.

| | Do not agree (1) | Agree slightly (2) | Agree moderately (3) | Agree very much (4) |
|---|---|---|---|---|
| I cannot ignore my worrying thoughts (1) | ○ | ○ | ○ | ○ |
| I monitor my thoughts (2) | ○ | ○ | ○ | ○ |
| I should be in control of my thoughts all of the time (3) | ○ | ○ | ○ | ○ |
| My memory can mislead me at times (4) | ○ | ○ | ○ | ○ |
| My worrying could make me go mad (5) | ○ | ○ | ○ | ○ |
| I am constantly aware of my thinking (6) | ○ | ○ | ○ | ○ |
| I have a poor memory (7) | ○ | ○ | ○ | ○ |
| I pay close attention to the way my mind works (8) | ○ | ○ | ○ | ○ |
| Worrying helps me cope (9) | ○ | ○ | ○ | ○ |
| Not being able to control my thoughts is a sign of weakness (10) | ○ | ○ | ○ | ○ |

Page Break

Q31 These questions are concerned with beliefs people have about their thinking. Listed below are a number of beliefs that people have expressed. Please read each item and indicate how much you generally agree with it. Please respond to all the items, there are no right or wrong answers.

| | Do not agree (1) | Agree slightly (2) | Agree moderately (3) | Agree very much (4) |
|---|---|---|---|---|
| When I start worrying, I cannot stop (1) | ○ | ○ | ○ | ○ |
| I will be punished for not controlling certain thoughts (2) | ○ | ○ | ○ | ○ |
| Worrying helps me to solve problems (3) | ○ | ○ | ○ | ○ |
| I have little confidence in my memory for places (4) | ○ | ○ | ○ | ○ |
| It is bad to think certain thoughts (5) | ○ | ○ | ○ | ○ |
| I do not trust my memory (6) | ○ | ○ | ○ | ○ |
| If I could not control my thoughts, I would not be able to function (7) | ○ | ○ | ○ | ○ |
| I need to worry, in order to work well (8) | ○ | ○ | ○ | ○ |
| I have little confidence in my memory for actions (9) | ○ | ○ | ○ | ○ |
| I constantly examine my thoughts (10) | ○ | ○ | ○ | ○ |

Page Break

Q32 I tend to bounce back quickly after hard times.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

Q33 I have a hard time making it through stressful events.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

Q34 It does not take me long to recover from a stressful event.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

Q35 It is hard for me to snap back when something bad happens.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

Q36 I usually come through difficult times with little trouble.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

Q37 I tend to take a long time to get over setbacks in my life.

- Strongly disagree (1)
- Disagree (2)
- Neutral (3)
- Agree (4)
- Strongly agree (5)

**End of Block: MCQ-30**

Start of Block: Demographic 2

Q38 What is your marital status?

- Married (1)
- Widowed (2)
- Divorced (3)
- Separated (4)
- Never married (5)
- Living with partner (6)
- Prefer not to answer (7)

Q39 Do you have any children, under the age of 18, living with you?

- No (1)
- Yes, I have 1 child that lives with me (2)
- Yes, I have 2 children that live with me (3)
- Yes, I have 3 or more children that live with me (4)
- Prefer not to answer (5)

Q40 What is your annual household income?

- Less than $10,000 (1)
- $10,000 - $19,999 (2)
- $20,000 - $29,999 (3)
- $30,000 - $39,999 (4)
- $40,000 - $49,999 (5)
- $50,000 - $59,999 (6)
- $60,000 - $69,999 (7)
- $70,000 - $79,999 (8)
- $80,000 - $89,999 (9)
- $90,000 - $99,999 (10)
- $100,000 - $149,999 (11)
- More than $150,000 (12)
- Prefer not to answer (13)

Page Break

Q41 What is your employment status?

- Employed full time (1)
- Employed part time (2)
- Unemployed looking for work (3)
- Unemployed not looking for work (4)
- Retired (5)
- Student (6)
- Disabled (7)
- Prefer not to answer (8)

Q42 What is your education level?

- Less than high school (1)
- High school graduate (2)
- Some college (3)
- Technical certifications (4)
- 2 year degree (5)
- 4 year degree (6)
- Master's degree (7)
- Doctorate (8)
- Prefer not to answer (9)

Q43 Do you have any comments or feedback?

_____

Q44 Would you like to receive a communication kit as a thank you for participating in this study? If you select yes, you will be redirected to a separate form for your address. Your answers in this survey will not be connected to your name or address.

- ○ No, thanks (1)
- ○ Sure (2)

*Skip To: End of Survey If Would you like to receive a communication kit as a thank you for participating in this study? If... = No, thanks*

**End of Block: Demographic 2**

# CHAPTER 3

# THE EXPERIENCES OF DISABILITY AND ABLEISM FOR INDIVIDUALS WITH HEARING LOSS DURING THE COVID-19 PANDEMIC

## ABSTRACT

Communicating during the COVID-19 pandemic through masks was a difficult and complex experience for individuals with hearing loss. Through a heuristic phenomenology approach, this study explores how eight co-researchers (i.e., participants) navigated masked conversations and reflected on how these conversations impacted their mental health. Qualitative analysis of their experiences resulted in four primary thematic categories: Communication barriers, personal strategies, response of others, and pre-pandemic mental health. Although the findings have implications for individuals with hearing loss, the greater implications are for their hearing communication partners and for helping professionals. Co-researchers suggest multiple strategies for hearing communication partners and helping professionals to increase their contribution for effective communication when masked.

Hearing loss is a condition that impacts multiple aspects of life, from navigating informal day to day interactions to employment and financial success (Borre et al., 2022; Tsimpida et al., 2022). Each individual with hearing loss has unique preferences with how they identify their hearing loss and how they navigate their communication experiences (James & McKee, 2022). Despite these differences, one shared trait of individuals with hearing loss is that most prefer to see a person's facial expressions and lips, to facilitate visual input as a communication aid. COVID-19 pandemic masking interrupted access to lips and faces (Garg et al., 2021; Ten Hulzen & Fabry, 2020).

Results from the exploratory descriptive quantitative study (paper 2) found a relationship between masked conversations and clinical depression/anxiety rates. As the daily number of hours in masked conversations grew for co-researchers (i.e., participants), depression and anxiety rates increased. However, this association was not found in individuals that identified as having depression or anxiety before the pandemic. For those who did not experience depression or anxiety prior to the pandemic, they were more likely to experience depression and/or anxiety during the pandemic. To help understand these findings and to learn from the experiences of those with hearing loss, an exploratory qualitative study was conducted.

## LITERATURE REVIEW

Masks, when worn by the person speaking, eliminates the ability to lip read and access facial expressions, both of which are primary accommodations that many deaf and hard of hearing people employ in order to navigate a listening environment. Lip reading is a visual process and needs uninhibited visual access to the mouth and facial features to

be effectively used (Chen et al., 2020; McGurk & MacDonald, 1976). A Canadian study conducted in 2021 surveyed 656 adults with hearing loss and found that 81% indicated it was difficult to understand people wearing masks (Poon & Jenstad, 2022).

Depression, characterized as a major mood disorder, has impacted many individuals throughout the pandemic (Ettman et al., 2020). The same trend is true for anxiety (Lakhan et al., 2020). Life disruptions, traumatic events, economic losses, isolation, and fear of health problems may all contribute to higher rates of depression and anxiety in the general population (Ettman et al., 2020). What makes individuals with hearing loss unique in context of the pandemic is how the communication barrier of masking influenced the depression and anxiety they experienced. The inability to lip read and see facial expressions due to the face being covered, cuts off social engagement, the ability to receive valuable information, medical care and multiple other listening situations in which lip reading has been essential.

The COVID-19 pandemic caused an interruption in health, livelihood, relationships, education, routines, and more for multiple people (Bates et al., 2021; Jazieh et al., 2020; Leroy et al., 2021; Papautsky et al., 2021). The virus and the resulting global shutdown had disproportionately negative effects on many vulnerable populations and these disproportionate effects brought to light deeper structural inequities (Gato et al., 2021; Khanijahani et al., 2021). The largest minoritized group in the United States and in the world, those with disabilities, was no exception to increased systemic inequities (Epstein et al., 2021; Kayess & French, 2008).

Historically, disability has been seen through the lens of the medical model with a focus on medical intervention and correction (Faeth, 2021). During the last couple of decades however, research has emerged to conceptualize disability, not as a problem that needs to be fixed but as a problem in the way society defines disability (Faeth, 2021). Critical Disability Theory (CDT) defines disability as a social construct, based on multiple aspects of a person's environment and *response* to their impairment, not just their impairment (Hamraie, 2016; Hosking, 2008). Through this lens, CDT suggests that environments have been built for those who are hearing and are oppressive for individuals with hearing loss.

Although masking measures were put into place to protect individuals from contracting and transmitting COVID-19 (Clapp et al., 2021; Gandhi et al., 2020), they notably widened the gap in society for individuals with hearing loss. To identify the lived experiences of individuals with hearing loss during pandemic masking, this study focuses on the following research question: What are the perceptions of DHH of communication, masking, and mental health?

## METHODOLOGY

### *Theoretical Framework*

***Heuristic Phenomenological Inquiry.*** This study was designed to gain a deep understanding of the experience of those with hearing loss during the COVID-19 pandemic. Conducted through the phenomenological approach of heuristic inquiry, this research focused on the lived experience of both the researcher and the co-researchers

(participants). Following the approach of Moustakas (1990), the key principles of heuristic research include the following:

1. Identifying with the focus or inquiry
2. Engaging in the process of self-dialogue
3. Acknowledging the importance of tacit knowing
4. Honoring individual intuition in coming to find answers
5. Engaging in a process of indwelling involving the search for deeper meaning in the answers
6. Creating conditions that allow the focusing on inner and outward data to clarify and answer the questions
7. Acknowledging the importance of the internal frame of reference of the individual seeking the answers

The methodology stages identified by Moustakas (1990) along with how each stage was completed in this research are outlined in Table 3.1.

> "Essentially, in the heuristic process, I am creating a story that portrays the qualities, meanings, and essences of universally unique experiences. Through an unwavering and steady inward gaze and inner freedom to explore and accept what is, I am reaching into deeper and deeper regions of a human problem or experience and coming to know and understand its underlying dynamics and constituents more and more fully. The initial "data" is within me, the challenge is to discover and explicate its nature. In the process, I am not only lifting out the essential meanings of an experience, but I am actively awakening and transforming my own self. Self-understanding and self-growth occur simultaneously in heuristic discovery" (Moustakas,1990, p. 13).

***Reflexivity***

Heuristic phenomenology inquiry was an appropriate qualitative framework because of the author's lived experience of hearing loss and professional experience of being a clinical social worker in the mental health field. I (K.S.) have genetic sensorineural hearing loss that was diagnosed at the age of four, which began as a mild loss and slowly progressed until I lost all hearing at the age of thirty. I received a cochlear implant (CI) when I was thirty-four years old and am considered bi-modal (wear a CI and

Table 3.1 Heuristic phenomenology stages (Douglass & Moustakas, 1985; Moustakas, 1990)

| **Methodology stage** | **Actions to complete stage** |
|---|---|
| Initial engagement | Observation of masking impact on myself, my personal networks of those with hearing loss, and in hearing loss support groups on Facebook. I began inner dialogue thinking about this population and the impacts of the pandemic. I gathered a team (SW mentors, audiology clinician, and audiology researcher), sought, and was awarded funding and began the quant portion of the study. In the quant analysis, I engaged in the questions that arose from the results and sought deeper understanding regarding the phenomenon. |
| Immersion | I conducted the data collection and immersed myself in the data. I read and reread, continued to self-dialogue, and consulted with my qual data dissertation chair, bracketed to keep my thoughts separate from the transcripts of my co-researchers, and allowed my tacit understanding to emerge in codes, categories, and subcategories within and across transcripts. |
| Incubation | I stepped away from the intense inner focus of the data, focused on other responsibilities and relationships, facilitated silence as intuition grew on an unconscious level, and felt ready for illumination once clarity began to surface in my mind. |
| Illumination | In this stage, breakthroughs occurred on intellectual, spiritual, and emotional levels. Re-emerging myself in the transcripts and research questions, I felt clarity, understanding, and connection with my co-researchers. For example, while reviewing a transcript, I recognized that I was illuminated with an answer that had arisen in the quant analysis. This answer didn't come until this stage of the process. |
| Explication | This stage was the result of all the "indwelling" that occurred in the previous stages. Themes and subthemes came together. A familiarity with the transcripts and my co-researchers, their facial expressions and descriptions facilitated a clear path of identifying quotes and perspectives that reinforced the themes. I reviewed the themes with my qual data dissertation chair. I sent the themes to an outside analyst and sent them to 3 of my co-researchers for member checking. |

Table 3.1 continued

| **Methodology stage** | **Actions to complete stage** |
|---|---|
| Creative synthesis | To honor the co-researcher's creativity and eagerness to share their creative works with me, especially their poetry, I created a synthesis in the form of a free-verse poem. To honor my approach to creativity, and to support my belief in disseminating research results to co-researchers, I created two infographics. The first was the result of the quantitative study. The second was the result of this heuristic qualitative inquiry. All three creative works are in the appendix. |

hearing aid). My CI allows me to have highly functional hearing in ideal hearing situations (no background noise, access to facial expressions and lip reading, low reverberation, etc.). However, in less ideal hearing environments (background music, crosstalk, intercoms, etc.), my hearing is quite limited. When the pandemic, and subsequent mask wearing began, I struggled to successfully navigate the hearing world. At the time, I was a new PhD student in the college of social work and out of concern for myself and others with hearing loss, I wanted to ensure our experiences were being noted and taken seriously. Before returning to school for a PhD, I had been a licensed clinical social worker for several years and am deeply invested in the mental health of vulnerable populations. When I could not find sufficient research studying the mental health impacts of the pandemic on those with hearing loss, I started this study. This research project became my dissertation and altered my research career trajectory.

***Participants and data collection***

***Subjects.*** Eight individuals met the inclusion criteria and agreed to participate in the study. The inclusion criteria were being 18 years or older, having any degree of hearing loss, having experience with masked communication, having reliable internet access, and be able to participate in an online Zoom call. The sample characteristics are in Table 3.2, in order of the age they received their hearing loss diagnosis. Six of the co-researchers were female, all were White, and the age range was from 26 to 74 ($M$=53.5; $SD$=16.8). All 8 co-researchers relied on hearing speech and lip reading to communicate. One co-researcher also uses American Sign Language (ASL) to communicate. Seven co-researchers were treating their hearing loss with audiological devices, the eighth is

seeking treatment. Most used additional technology to supplement their audiological devices (e.g., text messaging, telecoil, Bluetooth-streaming, etc.).

***Sampling Strategy.*** Those who chose to participate in the anonymous quantitative study (study 1) had the option to self-select into additional study opportunities. If they were interested, they provided an email address. These individuals were recruited through email with an invitation to participate in the interview phase of the masked communications study. For those interested in participating, they clicked a Qualtrics link and read the study consent. If they provided consent, the survey forwarded them to indicate their first name, best day/time for an interview, communication preference, and contact information. They were then invited to participate in a semi- structured interview that took place for 45-70 minutes through a live captioned, recorded Zoom/Otter.Ai video call. Once the recording began, co-researchers were again given the opportunity to provide consent to participate in the research study. Those who participated and chose to receive an incentive were mailed an electronic reusable notepad (Boogie Board) as a thank you for their participation. This notepad can be used by co-researchers to provide assistance in their interactions with others as it can be conveniently carried with an individual and notes can be easily written back and forth to ensure communication can occur. Once the conversation is finished, the screen can be easily cleared and ready for the next conversation.

***Survey Instrument.*** A semi-structured interview was used as the data collection instrument (in appendix). Questions focused on information about their hearing loss, how the pandemic impacted their hearing loss, and questions about depression and anxiety.

Table 3.2 Demographic characteristics of co-researchers.

| **Co-researcher** | **Gender** | **Current age/age of DX** | **Race** | **Primary form of communi-cation** | **Treatment of hearing loss** | **Frequency of masked interactions** |
|---|---|---|---|---|---|---|
| Barbara | Female | 42/birth | Caucasian | Oral | CI, HA | Daily |
| Melody | Female | 26/3 | Caucasian | Oral | HA | 2-3 days a week |
| Angela | Female | 52/6 | Caucasian | Oral, ASL | CI | Daily |
| Jayme | Female | 39/8 | Caucasian | Oral | BTE HA | Daily |
| Dorothy | Female | 67/8 | Caucasian | Oral | CI, HA, Crossover | 2-3 days a week |
| Leslie | Female | 69/12 | Caucasian | Oral | HA | Daily |
| Kevin | Male | 59/39 | Caucasian | Oral | CI, HA | Daily |
| Calvin | Male | 74/61 | Caucasian | Oral | None | Daily |

Definitions of depression and anxiety were read by the author mid-way through the interview. This was to ensure unbiased responses in the first half of the interview and a shared definition across co-researchers for the second half of the interview. The Interviews were recorded through Zoom (Zoom Version 5.12.9), backed up recorded through Otter.Ai (Otter.Ai Version 3.19.0.821and transcribed through Rev (Rev Transcription Version 2.0.0).

***Data Analysis.*** Transcriptions were uploaded into MaxQDA (MaxQDA Version 2022.4.1), a mixed methods data integrative software. Analysis closely followed the steps shown in Table 3.3, according to Heuristic Phenomenology analysis outlined by Moustakas (2011). In addition to, and in between each of these steps, the researcher kept memos (bracketing) of reactions and reflections, had multiple consultations with a qualitative researcher mentor, and kept an audit trail to document and construct credibility of data. To increase the rigor of the data analysis, the researcher utilized 1) member checking with three co-researchers and 2) sought feedback from a qualitative researcher who was not connected to the data in any way.

## RESULTS

The purpose of this study was to understand the perceptions of masked communication and mental health for adults with hearing loss or deafness. Semi-structured interviews and subsequent analysis produced in-depth accounts of the co-researchers' current and retrospective experiences with pandemic masking. There were several similar experiences across co-researchers as well as some differences. Results were organized into three main thematic categories: 1) Communication barriers and

Table 3.3 Analysis steps

| **Research question** | **Analysis steps (MaxQDA)** |
|---|---|
| What are the perceptions of DHH of communication, masking, and mental health? | 1. Enter descriptors and transcription into MaxQDA for first co-researcher<br>2. Immersion in data until it's understood in whole and in detail<br>3. Notes (codes): Identify qualities and themes<br>4. Construct an individual depiction: Retaining language & examples<br>5. Repeat process for each co-researcher<br>6. Composite depiction of the group<br>7. Identify 2-3 portraits of co-researchers who exemplify the group as a whole<br>8. Consultant reviews portraits<br>9. Member check the portraits<br>10. Design a creative synthesis of the phenomenon |

impact of barriers, 2) Personal strategies, and 3) Responses of others. These main themes have been broken down into subcategories. A fourth thematic category was a minor, but consistent, theme: Pre-pandemic mental health.

***Theme 1: Communication barriers and impact of barriers***

All co-researchers immediately identified masking as a barrier to effective communication because masks prohibited them from lip reading, a critical skill that those with hearing loss rely on to understand what a person is saying, albeit sometimes subconsciously. Some were fully aware of their need to lip read prior to the pandemic and some quickly learned how much they relied on lip reading at the start of the pandemic: "I could not understand people without reading their lips. I did not realize how much I depended on lip reading" (Dorothy). Co-researchers indicated that conversing with those wearing masks lead to significant negative impacts on their well-being: "Lip reading is big for me. It's a skill. I think that most of us that are hard of hearing learn on our own..... To me, it's survival. If I couldn't read lips. And so when people have masks on, it's very frustrating to say the least" (Leslie). Although masking was the main barrier, there were multiple barriers to communication and multiple impacts.

***Barriers.*** All co-researchers identified additional barriers to communication, resulting in poor understanding of speech. These barriers included the plexiglass windows, speakers with accents, speakers who mumble, speakers who change the subject, intercom systems, and background noise.

> I was back full-time in the office by June. Masks were still required at all times and we were also sitting behind plexiglass. So, between those two things, there was a lot of asking somebody to repeat themselves for a long time (Jayme).

> I would say now with people, whether people have a mask or not is obviously less than it used to be. But when they do have a mask, I have trouble. And I think people with a mask tend to mumble still. I think they speak lower. Now, I was also, when we got back out of the contact mode, or to the contact mode, and I started contacting people, it became more prominent that I couldn't understand them and I had to mention it (Calvin).

***Impact of barriers.*** Individuals with hearing loss deeply desire to successfully communicate and hear what the speaker is saying. When they cannot successfully navigate a conversation, their thoughts, emotions, behaviors, and mental health are affected: “I want to be able to understand, that's the biggest thing I want. I don't want any extra stuff. And if I can't understand and that makes my depression go up, that makes my anxiety level go up” (Barbara). Five of the co-researchers indicated that masking caused depression, anxiety, or both to increase.

> Just the anxiety leading up to. If I was going to an appointment or going to meet with a supplier, and we had to be masked. The anxiety of, "Am I going to be able to understand them? Am I going to be able to respond, and make the right decision? Am I going to say something that's completely..." If you have hearing loss, you probably had this problem. Somebody says something, you respond, and you're way off from what they asked. They're looking at you like, "What are you saying?" It's frustrating that that happens. It can be comical, at first. A lot of times the other person just kind of laughs it off like, "Oh, no. That's not what I was asking about." It's nice that they do that. When it happens over and over, you start questioning yourself and your value. "How much value am I adding to this situation, or scenario?" (Kevin).

> Well, seniors already have a lot of challenges where it's easy for them to be depressed. They need social experiences. So you take that away from us, that's more isolation and we feel more lonely, more cut off, more frustrated. It's like you don't look forward as much to your days because

> you can't see people, or communicate with other people. Very lonely (Leslie).
>
> That's when my anxiety kicks in. Even with medication, it gets to be overwhelming and I end up being one of those people who gets teary-eyed when I get frustrated, of course. So, it is mainly in my head. It's just pure frustration where there were times where I would have somebody actually come in who themselves didn't hear well and they didn't wear hearing aids. Even in the middle of the pandemic, I would pull down my mask and enunciate all my words. I think I just wanted somebody to do that for me (Jayme)

The barriers to communication, and the resulting impacts, were the most common and consistently discussed subject regarding how the pandemic impacted them. However, a very close second most common subject was about the constant work they put into communicating.

***Theme 2: Personal strategies***

Co-researchers described many ways they actively work on conversing with individuals who are masked. They discussed strategies and accommodations that helped them such as utilizing clear masks, asking for the speaker to repeat or speak louder, asking the speaker to pull their mask down, writing down important phrases, and using technology. Within these accommodations they employed additional strategies such as disclosing their hearing loss, advocating for themselves, and empowering themselves to walk away if the other person would not accommodate them. When their efforts were not enough, it led to negative coping strategies which included avoiding others, guessing/faking their way through the conversation and hiding their hearing loss. Because of its prevalent use as a strategy for both accommodation and avoidance, implementing the use of a communication partner is its own subtheme.

***Accommodations***. Co-researchers are well acquainted with the accommodations they need to hear others. Lipreading was the first go-to strategy to communicate with others. When their ability to lipread was impaired due to masking, several co-researchers (*N*=7) increased the use of additional accommodations, some of which worked well, some of which did not and some of which caused them additional concerns.

> Sometimes I would have to ask somebody to repeat two, three times. And if that didn't work, I would get a co-worker and say, "Let me find somebody that can better help you. I have a hearing loss. I'm not understanding what you're asking." ….. And I hate to say this, I'm by myself in my department. So in order for me to get help from somebody, I had to go to another department, interact with people there (Angela).

> I mean, at first it was really difficult. But then I realized that maybe I'm going to have to accommodate to it because I didn't know that we was going to get over this whole COVID situation. I thought it was going to be forever. So I just learned to accommodate hearing with a mask and work harder, listen harder, I guess (Melody).

> I think a lot of people got used to having to speak up. I did have coworkers that would send me an instant message to fill me in if they didn't speak loud enough (Jayme).

> I really appreciated the few places that used clear masks so that you could lipread, but those weren't very prevalent. That just made it very difficult. I even carried some clear masks with me. …… I would give them a mask and say, "Would you please wear this clear mask for me while we're talking? Then, you can throw it away when you're done." They would help. They would do that. Most people didn't quite understand it. Then, the mask kind of fogged up anyway. It didn't provide as good a benefit as I had hoped (Kevin).

> Then, my most recent one is the Roger On. So, this is the newest device, and it's supposed to be the best of the Select and the Pen together. So, this one works in the three different modes. You can use it in tabletop mode. You can also direct the beam so that you can focus in on a certain area. You can clip it on, and have it in presenter mode. Or, you can aim it at somebody at a 45 degree angle, and then it'll pick up that narrow beam. Got to figure out my cameras. It'll do that narrow beam. So, if I'm in a conference environment when I'm talking one-on-one to somebody, I can

> just aim it at them, and have it pickup, as well. I carry my little bag around, and I'm not embarrassed to do so. I just let people at the table know, "I'm going to put some microphones out. I'm not recording. This just streams into my ear so I can hear you." It makes things better for me (Kevin).

***Communication partner***. Seven of the eight co-researchers discussed their need to have a communication partner with them if they knew they were going to in a masked conversation. The eighth co-researcher did not specifically mention relying on a communication partner but did indicate their partner often suggested that he get help for his hearing loss, suggesting a reliance on the communication partner as well. The co-participants who spoke of it indicated they relied heavily on their communication partner, whether it was a friend, spouse/partner, or co-workers.

> Outside of work, I don't think I had too much of an issue, but that might be because I wasn't typically going shopping or anything by myself. I would have my husband or my children with me. My son has immaculate hearing, which is better than average. So, having him around is very helpful (Jayme).

> Yes. Well, I did not feel smart. I felt like they thought I was not very smart for some reason, but I would actually ask my husband to come with me and listen for me and that would help. If he was around to help me, if I was going on an errand or going someplace to a doctor's office or something, I always would ask that he come with me so he can help me hear. I did through the pandemic, have doctor's appointments that I had to go to. For the most part, I would always ask another person to come with me and help me here if it was a situation I was unfamiliar with (Dorothy).

Although most co-researchers indicated that their communication partners were helpful and comfortable with their role of being the “ears” for conversations, some co-researchers shared their concern with relying on a communication partner.

> You take a friend. So you lose all this independence (Leslie).

> I noticed that I wasn't enjoying going out to dinner with friends. I didn't like going to big gatherings because I just couldn't understand what was being said. I started staying home more. It was more of an impact... I'm happily married, and my wife has to bear the burden of this. Right? If we go out somewhere, she's translating for me, or repeating what people are saying all the time. So, I noticed that it takes away from her enjoyment, even though she never said anything or complained. I would notice that if I didn't hear something, I'd have to look at her, and have her repeat it to me. Because we've been married so long, I understand her voice, but I couldn't understand in a noisy environment (Kevin).

***Avoidance***. When co-researchers were unable to meet their communication needs successfully, or the efforts to communicate felt too big of a burden to bear, several of them would avoid social engagements, doctor appointments, large gatherings, employment situations, and other masked interactions.

> And they got frustrated sometimes because people get frustrated with people that can't hear, having them repeat themselves. So I felt like during the pandemic, I didn't really go out much because I mean, I didn't want to have to embarrass myself from not being able to hear and not have to deal with people getting frustrated with me (Melody).

> I would either just not go, or cancel. You know? I think there were a few times that I would take a notepad with me, and ask people to write things down. I would just avoid the situation if I could, at all (Kevin).

> So I avoid loud, noisy, crowded situations, parties. But most of my friends, if they know me, they know me, they know I'm hard of hearing. Sometimes I don't hear clearly what's being said, and I talk at a turn or I'll say something that was discussed previously and people have changed subjects and that's kind of embarrassing (Dorothy).

Many individuals with hearing loss choose to remain in the hearing world and employ many accommodations to effectively hear in their personal, social, and professional environments. When masking became a health strategy to protect people from the transmission of COVID-19, those with hearing loss had to face a nearly

insurmountable challenge: navigate the hearing world with the loss of lipreading, which was one of the biggest accommodation skills they had. Yet, many of the co-researchers in this study continued to implement accommodations to navigate listening situations. These accommodations had varying levels of effectiveness and the loss of lip reading remained a challenge. When negative strategies were embraced, it was often the result of having failed communications, in large part due to the reactions and responses of other people.

***Theme 3: Response from others***

A major theme in the data was how the responses of hearing people contributed to their communication success (or lack thereof). Most co-researchers discussed how the patience and attitudes of others impacted their access to communication and impacted their mental health, moods, and emotions. Subthemes are categorized as helping professionals and lack of understanding.

> I hate to say it, when people do that, it kills me because I know my store well. I can tell you how to get whatever product you're looking for, no matter where it is in the store, "This isle, this section, top shelf middle." That when people say, "Nevermind, you're good," it makes me feel like less of a person. And I can say it's part of being deaf, but I'm a fiercely independent person, so it does take its toll on me (Angela).

***Helping professionals***. Co-researchers had some communication experiences with professionals that were very positive: “And many of them would not pull the mask down. I was blessed, I had a doctor that would do it for me because I would keep my mask on” (Leslie). However, one of the consistent experiences across co-researchers was the lack of concern or a refusal for the helping professional to help them hear.

> But I go in there for a doctor's appointment my first time meeting him, and I tell them I have a loss. I'm having a hard time understanding with just the cochlear because at that time I was wearing an N5 and now I'm wearing an

> N6….. My programs were not really quite up to date. And I mean I had it as loud as I possibly could go….And he comes in wearing a mask and I said, "I will stand on the other side of the room. If you can please pull your mask down so I can read your lips or please write your stuff down." He refused to do any of that. And I was very, very emotional at the time, especially with the fact that I had lost the hearing and I didn't have anybody with me so I couldn't look to somebody else to tell me what they said. And I walked out of there crying. I was so angry, I was so upset. That's really the first time I felt like there's only been one other time that I felt like my hearing was used against me (Barbara).

One co-researcher had a sister with severe hearing loss who contracted COVID in a nursing facility and was quite distressed with the facility employees who lost her sister's hearing aids:

> My sister died partly because of COVID, because we were not allowed to go into the facility where she was recovering from hip surgery and make sure the nursing staff was taking the right care of her and making sure she was getting enough water. They were not taking the right care of her. So I feel like because of COVID is one of the reasons my sister's no longer here and she was cut off because sometimes the hearing aids are lost in long-term care hospitals and rehab places. And it was very, very traumatic experience for our whole family to see all that she was going through (Leslie).

Another co-researcher works in a grocery store, and when stocking shelves, is not able to see if someone is trying to talk to her:

> We had a nurse standing ten feet away from me screaming at me because she couldn't get my attention. I honestly didn't hear her. And one of my co-workers approach her and said, "Can I help you?" She goes, "Yeah, this one doesn't turn around." So my co-workers said, "Well, ma'am, she is deaf, but she knows what you can do with her." Believe it or not, she said, "Well, maybe she should have a sign on her back." I'm so insulted (Angela).

***Lack of understanding.*** Although each of the co-researchers had experiences with people who were patient, it was more common for them to share masked communication experiences that occurred with speakers who were impatient, lacked

empathy, and lacked understanding. These interactions had a strong negative effect on their perceived value and worth, as well as increasing their anxiety.

> The worry that people weren't wanting to accommodate or be understanding at least. I don't like confrontation at all, so normally I wouldn't be very confrontational about it. It just would make me breathe really fast. Even thinking about it right now, I'm getting the shakes and just the nervousness really (Barbara).

> The way most people would respond, unfortunately, is that the first time you asked them, they would respond, or repeat it. Then, after that, they'd just... "Oh, never mind. It's not important." I would get dismissed. It was not a good feeling because then it just made me withdraw even more (Kevin).

> That's my first impression anytime I see somebody with a mask. There's time when I know I'm having a rough day hearing, that I pray that I'm coming today as [inaudible ]. I don't know if I had the patience to try to figure it out because I'm already worried that you couldn't talk to me and your mouth is covered and my hearing is not good on that day. Inside it's just a little bit rough when I get, "Never mind, you're good." That's just... I don't know. It's like a slap in the face sometime when that happens. And it didn't help my anxiety because when we had the pandemic, everybody had a mask on. Couldn't come in the store without a mask. It was very stressful because I don't know that I had to deal with that when I try to... It's just terrible (Angela).

Many co-researchers offered solutions to the hearing population to help them decrease their biases towards those with hearing loss and to increase their awareness: “I would love to tell them, take a couple of earplugs, put them in your ears for one day and don't take them out. That's what it's like. Put yourself in their shoes and understand what they're struggling with, but they can't fix” (Dorothy).

A common experience for individuals with hearing loss, as emphasized by the co-researchers in this study, is that when they do not hear someone, the person speaking is quick to dismiss the topic by saying “never mind” instead of putting in the effort to

clearly communicate. Being dismissed in masked communications was a risk factor in increasing rates of depression and anxiety. However, not all individuals in this study experienced worse mental health as a result of masking.

***Pre-pandemic mental health***

Some co-researchers (*N*=2) did not believe that pandemic masking increased depression or anxiety, not because it was not stressful, but because they had learned to manage their hearing loss-related mental health issues prior to the pandemic: "I went through so much worse before the pandemic hit….I'll always just think of as being everyone wearing masks and not being able to read lips. It was not a trigger for me though (Dorothy).

> Anxiety is a lot of nervous energy. I don't know what to do about, I don't know where to go. Worry is a big part of that. Inability to put myself in a calm place. Nervousness. That was a big problem for me. I'll be honest with you, I started self-medicating myself because I didn't know how to calm myself down. I didn't know how to find that sense of relaxation and always on edge. I think that anxiety really went right along with my depression. I didn't know how bad it was going to get. I didn't know how to fix it, and I didn't know how I was going to live with it. It led me down a very, very dark path. Of course, when I start doing something like self-medicating, I'm only covering up the problem. It's not going away, and it's only making it worse. I pushed away from people around me that might have been helpful, but I just wanted to just be by myself and isolate. That was a very difficult time, and I'm not proud of the way I handled it. Through the HLAA, the support groups and the kind of love and support that I needed and the change in my lifestyle, I had to stop working. I went through a lot of that. God, I remember my mother was suffering from dementia and she couldn't talk. She developed aphasia, which is the inability to think of the words that you want to say. The few times she would try and talk to me, I could not hear her, and I would just be in tears (Dorothy).

> I've gotten over this aspect of it, but it made me feel like that I wasn't good enough for anybody to like me or to have a boyfriend or anything like that. I mean, I guess it did. I mean, it didn't make me that depressed, but there's been times where I have been depressed because of my hearing loss I

> mean, I just accept it now. If somebody doesn't want to be my friend or don't want to be with me because of my hearing loss then they're not worth enough to be in my life anyway. And I just really try to think of it that way instead of trying to get people to like me and trying to be friends with everybody and trying to keep up with the friends. I just let it be and I quit trying so hard. And I mean, it's really showed me who my real friends are and what's more important in my life, which is my family, my dogs, and my job and my mental health. I don't know. I try to think of a mindset of you're deaf, obviously, but you can't let that affect your life (Melody).

One co-researcher began losing hearing later in life (age 60) due to a series of bike accidents and did not believe his hearing loss impacted his mental health. However, he acknowledged that he sees a counselor to help him "deal with everyday things" and that if he felt depressed, he would talk with his counselor about it (Calvin).

## DISCUSSION

This research study was designed to gain insight and in-depth understanding of how the mental health of those with hearing loss and deafness have been impacted by COVID-19 pandemic masking and to help explain results of the quantitative study. Consistent with studies on pre-pandemic communication barriers (Hogan et al., 2011; Okoro et al., 2009; Sheppard & Badger, 2010), the results of this study found that for most co-researchers, they experienced depression and anxiety as a result of masking as a barrier to communication. All co-researchers in this current study reported difficulty hearing others in masked conversations, and most ($N$=7) reported adverse impacts of communication barriers on their mental health.

The prior study found that those with increased levels of depression and anxiety during masking were those who did not experience depression or anxiety prior to the pandemic. The findings of the current study may partly explain this trend from a couple

of different perspectives. First, some individuals identified and treated their mental health issues prior to the pandemic, thereby, having coping skills and strategies already in place to manage the increased stressor of masking. Second, some individuals intentionally isolated themselves prior to the pandemic because of no longer wanting to navigate a world made for hearing people. These individuals limited their interactions during the pandemic, thus not needing to navigate masked conversations often. Those who were engaged with the hearing world quickly learned during pandemic masking that they would not be able to rely on the same strategies they had been using. The lack of using lipreading and visual cues led to a negative impact on their mental health.

An additional finding in this study is that the attitudes and responses of others largely contributed to their negative experiences with masking. This was particularly true in medical and professional settings. Individuals with disabilities, traditionally, have had substandard medical care because of accessibility gaps despite the ADA guaranteeing equal access to care (Iezzoni et al., 2022). A recent study utilized focus groups to identify physicians' attitudes towards caring for people with disabilities and found high levels of bias among primary care doctors and specialists, even to the point of doctors and practices strategizing ways to turn away people with disabilities (Lagu et al., 2022). The results of the study revealed multiple discriminatory comments from the physicians about patients with hearing loss. They did not want to lose money through providing an accommodation (e.g. ASL interpreter), were concerned about violating HIPAA if they talked too loudly as people outside the examination room could hear them, or were more

comfortable talking with the communication partner that the patient brought with them than with the patient with hearing loss (Lagu et al., 2022).

Discomfort and discrimination from able-bodied people towards people with disabilities is not isolated to just medical care, but has also been widely studied in the helping professions and in the general population (A. Cooper et al., 2004; A. E. Cooper et al., 2003; Friedman, 2019; Kattari, 2020; Wolbring, 2008). It is common to avoid people with hearing loss and to put the burden of communication and accessibility squarely on their shoulders. While there are multiple studies on how people with hearing loss cope, the years of denial they experience before seeking help, and the psychosocial impact of stigma on help seeking behaviors (Barker et al., 2017; Bennett et al., 2021; Rogin & Abrams, 2016), there are fewer studies on how the attitudes and practices of society play a role in these coping and treatment behaviors. Society often frames hearing loss, and other disabilities, as a limitation of the individual that needs to be treated or cured and fails to identify how the limitation is actually created by able-bodied people (Hamraie, 2016).

***Implications for professional health care, agency workers, and social workers***

Findings of this study indicate that successful interactions are greatly hindered when the hearing population lacks patience, understanding, or tolerance of accommodations. Medical professionals were specifically pointed out as insensitive to addressing communication needs for the deaf and hard of hearing during pandemic masking. Multiple studies indicate there is a strong need for healthcare professionals to increase access to health through decreasing communication barriers for the deaf and

hard of hearing, with a special emphasis on the communication needs of older adults with hearing loss (Assi et al., 2020; Chen et al., 2020; Hommes et al., 2018).

Not just a problem with healthcare, co-researchers shared negative experiences with other helping professionals as well. Agencies such as the social security office and education systems such as IEP meetings were also identified as not just inaccessible, but intentionally discriminatory in their responses to individuals with hearing loss. Although co-researchers understood that professionals were concerned about COVID-19 transmission, they also believed that there were options to enhance communication, even with masking in place.

To address the need for helping professionals to increase accessibility in their spaces, there have been multiple calls to train physicians to learn how to communicate with deaf and hard of hearing individuals, especially given that hearing loss is one of the most common conditions they will see (Barnett, 2002). Some medical students receive empathy training through virtual reality simulations (McLaughlin et al., 2021) while others have been encouraged to ask about communication preferences (McKee et al., 2015; Scheier, 2009). However, these calls to accessibility may not be enough due to the systemic nature of treating individuals with disabilities as substandard people.

***Solutions from the perspective of co-researchers***

The final question of the semi-structured interview asked if the co-researchers had anything else they wanted to share about masking, hearing loss, and mental health. Several responses to this question offered solutions and advice to the hearing population, to help decrease bias. They suggested that others pull down their mask if requested

because of a hearing barrier and if the person didn't feel comfortable pulling their mask down that they should actively find another way to communicate. Co-researchers also suggested hearing people should work to increase empathy and understanding, as well as recognize that communication is a two-way street.

***Limitations***

Due to qualitative methodology, this study is not appropriate to generalize to all individuals with hearing loss. This study intentionally seeks to understand the lived experiences of the co-researchers, thereby providing possible insights and illumination into the masked world of those who rely so heavily on lip reading. Qualitative research coding is often done in teams due to the risk of bias and the need for triangulation. As this is a dissertation study, the research was conducted solely by the author. However, there were multiple strategies implemented to triangulate the data, strengthen the data collection and analysis process, and ensure research integrity. These strategies included regular coding meetings with a heuristic phenomenology expert, keeping an audit trail (emails with co-researchers and dissertation committee, taking detailed notes on personal observations and reactions), having an outside qualitative researcher review the findings, and member checking. It's also important to note that the methodology itself allows for the intuition and personal experiences of the researcher to interact with the data process.

Another limitation is the lack of racial and gender diversity among co-researchers. Although there was diversity with age and employment status, a weakness of the study is that only Caucasian people and either male or female gender are represented. Additional research needs to focus on recruiting diverse co-researchers, particularly because of the

unique experience of having more than one minoritized identity during pandemic masking.

Finally, recruitment could have been hindered because of the platforms used to conduct this research. It is common for individuals with hearing loss to avoid online interactions (or any interactions) if it will be a challenge to hear. For this reason, it was imperative that Zoom and otter.ai technology had a strong internet signal and was working well so that the live transcription could be effectively used. However, a backup plan was put into place if needed (questions answered through email correspondence or chat feature). Future research should take into consideration communication preferences and ways to reach individuals who may be avoiding communication interactions.

### *Future Directions*

This study sought to understand the impacts of masking on individuals with deafness or hearing loss. It also sought to help explain the results of the quantitative study. However, further research is needed to identify additional explanations. In addition, it is unknown if the impact of masking on depression and anxiety is short term or long term. Longitudinal studies need to be conducted to determine the longer-term effects of masking on mental health for those with hearing loss.

### *Creative Synthesis*

Upon completion of heuristic phenomenology, a creative synthesis is undertaken by the author to compile the experiences of co-researchers in a meaningful, artistic way. The first creative synthesis from this project is a poem, created in honor of the co-researchers and their passion for creative writing. The second creative synthesis is two

infographics. The first is a result of the quantitative study and has been disseminated to participants, social media platforms, and my website (hearinglossimpact.com). The second is a compilation of suggestions from the participants of the qualitative study for individuals who are wearing masks to ensure they are clearly communicating. All creative synthesis works are in the appendix.

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# APPENDIX 3

***INTERVIEW GUIDE***

Hello. My name is _____ and I am a PhD student at the University of TN. Thank you for meeting with me today. I will be asking you questions about what it has been like to communicate with people who are wearing masks and it has affected your moods. Before we start the interview, there are a few things I want to go over with you.

1) I will be recording the interview so that I can transcribe it. Once it is transcribed, I will delete the video recording.
2) I will provide a pseudonym (a code name) and not refer to you by your actual name on the video recording. This is to protect your confidentiality.
3) The interview will take 45-60 minutes.
4) You should already have read the consent. When I start recording, I will confirm with you that you consent to participate in this research.
5) At the end of the interview, I will put a link in the chat window that will lead you to a short demographic survey. At the end of the survey, you will have the opportunity to enter in your mailing address. If you choose to enter your mailing address, you will be sent a portable, electronic note pad by mail. Your contact information and address are not connected to any of your interview or survey responses.
6) After mailing the note pad, your address and any associated contact information will be deleted immediately, to protect your confidentiality.
7) Do you have any questions for me before we get started?

Push "record."

Interview Guide

1) Thank you for agreeing to meet with me today. Have you had a chance to read the consent? Do you provide consent to participate in this interview?

2) Will you tell me a little bit about your hearing loss?
(Prompts: What type of hearing loss? When did you lose your hearing?)

3) How did/has the pandemic affected your hearing loss?
(Prompts: What has been challenging?)

4) What is it like to have a conversation with someone who is masked?
(Prompts: What is hard? What helps?)

5) How do you define disability?
(Prompts: How do you know when someone has a disability? What do you see or hear in them?)

6) How did the pandemic impact people with disabilities?
(Prompts: What kinds of disabilities went unnoticed in the pandemic? Or which ones were more noticed?)

7) Would you define yourself as having a disability?
(Prompts: What would feel disabling to you?)

8) How do you think the pandemic would have impacted you if you did not need to communicate with people who were wearing masks?

9) Anxiety involves persistent and excessive worry that interferes with daily activities. This ongoing worry and tension may be accompanied by physical symptoms, such as restlessness, feeling on edge or easily fatigued, difficulty concentrating, muscle tension or problems sleeping. Did conversations with people who are masked cause you to feel anxiety? How so? What helped you when you felt anxious (or) what helped you not to get anxious?
(Prompts: What situations contributed to feeling anxious? What worried you about not hearing someone behind a mask?)

10) Depression is an illness that negatively affects how you feel, the way you think and how you act. Symptoms include feeling sad, loss of interest in activities once enjoyed, changes in appetite, trouble sleeping or sleeping too much, loss of energy, feeling worthless or guilty, difficulty thinking or making decisions, or thoughts of death or suicide. Did conversations with people who were masked cause you to feel depression? How so? If not, what helped prevent you from feeling depressed?
(Prompts: When you are unable to hear someone, what kinds of thoughts and feelings does it cause?)

11) Is there anything else you want me to know regarding communication with people who were wearing masks? Is there anything you want me to know about what it felt like to have a hearing loss in the pandemic?

Conclusion:

Thank you so much for your time today. I am posting the survey link in the chat box now. Do you see it? Please click on the link and it will open up a new window. If you will complete the questions in the short survey, and if you would like to, share your mailing address.

Survey questions:

1) How old are you?

2) What is your gender?
3) What is your race/ethnicity?
4) How often did you interact with people wearing masks?
5) What were the benefits of communicating in the pandemic?
6) What was hard about communicating in the pandemic?
7) What is your primary form of communication? (e.g. speech, ASL, text, etc)
8) What is your mailing address?

***CREATIVE SYNTHESIS***

I Just Want to Understand

My heart is pounding.

My voice is shaking.

“What?”

I’m straining to listen.

But I cannot see your lips.

“Can you repeat that?”

I lean in, I try to guess.

I have to disclose.

“I am deaf, what did you say?”

Never mind.

I think that is what you just said.

“Can you lower your mask?”

Forget about it.

Now that I understood.

# Impact of Masking on Individuals with Hearing Loss

Results from the Masked Community 2021 Study

We surveyed 100+ people with hearing loss from the University of Tennessee Audiology clinic and from social media hearing loss support groups during the COVID-19 pandemic when masking was required

Principal Investigator:
Kristel Scoresby, LCSW, PhD Candidate
kscoresb@vols.utk.edu
The University of Tennessee, Knoxville

## Listening comprehension, on average, decreased by 25% in masked communications across listening situations

### Quiet environments

How easy it is to hear in a quiet environment such as a small office

### Background noise

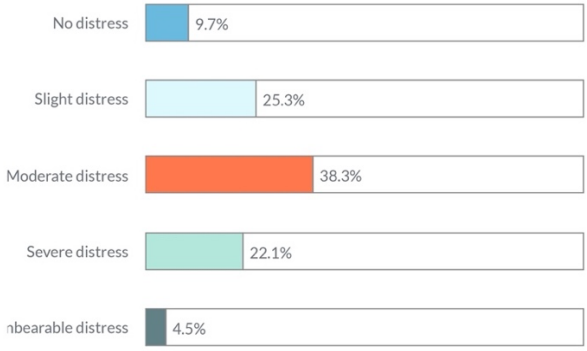
Listening to others when background noise is present such as in a grocery store

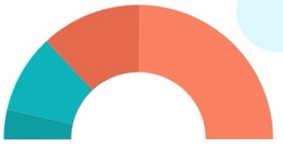
### Reverberation

Hearing when in a large room such as a theater or church service

## When talking with people who are wearing masks, what is your level of distress*?

*Distress defined as "extreme anxiety, sorrow, or pain."



Hearing loss levels of participants

- Mild (7.19%)
- Moderate (18.95%)
- Mod-Severe (24.18%)
- Severe (49.67%)

## Mental health factors



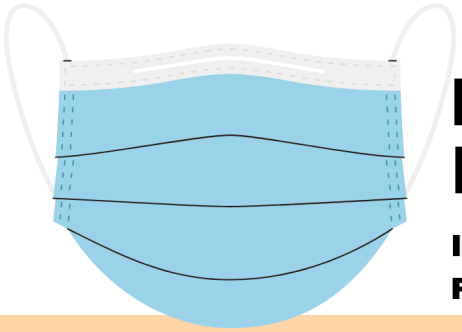
**43%**
**Met criteria for major depession disorder**

**36%**
**Met criteria for generalized anxiety disorder**

As number of hours per day in masked conversations increased, depression and anxiety scores increased

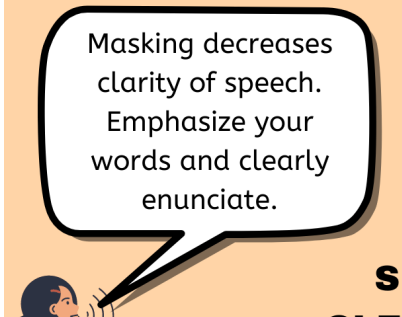
However, a more significant predictor of depression and anxiety was what a person believed about their thinking (e.g., constantly examining thoughts or focusing on worried thoughts)

HearingLossImpact.com

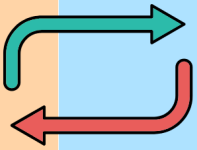


# MASKING REQUIRED?

## IMPROVE YOUR COMMUNICATION FROM BEHIND A MASK




### SPEAK CLEARLY



### BE WILLING TO REPEAT YOUR WORDS

Communication takes effort. Be okay with repeating or restating what you are trying to say.

### USE A CAPTIONING APP ON YOUR PHONE

Download a free app like LiveTranscribe or otter.AI to transcribe your words on your cell phone as a visual display.





### WRITE IT DOWN

Make it a habit of having paper and pen with you and writing down important information when communicating.

### MASKING CAN PREVENT MANY PEOPLE FROM HEARING YOU. BE AWARE AND DO YOUR PART FOR TWO-WAY COMMUNICATION.

Instead of waiting for someone to ask for a hearing accommodation, be prepared in all of your conversations to find ways to increase listening ability when your lips and facial expressions are covered by as mask.



Hearinglossimpact.com

# CONCLUSION

This dissertation explored the impact of COVID-19 pandemic masking on the metacognition, mental health, and experiences of individuals with hearing loss. As individuals with hearing loss rely on facial cues, lip reading, and uninhibited speech signals, the purpose of this study was to determine the effects of blocking those abilities through the use of face masks. The purpose of this dissertation was to 1) identify the rates of depression and anxiety, 2) understand how metacognition influenced depression and anxiety, and 3) to gain an in-depth understanding of how masking affected individuals with hearing loss.

The systematic review identified the communication barriers that contribute to negative mental health. Findings indicated multiple communication barriers: Listening fatigue, listening avoidance, lack of consideration from hearing partner, poor listening acoustics, reduced access to side conversations, communication abuse, and ableism. These barriers are associated with higher rates of heavy drinking, use of cannabis, depression, mental stress, and suicidal ideation as well as lower rates of quality of life and self-worth.

Several gaps in the literature were identified in the systematic review. One of the biggest gaps was the lack of research on the communication barriers that the COVID-19 has introduced, masking. The research questions arising from the review of the literature and that were studied in this dissertation were:

1. What is the prevalence of depression and anxiety for DHH during the COVID-19 pandemic?
2. What is the relationship between masking, metacognition, and mental health factors?
3. What are the perceptions of DHH of communication, masking, and mental health?

The quantitative study answered the first two research questions while the qualitative study answered the third research question. Utilizing an exploratory cross-sectional study design, the quantitative study utilized a web-based survey and standardized measures to identify the impact of masking on communication, metacognition, and mental health. Findings resulted in a statistically significant 25% decrease in understanding people who were wearing a mask. Approximately x percent of participants experienced depression and anxiety. As the number of hours of masked communication per day increased, so did the rates of anxiety and depression. In additional to number of hours in masked communication, metacognition was also a strong predictor of depression and anxiety. In a post-hoc analysis, there was a distinct difference in rates of depression and anxiety for those who had previously experienced depression and anxiety versus those who did not. Those who did not experience depression and anxiety pre-COVID were more likely to experience depression and anxiety during COVID.

To further explore these findings and to understand the perceptions of masking on mental health, a qualitative heuristic phenomenology inquiry was conducted. There were three main findings and one minor one. Participants experienced an increase of communication barriers in nearly every listening situation they encountered when people wore masks. With the increase of communication challenges, many of them increased the hard work and effort they already put into listening situations. They especially felt reliant on a communication partner and were fearful to face listening environments

without one. When their efforts to communicate were not successful, they avoided leaving their home and engaging in conversations with others, whether it was in informal gatherings, or formal appointments. Another main finding was how much bias hearing people had towards individuals with hearing loss when they could not hear well behind the mask. Although some people were patient and tried to help the person with hearing loss communicate, many demonstrated a lack of understanding, compassion, or willingness to accommodate. Of particular note were helping professionals, many of whom were unwilling to make the required effort for a successful two-way conversation. The final theme was the pre-pandemic mental health of participants. Those who struggled with depression or anxiety prior to the pandemic either figured out how to be resilient to the hearing world or avoided the hearing world and did not feel their anxiety or depression was triggered by pandemic masking.

The systematic review, quantitative, and qualitative study together identifies how communication barriers impact people with hearing loss. Pandemic masking increased these barriers, and in many instances, contributed to a rise in anxiety, depression, and challenging metacognitions. These barriers also increased the need for accommodations, avoidance, and reliance on others. Future research should address the long-term impact of masking as a communication barrier, skill development to navigate difficult metacognitions that activate in stressful communication environments and increasing the awareness and empathy of hearing individuals.

## VITA

Kristel Scoresby received her Bachelor and Master of Social Work degrees at Brigham Young University in Provo, Utah. She has extensive history in clinical social work, providing mental health counseling for individuals, couples, and families who have experienced non-bereavement grief, loss, and trauma. She maintains a clinical practice, is a graduate research assistant, teaches undergraduate and graduate social work students, and conducts research. Her interdisciplinary research focuses on the integration of mental health and audiology, impact of hearing loss and mental health, and reducing communication barriers of ableism for individuals with hearing loss. Kristel Scoresby will receive a PhD in Social Work in May 2023 and will begin an assistant professorship position.