ARTICLE 17

MOTHERSCHOLARS WITH DISABILITIES

Surmounting Structural Adversity During COVID-19

Stacey R. Lim
Central Michigan University
Jessica P. Cerdeña
Yale University
Katharina A. Azim
SUNY at Buffalo
Kathryn Wagner
Gallaudet University

Barriers for those with disabilities have existed before the COVID-19 outbreak, despite efforts to create equitable working environments and accessible accommodations. During the pandemic, however, existing barriers to equitable workplaces and accessibility support have been exacerbated for one of the largest, overlooked minority populations, with 1 in 4 people having some form of disability (CDC 2020). While the individual lives of people with disabilities are greatly impacted in their personal and professional environments, these issues exist on a systemic basis. The Social Model of Disability (SMD) posits that there are social and environmen-

---

Snapshots of History: Portraits of the 21st Century Pandemic, pp. 133–140

tal structures that are oppressive to those who have disabilities (Samaha 2007). Examples of barriers that individuals with disabilities face can be physical and environmental (e.g., lack of building access for wheelchair users), organizational (e.g., legislation), information-accessible (e.g., lack of closed captioning and/or American Sign Language (ASL) for someone with hearing loss), or attitudinal (e.g., discrimination). When the COVID-19 pandemic caused universities to shut down and swiftly switch to new teaching modalities, academics with disabilities were met with new challenges that they had not encountered before, such as, but not limited to: missing or faulty captioning in virtual meetings (McKee, Moran, and Zazove 2020), limited visualization of facial expressions with opaque mask-wearing (Saunders, Jackson, and Visram, 2020), and inadequate screening for those with previous mental health issues (Pfefferbaum and North 2020). Even when these options are made available, the burden is often placed on the individual with a disability by, for example, jumping through administrative hoops or paying out of pocket for services that should be existent in the first place.

In these narrative essays, we share our experiences as motherscholars with disabilities before and during the COVID-19 pandemic. For the purposes of this research, the term "motherscholar" denotes the intertwined and shared identities as women parenting young children while navigating positions in academia. We use the SMD as a framework for thinking through our individual experiences and discussing the barriers that we encountered during the pandemic. Just as our lived experiences differ, so do our narrative styles in which we try to give language to our encounters, thoughts, and emotions. We make recommendations on ways higher education institutions can create a more equitable and accessible work environment during and after the pandemic.

Unmasking the Challenges of Communication Access: Stacey R. Lim

Prior to the pandemic, my Americans with Disabilities Act (ADA) accommodations were straightforward—a personal amplification system provided to me by the university that I would use in meetings. However, the pandemic threw me into a tailspin: I was faced with listening situations so novel I had no idea what kind of accommodations I needed.

Before the pandemic, I would introduce myself to my students by sharing that I was born with a profound, bilateral, sensorineural hearing loss, and that I currently wear a cochlear implant that I received at 18 years old, having previously worn hearing aids since I was 8 months of age. In our current times, although I can still understand many mask-wearing people in an ideal listening environment, there's always stress and anxiety that I won't understand them. Masks obscure facial cues and lip movements, and negatively affect speech clarity (Saunders, Jackson, and Visram 2020). When the pandemic began, I worried about whether my students would have negative perceptions of me if I couldn't understand them, since people who are d/Deaf and Hard of Hearing are often stigmatized by those in the hearing community (David and Werner 2016).

This semester, I'm lecturing in a HyFlex mode to 90 students, some of whom attend in person and some of whom attend, simultaneously, online. It's exhausting to teach this way, being worried that I won't understand a student's response to a question, whether they are in-person or online. Sometimes, I ask a student in the front row to repeat a comment someone in the back of the classroom made—an environmental barrier in the SMD framework affecting communication access—because sound intensity decreases dramatically as the distance between the speaker and listener increases (Gelfand 1998). Occasionally, a disembodied voice sounds over the classroom speakers—but luckily, most online students prefer to type their questions into the chat box. I don't always understand the disembodied voice and there is always that one student that I simply can't understand, no matter what I do. Sometimes, I must pull out my phone to transcribe their voice.

The switch to virtual meetings also poses challenges for accessible communication. On the one hand, the positive benefit of meeting online for service-related or departmental activities means that I don't have to contend with trying to follow larger group conversations in a socially distanced and masked environment. If technology functions as intended, I should theoretically have visual access to everyone. On the other hand, videoconferencing can lead to "Zoom fatigue" due to the lack of true synchronicity between audio and video, challenges with technology, and lack of access to different non-verbal cues (Wiederhold 2020). For people with hearing loss, and particularly those who rely on speechreading, these challenges are exacerbated (Goad 2020).

The committee meeting starts, and because there are challenges in the quality of the signal being transmitted over the videoconferencing software, one of the committee members proposes, "Let's turn off the cameras to save bandwidth." One by one, the pixelated faces become blank squares, and I want to scream in despair. Neither option is great—videos lag or jump in spurts, with lips moving out of sync with the audio, or squares with no faces. Without visual cues, it is harder to understand the different accents and dialects (Tatman and Kasten 2017). This is the first meeting I have where I find it difficult to follow the conversation. Since automatic transcription is not yet available at the start of the pandemic on my university's videoconferencing platform, I take out my smartphone and open an automatic transcription app. For people who speak clearly and have standard American English accents, the audio is well transcribed. For everyone else, the app is essentially useless, transcribing nonsense or absolutely nothing. While automatic speech transcription apps provide some access, speaker characteristics (Liyanagunawardena 2021) and the acoustic environment still present challenges. How am I supposed to be an active member of this committee, when it is hard to follow, and I hadn't yet figured out what kinds of accommodations would work best for each situation?

An additional issue I faced as a new mom is caring for my child during these already exhausting meetings. Since my husband and I did not use our childcare during the beginning of the pandemic, my one-year-old daughter stayed home while we worked. During times I had to videoconference, I divided my auditory attention between the call and my daughter. Sometimes she babbled and was noisy, as toddlers are, during these meetings. These moments made it harder to hear what my colleagues were saying because background noise is challenging for those with hearing loss. The meetings lead to greater levels of fatigue due to the increased load of listening. Moreover, I felt as if my lessened ability to separate the two sets of conversations made it hard for me to keep my work persona separate from mine as a mother. Would this influence my colleagues' perception of my ability to work, and would I have the energy to take care of my daughter when the academic day was over, and the family day continued?

The committee meeting ends with the chair saying we are making progress. One by one, my colleagues' blank squares with their disembodied voices disappear. The irony of the chair's words strikes me because there is much more progress to be made in terms of accessibility.

Gone: Grief and Graduate Education amid a Global Pandemic: Jessica P. Cerdeña

"I need to evaluate your progress," my then-advisor snapped. "I obviously cannot say you are 'very satisfactory' because you were gone."

Gone.

Three months postpartum, breasts swollen with milk and prickling with an urgent need to be emptied, I *was* gone: away from my newborn son. I stared, my eyes heavy with sleep deprivation, as my former thesis advisor told me I had been *gone* from my work.

I handed her a list of products I had generated in the time I had been *gone*, that is pregnant with hyperemesis gravidarum, an extreme form of morning sickness that required multiple hospitalizations and caring for my newborn.

"I need dates. I need publication information. I'm your advisor, not your advocate. No one will care that you were sick and that you had a baby. They will want to know what you've accomplished," my then-advisor demanded. The conversation left me shaken and shocked—an attitudinal barrier through the SMD framework—with my pursuit of graduate education seemingly at odds with my motherhood. I spiraled into severe postpartum depression.

Postpartum depression (PPD) is a complex form of major depressive disorder characterized by sadness, fatigue, anxiety, appetite disturbance, and excessive or lack of concern for the infant (O'Hara and McCabe 2013). PPD affects roughly 9–15% of women within the first year of giving birth, though these numbers may be low estimates due to under-/misdiagnoses and missed postpartum screenings (Evins, Theofrastous, and Galvin 2000). Among women with disabilities the prevalence nears 30% (Mitra et al. 2015). Contributing risk factors for PPD include stressful life events and poor social or financial support in the peripartum period, with adverse consequences such as reduced likelihood of breastfeeding, impaired bonding with the infant, atypical infant and child development, suicide, and infanticide (Johannsen et al. 2016; O'Hara and McCabe 2013).

Graduate students experience particularly high rates of mental illness and are more than six times as likely to experience moderate to severe depression or anxiety as compared to the general population. Potential contributing factors include mentorship support and work burdens—the "work-life balance" (Evans et al. 2018)—that have become particularly salient concerns among academic mothers during the COVID-19 pandemic.

I returned to my dissertation work prior to the conclusion of my leave, two months after giving birth, in December 2019, just as the novel betacoronavirus began its scourge across Wuhan, China. Pressured by my advisor to recommence research before the conclusion of my guaranteed parental relief, I spent my days in the library writing, rushing to the pumping room next to the boiler in the library basement every two to three hours to strip off my winter layers and express breastmilk for my son—an organizational barrier that made me dread my return to academic life. Yet, there I was, having it all: my family, my work, and my self-worth.

One month later, I heard those words: *You were gone.*

That criticism by my former thesis advisor sent shockwaves through my soul. I felt as if I was drowning, choking on air. My baby, once my greatest joy, brought forth piercing wails from the caverns of my lungs. My trusted mentor had forced me to question his existence. As a result, I forgot how to breathe, how to sleep, how to eat. The simplest tasks of self-care required insurmountable effort. Cooking and exercising—two sustaining activities I previously enjoyed—became impossible. Another month after that, a global pandemic cast us all into isolation and made everything worse.

"Moms are not ok," write Davenport et al. (2020) in their study of 900 peripartum women, of whom 15% reported depression prior and 40.7% during the pandemic. The corresponding prevalence rates for moderate to high anxiety were 29% and 72%. The authors of the study attributed the stark jump in mental illness to fear of the virus, financial stresses, social isolation, and increased domestic workload. In my case, I did not see my parents, who normally visited every three weeks, for five months. My husband, a physician, risked exposing our family—including my diabetic father-in-law and infant son—to the virus to carry out his job. Anxious about my productivity in the wake of my advisor's censure and the institution's failure to protect me as a new mother, I watched the boundary between working from home and living at work blur.

Discussion and Implications

Existing inequities have worsened during the COVID-19 pandemic, with lack of access to resources, accommodations, and information. As the two narratives have shown, there are no simple solutions that fit the diverse needs of all motherscholars with disabilities. There are, however, overarching commonalities in struggles and the need for structural changes that we will discuss. Using the SMD framework to think through our experiences, we observed several overlapping factors in the two narratives. In both instances, the authors experienced a compounding effect of stressors that were well-documented before and remained unresolved during the pandemic. While large lecture halls already demand investment in equipment and organizational arrangements so the instructor can understand students, the spreading-out and mask-wearing of students and the additional layers of sound through virtual attendance create additional barriers. In relation to the second narrative, existing mental health concerns among graduate students, new mothers, and people with previous mental wellness issues are exacerbated by expectations of continued high productivity. The results are such that the amount of personal and organizational labor on behalf of those with disabilities becomes unmanageable and debilitating.

Further, in both narratives the burdens of problem-solving, advocacy, reinforcement, and continued compliance for accommodations by the institution are placed on the motherscholar herself. Systemic accessibility and reluctance issues are treated by the institution as personal struggles: the faculty must arrange a voice transcriber app and is necessitated to bring up accessibility concerns, while the student is responsible for reminding her advisor of and enforcing their compliance with postpartum-related protections and lactation laws. This portrayal of structural issues as individualized struggles stands in direct opposition to the SMD framework, underscoring the systemic nature of disadvantaging vulnerable employees and excluding their participation in the institution.

To address the compounding barriers motherscholars with a disability experience during the COVID-19 pandemic, higher education administrators need to commit to immediate and long-term changes in their policies by proactively taking initiative in seeking dialogs with these students and faculty and enforcing accommodation accessibility. Paid parental leave and compensation for caregiving work through course and service release, daycare stipends, and other organizational flexibility and financial support could produce immediate relief to parenting academics. University administration should proactively support student and faculty motherscholars by actively seeking dialog with employees who have a disability. The narratives show how scholars with disabilities may not be able to provide a ready solution, due to the unique circumstances posed by a global pandemic. Junior faculty or students may experience a power dynamic that discourages them from seeking accommodation. Proactive institutional support from administrators could identify and break down accessibility barriers to create solutions that address structural as well as individual struggles.

The authors would like to thank the Motherscholar Collective for their support.

REFERENCES

Center for Disease Control and Prevention (CDC). 2020. "Disability Impacts All of Us." https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html

Davenport, Margie H., Sarah Meyer, Victoria L. Meah, Morgan C. Strynadka, and Rshmi Khurana. 2020. "Moms are not Ok: Covid-19 and Maternal Mental Health." *Frontiers in Global Women's Health* 1:1–6.

David, Dana and Perla Werner. 2016. "Stigma Regarding Hearing Loss and Hearing Aids: A Scoping Review." *Stigma and Health* 1(2): 59–71.

Evans, Teresa M., Lindsay Bira, Jazmin Beltran Gastelum, L. Todd Weiss, and Nathan L. Vanderford. 2018."Evidence for a Mental Health Crisis in Graduate Education." *Nature Biotechnology* 36(3): 282–84.

Evins, Grace G., James P. Theofrastous, and Shelley L. Galvin. 2000. "Postpartum Depression: A Comparison of Screening and Routine Clinical Evaluation." *American Journal of Obstetrics and Gynecology* 182(5): 1080–82.

Gelfand, Stanley. 1998. *Hearing: An Introduction to Psychological and Physiological Acoustics*. New York: Marcel Dekker.

Goad, Kimberly. 2020. "Videoconferencing Tips for People With Hearing Loss." *AARP*, May 19, 2020. https://www.aarp.org/health/conditions-treatments/info-2020/videoconferencing-hearing-loss.html

Johannsen, Benedicte M. W., Janne T. Larsen, Thomas M. Laursen, Veerle Bergink, Samantha Meltzer-Brody, and Trine Munk-Olsen. 2016. "All-Cause Mortality in Women with Severe Postpartum Psychiatric Disorders." *American Journal of Psychiatry* 173(6): 635–42.

Liyanagunawardena, Tharindu R. 2021. "Transcripts and Accessibility: Student Views from Using Webinars in Built Environment Education." *European Journal of Open, Distance and E-Learning* 23(2): 37–50.

McKee, Michael, Christa Moran, and Philip Zazove. 2020. "Overcoming Additional Barriers to Care for Deaf and Hard of Hearing Patients During COVID-19." *JAMA Otolaryngology–Head & Neck Surgery* 146(9): 781–82.

Mitra, Monika, Lisa I. Iezzoni, Jianying Zhang, Linda M. Long-Bellil, Suzanne C. Smeltzer, and Bruce A. Barton. 2015. "Prevalence and Risk Factors for Postpartum Depression Symptoms Among Women With Disabilities." *Maternal and Child Health Journal* 19(2): 362–72.

O'Hara, Michael W., and Jennifer E. McCabe. 2013. "Postpartum Depression: Current Status and Future Directions." *Annual Review of Clinical Psychology* 9: 379-407.

Pfefferbaum, Betty, and Carol S. North. 2020. "Mental Health and the Covid-19 Pandemic." *New England Journal of Medicine* 383(6): 510–12.

Samaha, Adam M. 2007. "What Good is the Social Model of Disability?" *The University of Chicago Law Review* 74(4): 1251–308.

Saunders, Gabrielle H., Iain R. Jackson, and Anisa S. Visram. 2020. "Impacts of Face Coverings on Communication: An Indirect Impact of COVID-19." *International Journal of Audiology*: 1–12. https://doi.org/10.1080/14992027.2020.1851401

Tatman, Rachael, and Conner Kasten. 2017. "Effects of Talker Dialect, Gender and Race on Accuracy of Bing Speech and YouTube Automatic Captions." In *INTERSPEECH*: 934-38. https://doi.org/10.21437/Interspeech.2017-1746

Wiederhold, Brenda K. 2020. "Connecting Through Technology During the Coronavirus Disease 2019 Pandemic: Avoiding 'Zoom Fatigue.'" *Cyberpsychology, Behavior, and Social Networking* 23(7): 437–38.