"I DON'T WANT TO BE CALLED STRONG ANYMORE": AN EXPLORATION OF COVID-19 MORAL MESSAGES AND HIGH-RISK DISABILITY IDENTITY MANAGEMENT

by

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They mattered. They all mattered.
Imani Barbarin, 2022

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ABSTRACT

“I DON’T WANT TO BE CALLED STRONG ANYMORE”: AN EXPLORATION COVID-19 MORAL MESSAGES AND HIGH-RISK DISABILITY IDENTITY MANAGEMENT

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While adopting COVID-19 precautions, high-risk disabled individuals have had to come face to face with blatant messages about the worth of their lives. The goal of this study was to give voice to high-risk disabled individuals during the COVID-19 pandemic. This study employed negotiated morality theory (Waldron & Kelley, 2008) and social identity management (Silva & Sias, 2010) to guide a qualitative exploration of how high-risk disabled individuals processed stigmatizing moral messages and negotiated their many identities during the pandemic. The findings of this study suggest that high-risk people with disabilities experienced a significant identity shift due to the moral messages surrounding COVID-19. A thematic analysis of thirty interviews revealed the process of this shift through three main themes: the initial potential of a more accessible future, cultural negotiations of morality, and the reconstruction of identity

CHAPTER ONE: INTRODUCTION

> *I've always known that, like, society as a whole doesn't really care about disabled people. I knew it, but I didn't feel it the way that I have felt it during this pandemic. (Participant 6).*

Medical discrimination is nothing new for the disability community (Pendo, 2020) and yet, the COVID-19 pandemic amplified those issues in several ways (Shapiro, 2020a; Shapiro 2020b, Shapiro, 2020c). During the pandemic, everyone experienced a level medical fragility and became part of a conversation that is the heart of the disability community. Yet, too frequently, these conversations occurred without ever recognizing the community at the center of them. Outside hospital walls, media, celebrities, and peers constructed their own thought-pieces on the high-risk community. Fox News producer, Kyle Becker (2021), punctuated his opinion over twitter, "Covid did not 'kill 725,000 people' – this is blatantly false. The CDC reports "Covid-related deaths" 94% of these had serious comorbidities like heart disease and cancer." American singer-actor, Venessa Hudgens, explained her dislike of COVID-19 shutdowns on Instagram Live. "Yeah, like people are going to die, which is terrible, but like, inevitable?" (BBC, 2020). Friends, family, and coworkers engaged in the forming and sustaining stigmatizing messages online and in person.

The goal of this study was to preserve the voices of high-risk disabled individuals during this highly-stigmatizing historical period. Guided by negotiated morality theory (Waldron & Kelley, 2008) and social identity management (Silva & Sias, 2010), this study explores how high-risk disabled individuals processed stigmatizing moral messages and negotiated their many identities during the COVID-19 pandemic. As such, this study advances theoretical arguments such as expanding the definition of community, centering vulnerability in disability, and how morality can be socially negotiated.

Study Rationale

The theories used to sensitize this study have a wide array of backgrounds. Negotiated morality theory (NMT) has predominantly been used in the study of interpersonal relationships in family and romantic contexts (Waldron & Kelley, 2009; Waldron et al., 2014; Waldron & Kelley, 2017). This study explores negotiated morality on two levels centering on the perspective of high-risk disabled individuals. First, the largely public negotiations of morality that occurred about the high-risk community online and in-person. Second, the ways in which high-risk disabled individuals engaged in that negotiation as it pertains to their disabled and other identities. The bulk of existing social identity management literature has studied organizational identities (Silva & Sias, 2010; Ybema, 2009). These organizational identities have varied from places of employment (Ashforth & Johnson, 2001), community choirs (Meisenbach & Kramer, 2014), and teams (Zanin et al., 2016; Zanin et al., 2020). Studying organizational identity has provided key insights to how individuals manage salience with their nested identities (Meisenbach & Kramer, 2014; Zanin et al., 2016; Zanin et al., 2020). However, existing literature has not looked at how health identities are negotiated. Disability identity has been primarily studied in the context of disability disclosure (Blockmens, 2015; Braithwaite, 1991; Miller et al., 2019). Studying the ways individuals negotiate their disabled identities is particularly important in a global pandemic where an individual's life and livelihood is dependent on their success at managing their stigmatized and other identities.

The pandemic has made these issues even more salient due to the negotiation of life that is tied to them. The risk facing high-risk disabled individuals expands beyond COVID-19.

Medical shortages affected access to everyday care that many high-risk disabled individuals need (Pendo, 2020; Shapiro, 2020). As such, individual's access to independence and autonomy were also at risk making already difficult stigma management even more complicated. This study argues that the stigmatizing moral messages during the pandemic triggered a fundamental shift in the way that high-risk disabled individuals construct and negotiate their disabled identity.

Definitions of Disability and High Risk

Disability is generally defined as "a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions" (Merrium-Webster, n.d.). In this study, disability is not an identity readily defined. Many modern interpretations of disability vary between differing local and federal law. Even the embodied experience of disability fluctuates within one individual. The process of identifying as disabled is highly individualistic. Some disabled individuals have a formal diagnosis, and some do not. Medicine can only describe different health experiences as technology allows it. Even when an individual does have a diagnosis, this does not guarantee that they identify as disabled. An individual's high-risk status regarding COVID-19 is much the same. While high-risk is generally understood as an individual's preexisting risk to develop dangerous symptoms due to COVID-19, the parameters of who qualifies under that have shifted. As such, this study recognizes the fluidity of the disabled identity and high-risk status. During the recruitment and interviews, asking for self-identification provided participants with space to define both criteria for themselves. The recruitment flier specifically asked for individuals who self-identify as disabled and high-risk for COVID-19. Not using a distinct definition of disability helps include participants based off their lived experience rather than a rigid, medical definition of disability.

CHAPTER TWO: REVIEW OF LITERATURE

This study examines an identity shift within the high-risk disabled community as a response to stigmatizing moral messages. The review of literature, therefore, will present relevant literature to situate the study. The literature review will first present negotiated morality theory (Waldron & Kelley, 2008) to explore previous work in moral communication as a framework to explore modern public and interpersonal messages about and around COVID-19. The literature review will then explore social identity by first contextualizing disability identity and stigma management.

Negotiated Morality Theory

Waldron and Kelley (2008) argue that "human relationships are interpreted with reference to a system of implicit or explicit values" (p. 75). These values manifest and are dialogically communicated through stigmatizing communication (Goffman, 1963; Smith, 2007). Negotiated morality theory (NMT) was initially conceptualized within the context of forgiveness in romantic relationships (Waldron & Kelly, 2008) and has since been expanded in family communication (Waldron et al., 2014; Waldron & Kelley, 2017). Primarily, the theory suggests that relationships are heavily influenced by value systems which are then dialogically negotiated and enacted within the relationship itself. When an individual's value systems are threatened, the individual is motivated to reduce discomfort and uncertainty by negotiating the behavior or value internally or externally. Waldron and Kelley (2008) conceptualize this process within forgiveness which they argue is inherently a negotiation of morality. In comparison, this study conceptualizes negotiations of morality in the context of public and private discourse about high-risk disabled individuals during the COVID-19 pandemic.

When Waldron and Kelley (2008) proposed NMT, it was founded on eight key assumptions relating back to forgiveness. As NMT has been expanded in family communication, these assumptions have been reframed as four foundational ideas (Waldron & Kelley, 2018). First, NMT assumes that preservation of the family's concept of morality is a large motivator in family communication. When an individual or event threatens the family's concept of morals, the members of the family are motivated to go through a communicative sensemaking process. This study suggests that the same may be true for the members of the disability community. Previous literature has defined a community in crisis as "an entity with a common geographical boundaries and environments that interact with one another in intricate ways" (Norris et al., 2008 p. 128). Community crisis and resilience have largely been studied looking at communities that have a central geographical location such as school campuses (Ford et al., 2015; Wells, 2015), rural communities, (McCrea et al., 2014), and emergency housing (Brandhorst, 2018). The global COVID-19 pandemic has created a unique form of crisis. The disability community have had to not only respond to the imamate danger of COVID-19 as individuals, but also the public moral negotiations that devalued their community.

When an individual experiences highly moral public messages about the value of their life they may be likely to engage with a communicative sensemaking process with their community who are also experiencing the same messages similarly to families who bound by context and values. Negotiated morality theory also functions under the assumption that "feelings of pride, admiration, solidarity, and self-satisfaction are associated with moral compliance" (Waldron & Kelley, 2018, p. 236). The suppression, enactment, or response to moral emotions help family's dialogically respond to moral actions. Culturally endorsed actions that question family moral commitments are likely to challenge family communication (Waldron

& Kelley, 2018). Although existing work utilizes NMT's key assumptions in family contexts, this study explores NMT on a larger scale. In a time of restriction and loss, high-risk disabled individuals have had to engage in a communicative sensemaking process to identify which communities their values are compatible with. Every day individuals have dialogically and publicly debated whose lives are worth protecting. This study explores how high-risk disabled individuals have processed private and public moral messages about their lives and their disabled identities. High-risk disabled individuals have had to manage their own moral emotions in a variety of contexts such as family, friends, and organizational memberships.

In this study, I used NMT to examine the moral messages that high risk disabled individuals experienced and expressed about their varying identities. Hutz & Brown (2020) argued that moral discourse has the potential to breed polarization and animosity especially as it pertains to social roles. In their study, many couples felt stigmatized due to their choice to be child free. This stigma was frequently communicated in terms of moral responsibility to one's family and society. The framework for NMT understands that family and concepts of morality are not without their cultural and religious influences (Mete, 2018; Waldron & Kelley, 2018), however, previous research suggests that the enactment of an individual's moral identity occurs within the intimate relational space. The first of which is family. This study explores the same concepts in the context of a stigmatized community. Where families may be bound by a shared identity based off their shared values, so might a community which may feel pressure to present a unified front to combat social stigma.

Health choices are regularly interpreted in reference to an individual's perceived moral obligation to their family (Keeley, 2021). Family members of disabled individuals frequently perceive co-ownership of the disabled individual's trauma (Lindemann, 2012). Doctors are perceived as “moral pioneers” as they battle ethics in their academic journey to continue to push medicine (Shaw, 2019). Despite medical decisions and experiences being interpreted as highly moral, the individuals and the community at the center of these medical decisions are rarely considered as actors with their own agency and needs. This study centers disabled individuals, their value systems, and the obligations that are placed on them. Memorable moral messages between parents and children are more memorable when conducted in private and intimate spaces (Waldron et al., 2014). In turn, these conversations greatly impact the ways in which an individual views themselves in the world as a moral actor as they enact their varying identities. NMT adopts a “life course perspective” (Waldron & Kelley, 2018, p.235) which tethers moral negotiations to major life events both expected and unexpected. As individuals reach different milestones moral conflicts in their lives evolve. The COVID-19 pandemic provides both a unique and unexpected moral conflict in which high-risk disabled individuals must negotiate their relational obligations while also responding to the overwhelming societal discourse about their lives. The pandemic places extra pressure on disabled individuals as they must manage moral messages pertaining to their stigmatized and community identities. This study explores negotiated morality on two levels centering on the perspective of high-risk disabled individuals. First, the largely public negotiations of morality that occurred about the high-risk community online and in-person. Second, the ways in which high-risk disabled individuals engaged in that negotiation as it pertains to their disabled other identities.

Social Identity

Goffman (1959) originally outlined identity by arguing that identity is bred from the ways in which an individual’s self-concepts of interact with others. Individuals must reconcile the discrepancies between how they view themselves and the way others view them (Tajfel &

Turner 1986; Ybema, 2009). This study explores that conflict for high-risk disabled individuals as they negotiate their many identities. Silva and Sias (2010) defined social identity management as the "social process by which identities are constructed, maintained, and transformed" (p. 147). Varying interactions with others in family, organizations, and communities give birth to multiple identities that an individual may hold. An individual can be both a parent and a teacher, however, these identities may not always easily coexist (Ashforth & Johnson, 2001; Meisenbach & Kramer, 2014). These identities then become layered or nested and an individual may feel varying salience with any of their identities creating more pressure to enact that identity (Meisenbach & Kramer, 2014). Identity discourse pushes individuals to revisit, reinterpret, and redefine their own identities (Ashcraft & Mumby, 2004). This study explores the disability identity as it socially negotiated and communally maintained. The discourse around the pandemic pushes high-risk disabled individuals to re-evaluate their moral emotions and actions especially as it pertains to their various identities. The following sections will contextualize disability identity discourse and stigma management.

Disability Identity

In 1997 disabled individuals made up 19.7% of the United States population (U.S. Census Bureau, 2001). This number has grown substantially in the last two decades with a projected 36% of the United States population having a disability (CDC, 2019). Braithwaite (1995) predicted that the exponential growth in medical technology would give way to a whole generation of disabled individuals who previously would not have been able to survive. Medical technology has transformed medical definitions of fatal injury and illness. However, rather than eradicating the disability from the body, medical technology has made it possible for individuals to live with complex and sometimes life-threatening conditions. As disabled individuals, particularly young disabled individuals, integrate into their local communities their experiences are informed and shaped by their disability community, physical needs, and experiences of stigmatization. Simply, an individual's relationship to their disability expands beyond the isolated medical definitions of disability. As such, Braithwaite (1995) argued that communication scholars needed to conceptualize disability as both a culture and an identity.

The study of disability identity has a long history. Disability has historically been defined by the manifestation of moral ideas regarding life and the body. Goffman (1963) originally conceptualized the disability identity through the medical model of disability. Although initially conceptualizing stigma, the purpose of the work was to help disabled individuals rehabilitate into a non-disabled society. The medical model of disability demoralized the individual through language such as "cripple" (Andrews et al., 2019; Dirth & Branscombe, 2018). Disability under this model is restricted to the embodied experience of illness and healing. Disability is understood as an individual and, hopefully, temporary experience. The social model of disability was developed as a critique of the medical model. The social model of disability suggests that it is society's lack of accommodation that creates disability. For example, a child with a minor sight loss is disabled until they are accommodated with their first pair of glasses. Proponents of the social model historically have pushed for person-first language putting emphasis on the individual's humanity over their disability (Andrews et al., 2019). For example, they are not *disabled* they *have a disability*. Under the social model, disability is one part of an individual's experience, however, it is not a core identity that influences every part of a person's life.

The social model recognizes structural inequality for people with disabilities and is still widely used by many within the disability community (Dirth & Branscombe, 2018; Ionescu & Callus, 2018). The social model has been prominently used to describe the consequences of stigmatizing communication and tries to preemptively fight against stigmatizing rhetoric. Popular advocacy movements after the United States' historical implementation of the Americans with Disability Act focused on what people with disabilities could do and provide to the greater community. The social model of disability served an important role to advocate for accommodations and policy growth. However, the social model of disability has been heavily critiqued in social psychology (Andrews et al., 2019), critical trauma studies (Ionescu & Callus, 2018), and disability studies (Reynolds & Kiuppis, 2018). Under the social model, focus on accommodation places burden on the disabled individual to perform the socially constructed idea of disability or attempt to hide their disability entirely (Blockmens, 2015; Miller et al., 2019). The social model serves to humanize the individual, however, it does so by removing the embodied and social experience of disability (Dunn & Andrews, 2015). Disability under the social model using person-first language has an underlying assumption that disability is inherently bad. Person-first language particularly attempts to reduce potential stigma by separating the individual from the stigmatizing characteristic.

The emergence of identity-first language stems from global social movements such as Black liberation and LGBTQ+ rights (Dunn & Andrews, 2018). In recent years, young and newly disabled individuals are encouraged to see their disability as something to be proud of. Disability pride stems from shared history and experiences with other disabled individuals (Andrews, et al., 2019). Many young disabled advocates have taken to social media to call out the non-disabled community for their apprehension and stigmatizing responses to the word "disabled" (Andrews et al., 2019). Chapman & Dammeyer (2017) found that Deaf individuals who utilize creative and cultural identification are better able to negate the psychological pressures associated with stigma. Identifying as disabled serves an important role in where a disabled individual perceives themselves in the world (Dirthe & Branscombe, 2018). Like any other identity, disabled individuals perform their disabled experiences based off how they believe others will perceive them. Depending on the social situation and momentary salience, an individual may feel more pressure to hide their disability or express it (Meisenbach & Kramer, 2014). However, the choice to hide one's disability from their peers does not erase the disability or stigmatizing experiences (Braithwaite, 1991; Goffman, 1963; Hudson, 2011). An individual's disability identity may be enacted in and maintained in multiple social contexts. Within the community, choosing person-first or identity-first language is still highly contested (Andrews et al., 2019; Ionescu & Callus, 2018; Reynolds & Kiuppis, 2018). As a compromise, Dunn & Andrews (2018) encouraged scholars utilizing the APA writing style to discuss and honor both person-first language and identity-first and the APA has since adopted that advice into their manual (Oermann, 2019). In order to accurately reflect the identity of the participants, this manuscript utilizes both person-first and identity-first language as it is appropriate for the context.

Many disabled individuals have a complicated relationship with their own disability particularly if they have chronic pain or illness that may put their lives at risk (Andrews et al., 2019; Ionescu & Callus, 2018; Reynolds & Kiuppis, 2018). The disability pride movement and social model of disability has little space to conceptualize the relationship with one's disability as something that may be more complicated than simple terms of pride, stigma, and accessibility. If the world was fully accessible an individual with chronic pain would still have to seek out treatment for their pain. Ionescu and Callus (2018) argue for the adoption of social-relational model based off the United Nations convention on the rights of persons with disabilities. The social-relational model examines disability as it emerges from the interaction between the embodied disability and society. Under this model, disability identity assumed to be complex and fluctuating. In the same way that an individual who was not in pain today does not indicate they will not be in pain tomorrow, an individual may change the way they enact their disability identity when interacting with others.

Within the disability community, individuals identify with different subcategories of disability to describe and connect with others who share a specific experience (Ionescu & Callus, 2018). One such category is that of the "healthy" disability individual and the "unhealthy" also known as those within chronic illness and pain communities versus with more stagnant disability experiences. This study adopts the social-relational model of disability as it provides a space to look at high-risk disabled individuals. Previously, high-risk may not have been considered a category to bind a sub-community together, however, the context of COVID provides the academic community a new insight into a group of people least studied. Especially since many high-risk disabled individuals are alive due to the medical advances Braithwaite (1995) described.

Although this study adopts the social-relational model of disability it is also important to reflect Reynold and Kiuppis' (2018) British pathic model of disability. They first argue that British policy and academics traditionally adopt a 'strong social model of disability' overemphasizing disabled individual's ability to overcome in attempt to justify poor disability policy making.

> [The pathic model of disability] "finds its primary moral force in the claim, 'Do you see how much and in what way I am suffering?'... 'Do you see the way in which society is structured such that I suffer because the group to which I belong to is oppressed, which is to say, is structurally and systematically disadvantaged?'" (Reynold & Kiuppis, 2018, p. 558).

The pathic model is designed for advocacy. The conceptualization primarily focuses on disabled individuals in the most need for significant policy change when it comes to their basic healthcare. Individuals with chronic pain, illness, or progressive disabilities are frequently required to navigate medical institutions and fight stigmatization from their doctors and other healthcare providers. Although the pathic model does not adequately represent the way disability has been conceptualized in this study, it does inform some of the perspectives that may rise from the data. The population in this study have suffered significantly at the hands of their illness and at the hands of society that continues to stigmatize them. Using the social-relational model best fits the ever complex and fluctuating experience of disabled individuals as well as the communication studies perspective of identity both stigmatized and nested.

Stigmatized Communication Management

For individuals with disabilities, the discourse that surrounds their identity is highly stigmatizing. In Goffman's (1963) initial study of stigma, he called back to the Greek belief that the disabled body reflects an individual's moral insufficiency. Stigma "messages spread through communities to recognize the disgraced (i.e., recognize the stigmatized) and react accordingly" (Smith, 2007 p. 464). Meisenbach (2010) explained that stigma is used as a tool to draw the boundaries between in-group and out-group. Meisenbach (2010) built the theory of stigmatized management communication as framework to explore stigma through the perspective of the stigmatized. Stigma, like morality, is dialogically shaped by personal and social stories. It is also vast and can vary from person to person, experience to experience.

Just as stigma varies, so do the ways in which individuals attempt to manage stigma. These strategies may include all or some of the following: Accepting, avoiding, reducing offensiveness, denying, or ignoring/displaying. Individuals may better be able to manage stigma by using multiple strategies (Meisenbach, 2010). For people with disabilities, the strategies they choose to manage stigma largely depends on how well they can control the visibility of their disability(Blockmens, 2015; Hudson, 2011). Stigmatized individuals may try to cope through social withdraw and attempts to hide their stigmatized identity (Smith, 2007; Meisenbach, 2010). However, hiding a stigmatized identity is not always possible and when it is, the labor of hiding may only invoke further withdraw (Braithwaite, 1991; Goffman, 1963; Hudson, 2011). Blockmens (2015) adopts a spectrum approach allowing their participants to identify as someone whose experience with disability may not be visible or invisible on any given day. When an individual does choose to disclose their disabled identities or specific health information, they are not only managing the boundaries of privacy, but also the potential stigmatized responses to their identity (Braithwaite, 1991). Ryan et al. (2005) found that disabled individuals who used assertive communication strategies may be able to better mitigate *mindless* enactment of stigma.

Illness communities frequently enact identity through online support groups (Kruk, 2015). These sometimes-anonymous groups provide spaces for individuals to swap stories and express difficult emotions unrestricted. Ultimately, the nature of the group reduces the labor of managing potential stigmatizing responses because participation in the group stems from shared experiences of stigma (Kruk, 2015). The story telling opportunities in online support communities also serve a vital role in the sensemaking process necessary to recover from trauma (Witney & Bates, 2016). The importance of online communities only multiplies as individuals find spaces for their intersectional stigmatized identities (Miller, 2017). Traumatic experiences serve as turning points in an individual’s story (Bernsten & Rubin, 2006). Bernsten and Rubin (2006) argued trauma is born from perceived events that threaten one’s life and/or spurs significant peri-social emotions. Following this description of trauma, high-risk disabled individuals are likely to experience many significant traumatic events as they not only have to fight for their lives, but also the stigmatized responses from those who are supposed to protect them. Turner (1984) described individuals who share a social category definition, such as women or teachers, as a psychological group. A psychological group only evolves to a social group once they band together regardless of institutional support or formal organizational structures (Ashforth & Johnson, 2001).

The management of stigmatized disabled identities has been extensively researched in the context of disclosure (Blockmens, 2015; Braithwait, 1991; Miller et al., 2019). Disabled individuals frequently have multiple and evolving health conditions that grow and change with the individual (Miller et al., 2019). As such the *coming out* process as a disabled individual is never ending. Individuals with disabilities are not only having to manage the physical embodiment of their disability, but also the social labor of disclosure also classified as communication work (Donovan-Kicken et al., 2012). In addition to social and family disclosure, individuals with disabilities and chronic health conditions must also decide how to best reduce stigma at work (Jans et al., 2011; Westerman et al., 2015; Westerman et al., 2017). Many individuals choose not to disclose their disability unless visible or requiring accommodations (Blockmens, 2015; Jans et al., 2011; Westerman et al., 2015; Westerman et al., 2017). Stigmatized responses from employers may result in an individual's loss of face, career growth, and even their job (Dolen, 2021; Jans et al., 2011). Currently, one in three disabled adults in the United States have unmet healthcare needs because of prohibitive cost (CDC, 2019).

As stated previously, disabled individuals experience the world through their multiple identities. They are parents, employees, managers, and friends. However, whenever an individual interacts with others, they must manage the multiple layers of their identities (Meisenbach & Kramer, 2014). Where previously, individuals may not have experienced high salience with their disability identity or perceive it as a core identity, COVID-19 potentially shifts that salience for high-risk individuals due to stigmatizing messages. A disabled parent may not have enacted their disabled identity while going to a PTA meeting prior to COVID-19 but found it necessary to protect their life during the pandemic. In relationships where individuals may not have discussed their disability, the pandemic puts pressure on high-risk disabled individuals to actively discuss their private health information with employers and peers. As such, also putting themselves at risk of potentially triggering stigmatizing responses. Without directly talking about disabled individuals, prominent news sources and social media have decided that some individual's lives are a necessary sacrifice for the world's comfort (Shapiro, 2020). High-risk disabled individuals are then bound to traditional social expectations while their peers talk about whether people like them deserve to live. The pandemic has created a context in which high-risk disabled individuals may have had to adapt their stigma management strategies to better negotiate their various identities.

The COVID-19 pandemic provides a unique opportunity to explore a potential shift in identity management across multiple research fields. Concepts of disability have always stemmed from questions of morality (Andrews et al., 2019; Dirth & Branscombe, 2018; Goffman, 1963). Whose life counts and what does it mean to have a quality of life? Even in modern definitions of disability that include pride as a potential outcome (Andrews, et al., 2019), pride is still a moral emotion (Waldron & Kelley, 2009). Concepts of disability identity are also heavily tied to the ways in which an individual's disability is stigmatized (Andrews et al., 2019; Ionescu & Callus, 2018; Reynolds & Kiuppis, 2018). The pandemic highlights the ways in which society dialogically defines and stigmatizes disability in concepts of morality pertaining to health and life. Where stigmatizing moral messages about disability may have been more subtle in the past, the pandemic has created a catalyst for the expression of those more horrific ideas about disability (Davis, 2020; Shapiro, 2020a; Shapiro 2020; add cites from introduction). However, high-risk disabled have also had to negotiate their various identities and may have found that, during the pandemic, they have come into conflict. Regardless of how perilous the world feels, they must still be parents, children, employees, and friends. Yet, in this context, high-risk disabled individuals may find new saliency in their disabled identity as enacting their disabled identity as a means for survival. Previous literature placed within the pandemic leads to the following research questions.

> RQ1: How have high-risk disabled individuals experienced moral messaging during COVID-19?
>
> RQ2: How have high-risk disabled individuals negotiated their many identities during the COVID-19?

CHAPTER THREE: METHODS

The emergence of the COVID-19 pandemic is marked as a major historical event. Its global impact has shifted ideology and perceptions of reality. This study was conducted at the heart of the health crisis by giving voice to high-risk disabled individuals. Historically, people with disabilities have been highly stigmatized and understudied. This study gave voice to high-risk disabled individuals during a period of global tragedy that has directly affected their community. In this study, I chose to adopt qualitative methods to preserve the authentic voices of those within a highly stigmatized community. The list of interview questions is appended.

All semi-structured interviews were conducted through zoom due to both the high-risk status of the participants and restrictions given the COVID-19 pandemic. Although I did not conduct any in-person interviews, the virtual template allowed me to meet with individuals across the United States and Canada. Zoom was also more accessible and safer for both the participants and me. Participants were able to tell stories in their own homes and accommodate their own physical needs. Zoom also created the opportunity for participants who were hard of hearing or deaf to participate utilizing zoom's live closed captioning services.

Researcher Position

In this study, I am a complete member researcher (CMR) which means I am fully enmeshed in the population I am studying (Anderson, 2010). I am a high-risk disabled woman who is trying to give voice to my community. As an ambulatory wheelchair user, I consider myself to have a disability with alternating visibility. For me, this meant that when my participants talked with me over zoom, I did not appear to have a disability. However, in the recruitment process I was open about my own diagnosis and included a picture of myself in my wheelchair. I also employed my personal social media accounts such as Tiktok and Facebook where I am vocal about my disability identity and advocacy. As a CMR, participants may have felt like they were talking with a cultural insider which created space for them to feel safer when disclosing potentially sensitive information. I also had the cultural education from my experience to have context for the various stories my participants told me relating to the medical care, social media trends, and law. My experience within my community educated me on how to use closed captioning services and other accommodative technology prior to participants asking. Overall, my proximity with the population studied served as tool to enrichen the research.

Participants

To provide participants the most freedom to tell their stories, I employed in-depth semi-structured interviews. This choice was made to foster rich responses and help participants feel safe when disclosing potentially difficult information 3Participants in this study all identified as high-risk for COVID-19 and a person with a disability. This study included a sample of 30 participants (*N*=30). I continued to conduct interviews until I reached saturation at which point new information provided little to no change in emerging themes (Tracy, 2020). Participants were required to self-identify as high-risk for COVID-19 and as a person with a disability. Individuals who only identified as high risk for COVID-19 or only identified as disabled were excluded from the study as the aim of the research is to examine the stories that occur at the intersection between these identities.

For this study, I adopted a spectrum approach to disability visibility (Blockmans, 2014) to which participants were asked to identify as being invisibly disabled (43%, *n* = 13), visibly disabled (30%, *n*= 9*),* or alternatingly visibly disabled (27%, *n* =8). Most participants identified as women (63%, *n* = 19), nearly a third of participants identified as non-binary or otherwise genderqueer (33%, *n* = 10), and only one participant identified as a man (3%, *n* = 1). Most of the participants identified as White (81%, *n* = 24), a small percentage identified as mixed race/ethnicity (10%, *n* = 3), Indigenous (7%, *n* = 2), and Pacific islander (3%, *n* = 1).

Data Collection

I recruited participants through snowball sampling starting with initial recruitment with personal contacts and personal social media (Twitter, Facebook, Instagram, and TikTok). After asking permission from moderators, I also posted recruitment information and the flier in private online support groups. The flier included basic information about the study, a picture of myself in my wheelchair, and a brief description of my background. On social media, I included photo descriptions that described the flier so that individuals who used visual assistive technology could read the flier. I asked participants and personal contacts to share my flier and image description on their social media and reach out to those they thought may be interested.

Interested participants were encouraged to reach out to me via text, messaging, or email. After recruitment, I scheduled semi-structured interviews based on participant availability. The interviews were semi-structured with guiding questions to provide space for further probing regarding the participant's unique experience during the pandemic. Some participants had to reschedule due to personal health emergencies, unplanned hospital visits, or other unplanned events. When this occurred, I scheduled them for the next closest availability. Each interview was audio-recorded and transcribed verbatim using Zoom's automatic transcription services to create textual data for analysis (Tracy, 2020). In order to protect participant confidentiality, participants were assigned a participant number. All names or potentially identifying information from the interviews have been redacted and participants will be referred to by their participant number. Interviews lasted an average of 44 minutes and verbatim transcriptions resulted in 1210 pages of single-spaced data.

Data Analysis

The data was analyzed using an iterative analysis approach that balances emergent themes with reflection towards previous literature (Tracy, 2020). Through the iterative analysis process, I employed both inductive and deductive processes of analysis. I visited the data multiple times to develop a deep understanding of the data and its themes. This approach allowed me to analyze the data in the greater context of both academic and social work. This is vital during a historical period when individuals' ideologies are being called into question and potentially shifting. Through this study, I identified research areas that will need continued exploration as theory evolves in a post-pandemic age. Utilizing iterative analysis was also important as the population is greatly affected by the world around them. To fully explore the richness of the data in stigmatized groups, the researcher must comprehend a greater social structure and influence. Thus, the analysis highlights inequalities and insights for social growth (Tracy, 2020).

Data analysis was attained through first-cycle coding and second-cycle coding. First, I open coded the data to identify meaningful themes across all interviews (Lindolf & Taylor, 2002). To do this, I read the data line by line and code the initial themes that I identified during this reading of the data (Tracy, 2020). I developed the initial codes into a coding schema documented in a memo book. To create the coding schema, I collapsed the established codes from the first cycle coding into thematic categories which were used in the coding schema. The coding schema reflected each instance the data coded to help me keep track of how and where the codes were employed in the data (Lindolf & Taylor, 2002). During second-cycle coding, I coded individual lines of data using the developed schema from the first-cycle coding. All coded data was placed in the coding memo books and marked with a color-coding system in the original transcripts (Tracy, 2020). From the data analysis, then constructed my results using exemplars from each theme to represent the themes in the data. Throughout this manuscript I employed participants preferred pronouns including she/her, he/him, and they/them to reflect the participants in a way that honors their identities.

CHAPTER FOUR: RESULTS

This study explored the moral messages high-risk disabled individuals experienced during the COVID-19 pandemic and how high-risk members of the disability communicatively responded. Thematic analysis revealed three main categories including the potential for a more accessible future participants experienced early in the pandemic, cultural negotiations of morality, and disabled individuals' reconstruction of identity. The following themes utilize a temporal flow to describe the experiences of high-risk individuals over the first year and half of the pandemic.

The Potential of a More Accessible Future

High-risk disabled individuals described their early pandemic experience with hope for a more accessible future. First, they compared their experiences before and after the pandemic. They explained, that prior to the pandemic, they frequently participated in small quarantines to protect themselves from illnesses such as the flu. Participants had hoped that the pandemic would help non-disabled individuals to have more empathy for their experiences. Second, they described the initial support they received from their immediate communities in the early stages of the pandemic. Participants also described their excitement of the creation and popularization of technology such as Zoom. Before, this technology was said to be too expensive and too difficult to use just for people with disabilities. However, participants hoped that the pandemic would create the framework to include the technology after the pandemic was over and as such, include them as well.

Compared Experiences

Immune-compromised participants contrasted their experiences during the pandemic to those before it. Previously, participants had practiced navigating outbreaks of different illnesses with compromised immune systems. Participant 19 explained that her family had gone into "soft lockdowns" during cold and flu seasons. Other participants said they had quarantined during the 2009 H1N1 crisis or had practiced wearing masks in public during illness seasons. Despite self-preserving practices before the pandemic, participants explained that many of their able-bodied peers did not have the language or the context to understand those practices until COVID-19. Participant 8 described their tentative hope that non-disabled people would continue to wear masks when they were ill after the pandemic. "The thing that I love about the pandemic is hey, people are wearing masks. It can be less likely for me to get sick." Participant 5 explained how they had previously altered their language with non-disabled peers choosing to use non-disability-related reasons to opt-out of unsafe events. However, participant 5 said that a year and a half into a global pandemic their able-bodied peers are "somewhat better at talking about the nuances of it [disability]." Thus, reducing communicative labor they had previously experienced. Participant 4 felt that emergency medical staff were also more understanding. She explained that previous messages had felt hostile "god, they're back." Whereas, at the time of the interview, messages from emergency medical staff felt more understanding "let me listen to you."

Initial Support

Participants also explained that early in the pandemic they received support from their non-disabled community. This support came from friends, family, professors, and medical staff. In the beginning, some friends who were not at risk would deliver groceries and medicine. Participant 1 said that those who knew her personally said they would take COVID-19 precautions for her. Many of the non-disabled individuals who supported high-risk individuals were those who had some understanding of the participant's disability prior to the pandemic.

> There were some really great friends that would come outside and sit at my patio with me on one side and them on the other side. Just have evening talks or ice cream sandwich parties because friends were willing to come and distance and when the outside. I mean its Texas, so it was hot… but they were willing to distance and sit outside, for me (Participant 2).

Two high-risk disabled students felt their professors were more proactive with accommodations and that their universities' public messages about social distancing and quarantine procedures were largely positive. Participant 2 told a story about medical staff helping her find places to practice for the varsity band while she was in the hospital.

While many cases of initial support occurred on the individual level, 11 of 30 participants explained how the rise in virtual accommodations initially gave them hope for a more accessible future. Participant 10, a deaf woman who was able to participate in the study due to Zoom's captioning feature, said that she believed that the extreme development of closed captioning technology was only possible due to COVID-19. Chronically ill participants explained how the popularization of virtual meeting spaces such as Zoom made it possible to connect with others. "I was more busy than ever. I was doing Zoom calls every Friday night and then all my other friends wanted to hang out because we were all locked at home" (Participant 5). Participant 2 claimed that "it's actually been a blessing in disguise, that culture is now built hybrid."

The option for telehealth also improved the lives of participants who were able to seek out diagnosis and care without having to manage the physical boundaries of travel. Participant 17 said that before the pandemic they were not "necessarily looking even having a future" due to their health issues. However, telehealth gave them previously inaccessible resources. Participant 17 also said that, as a community advocate, she previously found government buildings largely inaccessible and exhausting to navigate. However, Zoom made it possible for her to be present at public government meetings regarding policies that affect the disabled community. High-risk disabled students envisioned a future where they could take classes online when they were too ill to be present. Participant 19, a high-risk disabled mother to two high-risk disabled teens, said that she had not been able to go back to school without the fear of one of them becoming ill. However, virtual accommodations allowed her family to take the precautions they needed to stay well and for her to pursue a college degree alongside her son. Work from home options provided high-risk disabled individuals the opportunity to reflect on their needs prior to the pandemic. Participant 5 quit her previous job for an entirely remote organization. “That was truly amazing because all of these things that we thought as accommodations like working from home… that was just the norm at this job.” She continued to say that she had never considered a remote job previously.

However, many participants recounted the frustration that came with virtual accommodations. “(The) work from home situation really brought to light that like, they could do that [virtual accommodations]… work and doctors and telehealth visits and things that we always wanted to be accessible and never were” (Participant 25). Participants felt that it was only due to the non-disabled population needing accommodations that accommodations were suddenly accessible and normative. Thus, making them reflect on the effects of stigma in their lives prior to the pandemic.

Cultural Moral Negotiations

The hope that participants experienced for a more accessible future only aggravated the stigma they felt when experiencing cultural moral negotiations which debated the value of their lives. Participants reflected that, despite the technology being available, as the pandemic wore on, the accommodations and support they initially received were slowly taken away. Messages that occurred across media and interpersonal interactions suggested that accommodations and COVID-19 precautions were a matter of politics rather than a matter of life and death for participants. These largely public debates left participants having to go through a sense-making process where they deconstructed their identities, internalized dehumanizing messages, and isolated themselves from those around them for their own protection.

Non-Accommodating Messages

Coded data in this theme described the messages participants experienced after the summer of 2020 when institutions and people refused to accommodate participants' health needs. High-risk disabled individuals found that after a few months of a soft quarantine, many of the accommodations they had come to enjoy were stripped away. In fact, 21 of the 30 participants said they experienced some form of non-accommodation from either an organization, medical staff, or friends and family. The shift away from virtual spaces, masks, and social distancing occurred as a mass attempt to shift back to a form of pre-pandemic life. However, for high-risk disabled individuals, this meant losing the accommodations they only just received.

> That's the grossest part of it all. They took our words and started using them and now they're taking it away. They were accommodations and they called them that. And now they're saying they're not necessary. (Participant 17)

Two participants described their church's refusal to wear a mask or social distance which put the participants at odds with their religious needs and their needs as high-risk disabled individuals. Several participants experienced pressure to return to work and school in person despite their high-risk status especially after the COVID-19 vaccine was released to the public. Participants largely viewed the vaccine as the “light at the end of the tunnel” (Participant 14). However, seven participants expressed their concern for those who could not get the vaccine due to their immune-compromised state or how the vaccine did not guarantee that they would be safe. Some participants found that they were able to receive partial accommodations from the organizations they associated with while others had to leave the organization or submit to the new requirements.

While Participant 1 was hesitantly permitted to attend her graduate courses virtually she said she felt isolated. Particularly when one of her professors refused to use any live virtual conference technology such as Zoom. Participant 1 was instructed, “you just sit in the front and you can designate two or three rows and just ask that people not sit there.” The only alternative they were offered to receive credit was to attend the class asynchronously without any access to lectures or class discussions. Participant 15’s graduate cohort was given the option to move all classes online, in-person, or remain hybrid.

> Those of us online were saying, like, ‘hey, it’s really hard to be online when there are people in person because y’all do not pay attention to what we’re doing. I don’t want to take anything away from your experience, but this is taking away a lot from mine” and ultimately nothing changed.

Participant 2, an undergraduate student, said that she frequently would attend Zoom classes looking at a wall because she was the only virtual participant. Participant 14 said they were unable to continue their education online or in-person as their university failed to supply sufficient academic accommodations given the added demand from the pandemic. Participants who were in academic spaces found that their universities did not have consequences for students and faculty not wearing their masks appropriately. Participant 11, who works in student life, was required to return to work in person and attend in-person events with students who were non-compliant about mask-wearing.

Six participants struggled to find a balance between their workplace identities and their needs as high-risk disabled individuals. Participant 25 struggled to keep up with the ever-increasing demands of their job. “They don’t see it as I’m disabled. They see it as I’m not reaching numbers.” Participant 25 was then put on probation after being up for promotion only a few months prior to the initial lockdown. Participant 30 said that they quit their job after their employer "ripped it all away" after 5 months of virtual work and required them to return in person despite providing medical documentation.

> They just kept saying, ‘Oh well, we're being careful. We're being careful.’ And I’m just like, ‘how do you know? It's only like five months into the pandemic and things aren't looking up at all. They were getting worse, and any sort of like concerns are brought up were just completely ignored.

Medical staff were also largely non-accommodating. Three participants said they believed medical companies used COVID-19 as an excuse to increase prices and limit supply. Both participants had to fight repair companies to take them seriously and take care of necessary items such as a wheelchair and IV pump. Participant 3 said that the refusal to acknowledge the problems in her IV pump resulted in the pump exploding and starting a house fire. "I'm like now, do you believe me? Now, do you believe me so then I lose two-thirds of what I own?" While the repairs were underway Participant 3 lived in her garage as no accessible housing was available. Other medical staff were non-accommodative by refusing to wear masks or not requiring masks in the offices that high-risk disabled individuals frequent. Individuals who refused to wear masks after participants asked them came up with a variety of reasons why they would not. “It’s too hot” (Participant 7) or other forms of discomfort being the most frequent reason. Participant 7 described her frustration when her personal aids refuse to wear masks around her. “I’m dependent on someone to transfer me in and out of bed and do personal care. And I don’t want someone spewing germs in my face while they’re doing it.”

Refusal to accommodate from medical staff, friends, and family was perceived as an attack on the participant’s autonomy and individuality.

> They were so concerned about their own personal comfort they took away our freedom and so since March of last year, my freedom, my son's freedom, my husband's freedom, and my daughter's freedom and many people like me, have been limited to our homes" (Participant 19).

When discussing friends and family, participants told stories of family members refusing to mask, vaccinate, or social distance when interacting with them despite being made aware of the participant’s high-risk status. Participant 10, who frequently looked after her grandchildren, had to isolate for her own safety after her son-in-law refused to get vaccinated. “I said, ‘do you realize if I get COVID the chances are I would not survive with my medical issues?’ And he said ‘yes.’” High-risk disabled individuals received messages claiming that the disabled individual was overreacting or that they were not high-risk. Participant 2 summarized her experience with others' refusal to accommodate.

> It’s basically a line that I could not cross. Maybe the general public doesn't have these high-risk elements. You know, they could cross that line in terms of wearing masks… They just didn't cross that line. When we’re on two opposite sides I couldn't cross it and they weren't willing to do. So, we're at the end of the day, no matter how long we go around in the circle try and come up with these extreme ideas and how to keep me involved. It was really hard because I want to be around those people. I want to be around my friends, but you keep going around in a circle and we’re never going to compromise in terms of where that line is.

Politicizing Disabled Bodies

Participants described the dehumanizing messages they experienced by those who politicized disabled lives, bodies, and deaths. Eleven participants explained that they tried to respond to non-accommodating messages the way they had done in the past. Before the pandemic, they frequently engaged in online awareness campaigns which, at worst, may have been met with indifference. However, after the pandemic, their advocacy was met with rejection. Regardless of advocacy, 20 participants experienced some form of political messages about the pandemic, COVID-19 precautions, and the deaths of the high-risk.

Participants who attempted to advocate for themselves and their community adopted a variety of strategies. Two participants said that they understood others' hesitancy as non-disabled individuals did not have the framework to understand the pandemic and its effect on the disability community. Both participants believed that with enough patience and education, those who had rejected them would learn the importance of COVID-19 precautions. Six participants said they used their social media to try to break down misinformation and provide the “disability perspective” (Participant 6) to the pandemic. Participants 3 and 4 said they tried to be open about their unmet medical needs on social media. They discussed delayed procedures due to overflowing hospitals and missing medical supplies due to demands. High-risk disabled individuals tried to engage non-disabled individuals' sense of empathy and faith. "I was like, okay, I understand that you don't take this seriously, but I need you to for this other person" (Participant 30). Participant 19 said that she tried to specifically call out her Christian community by calling on their "social responsibility" and their "biblical responsibility.”

Despite attempts to spread awareness all participants who said that they try to advocate on social media also said they observed extreme politicized responses. Participant 3 said people “jumped down (her) throat” when she posted recent COVID-19 numbers in her area. In fact, 20 of 30 participants said they received some form of politicizing message from friends, family, and personal aids in person and on social media. Most of the politicizing responses reflected hesitation on wearing masks and vaccination due to their belief that the government was trying to control them and suppress their freedom. Participants described a discrepancy from their perception of a health issue whereas others perceived it as a declaration of their political party. “It’s politicized to the point where people aren’t making science-based decisions about their health. They’re making a political based decision about their health.” Two participants were called “sheep” for their advocacy. Participant 28 said that she feels “frightened” of those who are publicly anti-mask and attended anti-mask rallies.

Participants attributed misinformation to the spread of fear towards the vaccine and the misuse of the ADA. High-risk disabled individuals discussed the conspiracy theories stemming from QAnon such as the pandemic being fake, the vaccines are being used for population control, or that masks were “child abuse” (Participant 3). Participant 16 said she tries to fight against the misinformation, “I’m like, you have a phone. You have a social security number. It’s already happening.” Participant 10 said that people from her church were “buying in” to the conspiracy theories.Participant 20 said he tries to avoid social media altogether due to the increased politicization on Instagram. Participant 9 said that she felt like she did not know her in-laws anymore after they started expressing beliefs shared among conspiracy theorists.

Internalizing Messages

Over the course of the pandemic, high-risk disabled individuals faced frequent demoralizing messages. These messages were largely public and triggered a sense-making process where they internalized dehumanizing messages. During this process, high-risk disabled individuals deconstructed their identities, processed messages which stated that their lives were a worthy sacrifice and isolated from those around them for their own protection. All participants had an experience with demoralizing messages. The demoralizing messages included messages that existed prior to the pandemic; however, the context of the pandemic was made more painful and caused a re-evaluation of their identities and value compatibility with those around them.

Deconstructing Identity

For high-risk disabled individuals, the dehumanizing messages they experienced may have not been new, but they triggered a deconstruction of identity. Participants had to re-evaluate their social and interpersonal roles in the context of their disabled identities. For participant 3, this re-evaluation occurred after her young, autistic daughter overheard her arguing with a medical provider over the phone.

> My daughter grabbed a chair, and she pushed all the way up against my wheelchair. I can't move and I’m like trying to deal with the provider and she's just sitting there against me like physically against me. I'm like, ‘[name redacted], what are you doing?’ She's like, ‘I'm here to protect you. They're going to kill you’… Before, like I go to the doctor,

> she was at school, and then I come back… She never had to hear anything she had no idea what's going on and it's not like I tell her much. Because that's not – She doesn't need to be worried about that. That's not kid stuff.

Eight participants explained that being an advocate was central to their disabled identities. Not only did they follow the work of disabled advocates who came before them, but they also tried to preserve their history and pride. Despite their work to protect the disability community, they would have to debate non-disabled individuals until the non-disabled individuals became disabled themselves or had someone close to them become disabled. This was especially difficult for participants when facing individuals who had become disabled due to COVID-19. Participant 14 expressed their frustration with newly disabled individuals who were upset by the infrastructure failures they had previously ignored. "They get very frustrated, and they get very upset that things aren't getting done and the most I can say is, we've been fighting this fight for years." Participant 14 explained that they struggle to empathize with those who became disabled from COVID-19 due to their refusal to take precautions and putting the rest of the community at risk.

"A Sacrifice I'm Willing to Make"

Twenty-one participants experienced stigmatizing messages which suggested that high-risk individuals' lives could be sacrificed for the sake of the economy and the comfort of others.

> I've always known that, like, society as a whole doesn't really care about disabled people. I knew it, but I didn't feel it the way that I have felt it during this pandemic. Like there was there's just this- I guess it was news stories where people are like, 'oh only disabled people are going to die.' News stories that feel like, 'oh, only you're going to die and that's the sacrifice we're willing to make.' Every day just kind of wears down on you after

> a while. And so, it was just like all of these things that I knew on a surface level I got to really, really feel (Participant 6).

Participant 8 overheard a man at her local store upset that he had to “make concessions” for “the unnecessary people.”

> I remember specifically saying to one person like, “do you know. Anyone in your life that you love that is high risk?” And they were like, “well, my grandma's lived a good life if she has to go for the sake of our economy, she has to go” (Participant 26).

Participant 21 said that one of their local politicians said that seniors should give up their lives to restart the economy. Participant 24 described her difficulty with messages that dismissed the high-risk who had died from COVID-19. “Like, those people are still loved. They’re still someone. They don’t mean less because they’re high-risk.”

When participants were not being told to give up their physical lives, they were told to give up their quality of life. Participant 28 described a TikTok they saw where disabled individuals were told: "just stay home if they don't want to die."

> People are like oh if you're afraid to die just stay home. I’m like, I’m not afraid to die, but I am afraid to not live, and I feel like right now, a lot of people are not living their life. And I’m like, why am I wasting my last remaining good years, potentially, just like stuck in my house? (Participant 26)

Participant 12 said that the general population has a "narrow view of what a disabled person looks like." As such, there is an expectation that all high-risk individuals did not have quality of life prior to the pandemic and do not contribute to society. So, their participation in society would not be missed. “It kind of just sounded like everyone wanted me to put my life and hold so that way they could continue to do the things they wanted to do” (Participant 14).

Considering these demoralizing messages, participants perceived the behaviors of the public as statements about their life. When non-high-risk individuals have publicly refused to wear a mask, throw public tantrums, or post about their vacation to developing countries, participants felt that these individuals were saying they “don’t care” (Participant 7) about disabled lives. “It almost feels like someone with a disability or who identifies as disabled had a completely different pandemic experience from someone who doesn’t” (Participant 15). As such, high-risk disabled individuals felt left behind by their government, local community, family, and friends. Participant 8 explained that if she could not find a remote position soon, she’s “essentially back on the streets.” Five participants described interpersonal conflicts where family members invited them to birthday parties or other events that they had to decline. “I just can’t risk my life over a 6-year-old’s birthday party” (Participant 7). Participant 11 said she had to decide whether to miss a friend’s wedding or risk her life.

Nine participants said they experienced patronizing messages that questioned their decisions and belittled their personal advocacy. Participant 1, a graduate student pursuing a Ph.D., was compared to a professor’s child while fighting to be able to attend classes remotely.

> They should have the expectation that I can do these things. Like, I’m an adult. Let alone an adult who’s able to get into this program. I should not be questioned as much as I am. Like, I know I can do this I just need these simple accommodations.”

Participant 13 said they struggle with their family taking COVID-19 precautions seriously because they are "fine before" and they are invisibly disabled. Participant 16 said that she was only able to get her wheelchair fixed after her able-bodied mother went to the wheelchair repairer in person. Participant 23 said she understood her fear of hospitals after seeing a TikTok during the Black civil rights protests in the summer of 2020 which said that, for Black women, the risk is hospitals. "Because every time I would end up in a hospital, I was never listened to. As a biracial woman, my mother was White, they would listen to my mother before they would listen to me." This fear then impacted their decisions to seek out care while they were sick that summer.

Demoralizing messages left participants feeling betrayed by friends and family who knew more about their disability prior to the pandemic. Participant 6 described her feelings of betrayal listening to her cousins say that COVID-19 is not that bad. “They know me. They know what happens when I get sick. They’ve seen. They’ve taken care of me while I was sick.” Participants frequented re-evaluated if their values were compatible with the people they had known their entire lives. Participant 23 reflected,

> Like I've shared so much of my time in my life and my stories with this person. Little did I know, deep down that they really didn't care or couldn't care as soon as this one tiny little thing comes up.

Participant 4 said that for the first time in 56 years, "I have looked around at people, and instead of eyes of love I've looked with eyes of fear. Everyone around me feels like a hand grenade and it's terrifying."

High-risk disabled individuals also experienced messages through the stories of other disabled individuals. Disabled individuals are frequently connected with other disabled people and participants recalled their friends' stories. Participants also reflected the stories of high-risk disabled individuals like themselves in the news and talked about them on social media.

Participant 23 described a frantic call from a high-risk friend who had been admitted into the hospital COVID,

> I got a phone call like, 'Please take care of my fiancé. Because I'm going to die.' And then, when he was in the hospital, he would hear the nurses being like, 'yeah, the patient in bed number two isn't going to make it. We're not going to bother.' And he could hear them talking about the person that he's sitting next to. Like, how can you deny that kind of thing happening? Like, this is not inconsequential. This is not an overreaction. This is real. Just because you don't know someone who hasn't had to go through it doesn't mean that it doesn't actually exist.

Participant 21 explained the impact of a news story about a disabled man who left to die in a Houston, TX hospital. Michael Hickson was quadriplegic with a brain injury and when he became ill COVID-19 his hospital determined that his quality of life did not warrant further care. However, the hospital refused to put Mr. Hickson in hospice. Instead, the hospital "basically shoved him in a dark room." Participant 21 explained that Michael Hickson died from starvation after the hospital stopped his feeding tube. Participant 21 said that she did not expect the hospital to go to extreme measures but make the death as painless as possible. When she told people about this story "they were like, 'it happens all the time.' But that's not the point… Having a DNR in place is different than, 'hey, let's starve this person.'"

Stories like these furthered participants' sense of isolation as the non-disabled individuals reacted to them with indifference at best and hostility at worst. These reactions were interpreted as not only a dismissal of other disabled people but also a dismissal of the participants themselves. "They're just trying to stay safe. I'm trying not to get sick. I'm trying not to go to the

ICU or ER or dying. You know? And I have had friends and family who died of covid" (Participant 7).

Isolation

All participants were isolated from others at some level for both their physical and mental health. For participants, having to isolate for their safety stripped of them of their agency and made them "forced" (Participant 26) to stay at home or not interact with their non-disabled communities. When non-disabled individuals depended on social media so heavily during the early pandemic, Participant 17 said they believed that non-disabled individuals brought harmful messages and conspiracy theories with them. At the same time, Participant 17 felt that non-disabled individuals discredited social media. "Like when they're saying things like social media is not a place to get information, they're saying that disabled like voices don't matter at all because that's where we are." Five participants expressed their fear of posting fact-based information on social media due to the public negative feedback they experienced. Participant 6 is TikToker who uses their social media to promote their small business and talk about their experience as a service dog handler. However, despite trying to be open on the app they were worried about the app suppressing their content or banning them altogether as they had seen done to other disabled TikTokers. Participants frequently disengaged from social media, interpersonal relationships, and mass media. Ultimately, high-risk disabled individuals felt that they had been pushed out of the spaces that they had created for themselves.

Five participants said that they struggled with feelings of being a burden. Despite trying to fight for other disabled people or even themselves, the messages, at the time, become overwhelming. Participant 15 said they question themself.

> “It makes me feel like I’m crazy like I'm overreacting and like I should be back to normal when I know that I shouldn't. And it takes a lot of effort to kind of walk those thoughts back and remind myself, like, no I’m doing what's safe for me. I'm doing what's should be safe for everyone that everyone should be doing in the first place and I’m not the only one that's doing this.

Participants 36 and 26 said they were more afraid of asking for accommodations from friends and family. Participant 26 said that she has struggled with suicidal ideation in the past, however, has especially struggled with internalizing demoralizing messages. “Like part of me is like yelling for my friends that are disabled and how their lives matter. And then I’m like but does mine?”

Reconstructing Identity

In response to demoralizing messages, high-risk disabled individuals had to re-evaluate their relationship with the non-disabled community and reconstruct their identities by centering their disability. This process required a time of self-reflection where the individual looked at the role their disability played in their lives. Then, all but three participants described separating from the non-disabled community. Unlike the isolation, they felt prior, the act of separating oneself from the non-disabled community re-established agency in the eyes of the participants. Finally, 18 participants went through a process of reclaiming their non-disabled identities by centering their disabled identity.

Self-Reflection

Twenty participants said that the messages they received triggered a period of self-reflection. This stage of self-reflection encompassed individuals' perception of their disabled experience, their role within their families, and their disabled identity. Thus, this period of self-reflection created a fundamental shift in participants' perceptions of themselves.

Participant 14 described their experience having to address their “internalized ableism”.

> When I was told I was disabled it was really hard for me to grasp that concept because, in my head, I was still able to walk. I was still able to talk. I was still able to do all these things and something like the pandemic really shoves it in your face about how disabled you are.

Participant 22 has type 1 diabetes said that they had not thought of themselves as disabled until doctors labeled them high-risk and their non-disabled communities did not take precautions to protect them. Other participants said that COVID-19 taught them to re-evaluate the help they can offer and their hesitation to ask for help. Participants 23 and 34 struggled as they were previously seen as a helper in their family, but due to the pandemic and other health issues they were no longer able to play this role in the way had done prior to the pandemic. Participant 16 said that she did not think that the pandemic made her think differently about herself. However, it changed the way she viewed others. This was especially true for three participants who said that their churches’ response to the pandemic made them separate their faith from their identity in the Christian community. Participant 29 said that COVID-19 precautions “shouldn’t have been a question.”

High-risk disabled individuals had to come to terms to the person they were before the pandemic and the person they became while trying to survive it. Five participants described a fundamental personality shift. Where previously they had seen themselves as driven and optimistic, they now saw themselves as “jaded” (Participant 19), “bitter” (Participant 22), and “angry” (Participant 2, 5, and 39). “I view myself as more other. Like, I’m not part of the “norm” and that’s fine. It’s obvious that the norm doesn’t want me anyway” (Participant 22). However, otherness gives freedom to embrace participants' disabled identities. Participant 17 said that they learned more about disability history than they had ever done before. Participant 9 said that TikTok played a key role in how they connected with the greater disabled community.

Separated from the Non-Disabled Community

The second-largest theme with 27 participants is that of separating from non-disabled communities. Unlike isolation where the individual felt they had no choice; separation was born from a form of re-empowerment where high-risk disabled individuals remove themselves from the larger non-disabled community. Participants' separation was also marked by an added sense of unity with those within the disabled community and an added expectation on the non-disabled individuals who wish to remain in the participant’s life.

Participants described a process of centering their own needs telling those who come into proximity with them, “if you’re not going to wear a mask around me, don’t bother” (Participant 4). Centering their own needs also appeared in response to moral messaging. Participant 2, a freshman in college, explained that “maybe right now I just need to focus on surviving.” Participant five said that they separated from friends and media due to the emotional drain they experienced while sharing time and space with those who were willing to “debate something obvious like masks.” Participant 12 said that after listening to a close family friend make demoralizing comments about high-risk individuals they said, “you do realize that’s me.” After the conversation Participant 12 said they cut off their family friend. High-risk disabled individuals also frequently worked with mental healthcare workers to process their trauma and learn how to better advocate for their needs. Participant 14 said that they have watched themselves move from accommodating messages such as, “can you please” to telling those in their life, “if you’re not willing to make these accommodations knowing how sick I could get I’m not willing to be around you.” As mothers of high-risk disabled children, three participants said they realized it was time to separate from others when they realized their friends and family did not care about their children.

While high-risk disabled individuals described a loss of friendship with those unwilling to do what must be done to protect them, relationships with those who remained became closer.

> It really changed the way that I view friendships because I watched a bunch of people I thought cared about me tell me that like, “Oh well, it's fine if you die as long as I don't have to stay in the House any longer.” And now I feel like every friendship I have is so much deeper, and we know very intimate things about each other because we almost have to say those things first just to make sure we don't get hurt later. Like, I need to know what your stances on ABC because if it's you know this, we can't talk to each other. So, it's created all of these really deep close friendships that are based on mutual respect instead of just oh you're near me.

Fourteen participants said that over the course of the pandemic their friendships have mostly expanded in the disabled community. They said they frequently connect over TikTok, video games, and live conference technology such as Zoom. Participant 11 described a wedding they attended where they spent most of the time with another high-risk guest. Participant 11 said that they “knew” that the other guest was going to take COVID-19 precautions seriously due to their own high-risk status. As such, they trusted the other high-risk guest over the guests who refused to wear a mask or social distance. This was a common theme among participants. Participant 6 continued to explain,

> The new community that I've built with a bunch of other disabled people who are all feeling the strain, where we all support each other when we can. there's a joke about her disabled people have like this one $10 bill that we keep passing around to each other every time we need something.

Trust within the community was important for many participants and even created a bridge with those they had become disconnected from prior to the pandemic. Two participants said that discussing shared health concerns with estranged family members assisted in improving their relationships with those individuals. However, participant 5 was concerned about high-risk individuals who did not separate. While the disability community tries to figure out who was safe enough, high-risk individuals who publicize their lack of COVID-19 precautions potentially send mixed messages to the non-disabled community.

> I think that is somewhat harder because there are some people with disabilities who are immune compromised who are going out to bars and dinners and posting about that. So, I think it made it also harder, in some ways, within the community to figure out who is being safe enough, and what should we all be doing.

Participants also received support from the non-disabled individuals in their immediate circle. Participant 1 and 10 described their partners stepping in-between their partner's families and the high-risk individual. Participant 1 and her fiancé struggled with her fiancé's family after they declined an invite to their nephew's birthday party. Participant 19 said that her husband feared bringing home COVID-19 after his office returned to in-person. Other participants described the importance of reaffirming their relationships with those who were willing to take the precautions necessary to protect them.

Reclaimed Identity

As a byproduct of a period separation, 20 participants experienced a form of reclamation of their disabled identities. Where separation was marked by the participants removing themselves from non-disabled communities, reclamation was shaped by high-risk disabled individuals reintegrating with society while centering their disabled experience. “We're starting to realize the value of our own lives versus what society thinks” (Participant 13). Five participants described a passion to dedicate their lives and energy to fighting for the disability community. Participant 6 said they became more involved in local politics so that they prevent future disabled individuals from experiencing the demoralizing messages they experienced during the pandemic. “I know that these people definitely won't help me. The people who will help me will stand with me and we're going to do something about it don't know what but something.” Participant 12 changed career paths from makeup artistry to nursing. While the need to help the disability community was not new, participants described their new passion for advocacy as central to their disabled identities.

Four participants said that the reclamation of their disabled bodies occurred at the same time they claimed their trans identities. “It was finally a time where we could take a step back from what society wanted us to look like and just exist” (Participant 14). Participant 14, a Black mixed-race individual, experienced identity shifts across their intersectional marginalized identities. “Dealing with the internalized racism definitely helped kind of kickstart dealing with my internalized ableism.” During COVID-19 Participant 14 came out as nonbinary and was diagnosed with autism in addition to their physical disabilities.

Participants also reclaimed their agency by finding moments of joy or laughter in their disabled experience. Participant 5 said that, as a teenager, she swore off being one of those “sticker people” who had stickers all over their notebooks and computers. However, during the interview, they proudly showed off their water bottle covered in disability-related stickers. Participant 6 bonded their sibling who also has a disability by making fun of those who made demoralizing remarks about COVID-19 and high-risk individuals, “I’ll be like guess what blank said today, and then I say it, and we both laugh in that way that's like this isn't funny but if I don't laugh or cry so let's laugh.”

Participants also described a new relationship with their disabled bodies. “Maybe I should actually talk about my needs instead of trying to pretend that they're not there to make everyone else comfortable” (Participant 30). Instead of “downplaying” (Participant 18) their needs participants described feeling “empowered” (Participant 17) to take care of their own bodies.

> Now I’m more straight up with people. Before the pandemic I would brush it off a lot and like downplay my limitations and now I tell people my limitations before I even show up. So, yeah, before I used to push myself until I was injured and now I warn people that if it's not accessible I’m not going because I’m not getting injured… And that's where my mindset is… I see myself is more confident in my ability to care for my body (Participant 25).

Participant 27 said they "own being disabled" however before the pandemic they would have associated disability "with strength." However, the pandemic reinforced the vulnerability of being a high-risk disabled individual. "I don't want to be called strong anymore. I don't want to be called resilient. I don't want to be called stoic or stubborn. Like I just want to relax for once, please" (Participant 26).

Summary of Results

This study was guided by the following research questions:

RQ1: How have high-risk disabled individuals experienced moral messaging during COVID-19?

RQ2: How have high-risk disabled individuals negotiated their many identities during the COVID-19?

Moral messages regarding the high-risk disabled community were largely dehumanizing. When faced with these largely public messages from valued members in the individual's life including celebrities and family, participants described going through a process where they reconstructed their disabled identity as central to who they are. This reconstruction process was triggered by dehumanizing messages which said that the contributions of high-risk individuals were not significant enough to warrant COVID precautions. Participants not only had to reconstruct their disabled identities but also their other social and familial identities. High-risk disabled individuals processed moral messages through this reconstruction and negotiation. Early in the pandemic, participants had hoped that the lockdowns and development of technology would help those around them become more sympathetic to their experiences. Instead, participants described going through a period where they internalized messages which patronized, politicized and dehumanized their community. They coped with moral messages by connecting with other disabled individuals who were experiencing the same messages the participants were.

Negotiation of one's identity became a valuable tool for processing moral messages. While in a period of internalizing messages, participants felt they were forced to go into isolation. In isolation, they felt they were stripped of their ability to enact any identity beyond their stigmatized disabled identity. To enact their other identities, they had to compromise their needs as a disabled individual. However, if they did so, they were risking their lives. Participants negotiated their differing identity needs by centering their disabled identity. When doing so they reconstructed their sense of agency by choosing to no longer compromise their needs as a disabled individual. For many participants, this meant removing themselves from spaces and people who would not allow them to enact their disabled identity. Doing so, they found a stronger community among other disabled individuals who also centered the needs of the high-risk. Participants reclaimed their other identities by making their disabled identity a central part of the way they enact those identities.

CHAPTER FIVE: DISCUSSION

The long-term consequences of COVID-19 have yet to be seen and have only just started to be explored. The goal of this study was to preserve the voices of high-risk disabled individuals during this highly-stigmatizing historical period. Thirty interviews with high-risk disabled individuals from North America revealed the potential they felt for a more accessible future, the demoralizing messages they experienced, and how they reconstructed their identities during the pandemic. Participants described their hope for a more accessible future during the early 2020 shutdown due to the growing technology and the initial support they experienced. However, as the pandemic went on, their accommodations and support were revoked and replaced with politicizing and dehumanizing messages. These largely public negotiations of morality were generally directed to non-disabled people and were under the disguise of cultural commentary or matters of opinion. However, participants described how they internalized messages that claimed that their “unnecessary” (Participant 8) lives were worth the sacrifice “for the sake of the economy” (Participant 26) and the convenience of non-disabled people. Yet, individuals responded to dehumanizing messages by reconstructing their own identities to center the value of their life and the disability community. The themes explored in this study warrant an in-depth discussion to highlight the theoretical and practical advancements found in the data such as expanding the definition of community, centering vulnerability in disability, and how morality can be socially negotiated.

Redefining Community

The findings of this study suggest a broader definition of “community” including communities that are not geographically bound. Previous literature has defined a community in crisis as "an entity with a common geographical boundaries and environments that interact with one another in intricate ways" (Norris et al., 2008 p. 128). Community crisis and resilience have largely been studied by looking at communities that have a central geographical location, such as school campuses (Ford et al., 2015; Wells, 2015), rural communities (McCrea et al., 2014), and emergency housing (Brandhorst, 2018). The global COVID-19 pandemic has created a unique form of crisis. Unlike epidemics which only affect certain communities, the pandemic has touched almost every community and every person. The disability community has experienced stress due to the pandemic twofold; first, fear for their lives, and second, a fear of those who belittle the worth of their life. In the context of this study, neither the crisis or the community are geographically bound. The self-organizing (Landau, 2007) nature of the disability community during this period has been prompted by the othering disabled individuals experienced at the hands of those who physically surround them.

The data suggests when participants' local communities started to open again and demoralizing messages became more prevalent, participants felt completely otherized and rejected. Online spaces were coopted by othering and stigmatizing messages from non-disabled profiles. For many participants, those in their immediate space were also those putting them in the most danger. Social media and technology such as Zoom then became a vital resource for the disability community to organize as disabled individuals separated themselves from non-disabled spaces. The disability community has a long history of organizing online largely through support groups (Kruk, 2015; Miller, 2017; Witney & Bates, 2016). After all, identity-first language was developed online among young disabled social media users prompted by other social justice movements (Dirthe & Branscombe, 2018; Dunn & Andrews, 2018). During a crisis, online spaces such as Facebook, Instagram, and Twitter have been integral for individuals to express their stories and find catharsis (Veer et al., 2016). Conferencing technology, such as Zoom, and social media played an integral role in keeping the non-disabled world connected during the early stages of the pandemic. However, for participants who had frequently been left out of physical spaces, technology such as Zoom made the world accessible in a way that it had never been before.

Zoom and Discord provided channels for people with disabilities to communicate directly with those with whom they had previously been passively interacting online. Social media feeds became a means to advocate and re-emphasize the digital borders of the disability community in a way that put the dignity of people with disabilities at the forefront of the movement. While non-disabled individuals may be invited into disabled spaces, they must adhere to the communicative rules established by the disabled leaders rather than the non-disabled social norm. Previous literature has suggested that those with invisible and visible disabilities adopt different strategies to manage communication such as hiding their disability or preemptively breaking down limiting beliefs (Blockmens, 2015; Braithwaite, 1991; Goffman, 1963; Smith, 2007; Meisenbach, 2010). Yet, disabled individuals use these strategies as an attempt to integrate with non-disabled spaces. The separation identified in this study suggests something entirely different. Rather than attempting to integrate, disabled individuals created space for themselves. While disabled individuals may experience different forms of stigmatization due to the perceived visibility of their disability, the stigmatizing beliefs expressed during the pandemic have a universal application to nearly all high-risk individuals.

Centering Vulnerability in Disability

The findings of this study also suggest that COVID-19 and the messages that surrounded it created a fundamental shift within the disability community. Previous research on the disabled identity was largely individualized with a focus on how the individual claims pride and space in an inaccessible world (Dirth & Branscombe, 2018; Ionescu & Callus, 2018). While the data in this study verifies those perspectives, it also suggests an expansion of the disabled identity to focus on the embodiment of disability and the disabled community through communal vulnerability.

Reynold and Kiuppis (2018) proposed the pathic model of disability which focuses on pain to counteract the expectation that people with disabilities must be resilient and strong. Most models of disability following the medical model have developed as a means of disability advocacy (Andrews et al., 2019; Dirth & Branscombe, 2018; Ionescu & Callus, 2018). However, the data suggests that the shift to centering vulnerability is inwardly focused to meet the needs of the disability community. When disabled individuals were isolated, their communal identities were strengthened as part of a unified outgroup. Dehumanizing messages were largely directed at the high-risk community rather than the individuals. “Only disabled people are going to die” (Participant 8) and if a high-risk person was worried, they should “just stay home" (Participant 28). While the messages may have been perceived as a personal attack, they distinctly addressed the community, thus highlighting communal vulnerability. Participants found that by centering their vulnerability, they demanded more of their non-disabled peers. When their non-disabled peers discarded their vulnerability, the disabled individuals reclaimed their agency by removing themselves from those relationships and claiming space in a community that protects itself.

Participants relied on their disabled community to not only cope with the pandemic but also to serve vital social roles in disabled individuals' lives. Previous research that looks at relationships between non-disabled and disabled individuals largely adopted a patronizing care-focused perspective where the non-disabled individuals could take care of a person with a disability (Keeley, 2021; Lindemann, 2012; Shaw, 2019). However, the data suggest that high-risk individuals viewed members of the disabled community as more trustworthy because they were also vulnerable. When interacting with others in the disability community, participants were able to step away from the stereotypes and expectations placed on their disabled identities without compromising their needs as disabled individuals. In other words, they do not have to appear strong or resilient while in the comfort of their community. Within the community, they can honor their vulnerability and humanity.

While the dehumanizing messages participants experienced may be limited to the pandemic, the data suggests a fundamental shift in the way that high-risk disabled individuals view themselves, their community, and those outside the disability community. Traumatic experiences serve as turning points in an individual's story (Bernsten & Rubin, 2006). The pandemic has been traumatizing for a wide array of people, and communication scholars will need to continue to explore the effects of that trauma. Previous research has suggested that online support groups have been beneficial for individuals to express their pain in an unrestricted way without judgment (Kruk, 2015; Miller, 2017; Witney & Bates, 2016). This study suggests that, for disabled individuals, the communal identity built during the pandemic extends beyond an isolated and sometimes anonymous support group. Previous research has explored how individuals reveal and conceal their disabled identities as a form of stigma management (Smith, 2007; Meisenbach, 2010). The disabled identity was one of many identities an individual could express and may have been able to be separated from the other nested identities an individual holds such as parent or employee (Meisenback and Kramer, 2014). Ashforth and Johnson (2001) described nested identities through high order or low order. However, the data suggests that disabled individuals, by enacting their disabled identities in the disability community, may center their disabled identity in a way that paints all other identities. By making their disabled identity non-negotiable, individuals enhance their agency to enact their other identities by reducing the potential conflict between their identities. They are a disabled parent, artist, or employee which means that accessibility and safety becomes a central necessity for all identity enactment. Future research should explore if and how this shift may be sustained as we move closer to a post-pandemic world.

Socially Negotiated Morality

This study proposes that high-risk disabled individuals experienced and expressed a cultural negotiation of morality. Participants reflected times where non-disabled individuals publicly called disabled people “unnecessary” (Participant 8) and suggested their lives were a worthy sacrifice “for the sake of [the] economy” (Participant 26). Data suggests that when stigma questions the value of an individual’s life, stigma management is inherently a negotiation of morality. The cultural negotiations in this study occurred in public and under the disguise of cultural commentary rather than messages that impacted the disability community. Participants expressed their own moral negotiation, centering their lives and refusing to compromise their wellbeing or safety.

Previously, Waldron and Kelley’s (2008) negotiated morality theory has been used to explore forgiveness in intimate relationships. They argue that all relationships are “interpreted with reference to a system of implicit or explicit values” (p. 75). However, the findings of this study suggest that moral negotiations can be communicated on both a social level and an individual level. Participants described experiencing a negotiation of morality in the form of debate about the value of their lives. Moral messages come from potentially valued social influencers such as leaders, celebrities, organizations, peers, family, and friends. Demoralizing messages both public and private prompted participants to re-evaluate their own and others' implicit values in the form of processing their "internalized ableism" (Participants 14, 23, 26). This processing required participants to re-evaluate whether their values were compatible with society and their peers.

Before the pandemic, disabled individuals negotiated their human rights, such as equal access to school and work, by compromising their comfort and dignity (Blockmans, 2015; Braithwaite, 1991). The findings of this study suggest that prior to the pandemic, participants largely attempted to reduce future stigmatization through education under the assumption they shared a moral foundation with their peers, families, and the greater community. Yet, the mass rate of demoralizing messages throughout the pandemic required participants to center their own lives in future negations. “We're starting to realize the value of our own lives versus what society thinks” (Participant 13). When life-threatening stigma is normalized and produced on a mass scale, individuals must identify where the negotiation of their values ends and begins.

Health choices are regularly interpreted as reflections of an individual’s moral obligation to their family (Keeley, 2021). However, in the context of COVID-19 participants were asked by family and friends alike to sacrifice their safety to preserve previously held social roles and identities. Participants expressed their negotiation by refusing to compromise their health and safety in the form of separation, thus reinstating their agency. Non-disabled individuals perceived this decision as a refusal to negotiate rather than as high-risk disabled individuals’ choice to no longer be the only compromising party. This study proposes that negotiated morality theory (Waldron and Kelley, 2008) may be a useful lens to interpret resistance in highly stigmatized communities especially within communities where resistance is interpreted as an indication of moral failings.

Negotiated morality theory assumes that the preservation of family concepts of morality motivates and shapes family communication (Waldron & Kelly, 2018). When an individual or an event threatens family values, members of the family are prompted to go through a communicative sense-making process. However, the data of this study suggests the same concepts in families may be applied to highly stigmatized communities where shared concepts of morality are necessary for the perseveration of the community. Participants described a communal interpretation of behaviors such as wearing a mask and social distancing as moral. Value systems within the disability community were established on social media and through other virtual means by which high-risk disabled individuals engaged with each other. While a non-disabled stranger not wearing a mask may cause distress, individuals within the community were held to a higher moral standard. Brandhorst (2018) argued that communal resilience may be built by creating safe and enjoyable spaces. In their study, participants did this by emphasizing the individual's agency to act as a responsible member of the community. When an individual within the disabled community did not wear a mask or social distance, the behavior motivated a communicative sense-making process initiated by community leaders such as Participant 5. This sense-making process occurred to prompt moral cohesion within the community: thus, infusing the tools necessary for community resilience.

Practical Implications

The data also suggests two practical implications for the disability community. First, the member expansion of the disability community, and second, the expansion of disability theory within the community. COVID-19 has been a mass disabling event. As such, the influx of newly disabled individuals will highlight the cracks in supportive systems. According to the American Medical Association, 10% to 30% of COVID-19 patients will experience "long COVID" also known as “COVID long-haul” (Berg, 2022). Symptoms of COVID long-haul include, but are not limited to, heart and lung disease, acute muscle weakness, and other disabling symptoms. Long-haul is most likely to develop in unvaccinated adults (Ducharme, 2022). The data suggests that participants experienced some hesitancy against those who were disabled by COVID-19. Participants reflected the belief that others typically do not understand what it means to be disabled until they or someone they are close to becomes disabled. Individuals disabled before the pandemic struggle with limited resources due to an already overburdened system. COVID-19 has been a mass-disabling event and the influx of people with disabilities puts pressure on the already insufficient systems of support for people with disabilities. Participant 14 described interacting with long-haulers: “They get very frustrated, and they get very upset that things aren't getting done, and the most I can say is, we've been fighting this fight for years.” While integration into the disability community for long-haulers may take longer, the added pressure on social systems will continue to highlight the cracks that people with disabilities frequently fall through.

Despite the added pressure, the data suggests that we are culturally moving to a space where disability is more readily discussed. Participants described addressing their internalized ableism and work to destigmatize the ways they interact with the mobility aids and other medical supplies they needed before the pandemic. Centering the disabled identity means taking care of the disabled body and community first. Care cannot occur if an individual is unable or unwilling to use the tools necessary for them to interact with the world around them. By breaking down their internal boundaries, people with disabilities can better connect with those within their community. Thus, the disability community has no physical home ground and has expanded its organizing power. Participant 14 said that she learned about disability history online for the first time during the pandemic. By being predominantly online, the disability community has been able to archive their work educating the community and those outside of it. Largely, since the pandemic, the disability community has been able to access information previously trapped in the ivory tower of academics and involve members of the community for natural evolution and application of theory. Conversations around disability have become more complex as members of the community have become interconnected. This is especially true as those with intersectional identities bring them critical perspectives that are better able to get at the heart of ableism.

Limitations and Future Research

The limitations of this study provide a path for future research. Exploration of how individuals negotiate morality around their stigmatized identities could strengthen literature in both negotiated morality theory (Waldron & Kelley, 2008) and stigma management theory (Meisenbach, 2010). As previously discussed, negotiated morality theory (Waldron & Kelley, 2008) has the potential for fruitful research when the worth of an individual's life is being socially debated. Communal coping (Affifi et al., 2006) may be a fruitful area of study to further explore disability community resilience. Limitations of this study include narrow sampling criteria, the limited period in which the data was collected, and the limited racial diversity of participants. This study focused on high-risk disabled individuals during the pandemic which does not reflect the entirety of the disability community. Future research should consider exploring the communicative messages and responses of disabled individuals who were not high-risk during the pandemic. While not as directly affected by the immediate risk of COVID-19, disabled individuals who were not high-risk still potentially experienced some of the same systemic pressures such as medical shortages described by participants of this study. The interviews cited in this study were also conducted in September of 2021 when transmission rates were high and return to in-person policies had just begun. Future research should explore if the findings of this study sustained over time and what changes, if any, occur as we move towards a post-COVID future.

Another limitation is the lack of racial diversity of the participants. People of Color make up the majority of the disability community in the United States with Black and Indigenous peoples representing 27% of the disabled populations (Ross & Bateman, 2018). The communities most directly affected by COVID-19 have been low-income communities of color. Black, Indigenous, and Latinx individuals are more likely to get sick and die of COVID-19 due to social and medical inequity (CDC, 2022). Disabled People of Color have faced a variety of stigmatizing messages which warrants further and more in-depth research. Both Black participants in this study said that deconstruction of their internalized ableism was aided by their deconstruction of white supremacy. Further research should explore how individuals with intersectional identities managed those identities alongside historical events following COVID-19 such as the violence against Asian, Black, and Indigenous communities (Dharmaraj, 2020). Future research should explore intersectional perspectives to the pandemic and stigmatizing messages especially as race, gender, and sexuality intersect with the disabled identity to understand the full evolution of the disability community. Overall, communication scholars should continue to explore other stigmatizing messages towards marginalized communities during the COVID-19 pandemic. Social media has become a tool for community organization and advocacy, and as such, has a wealth of implications to explore further. Finally, future research should explore the disability communities across the globe. All the participants in this study resided in North America during the pandemic. Perception of moral messages can be highly influenced by an individual's immediate culture. Zoom and similar technology have now provided the tools necessary to adopt a perspective of the disability community that expands beyond geographical boundaries.

Conclusion

During the COVID-19 pandemic, high-risk disabled individuals experienced very public and stigmatizing negotiations about the sanctity of their lives. This study explored those messages and how participants reconstructed their identity to reclaim agency and participate in those negotiations. The community studied has no geographical bounds and suggests that future research into stigmatized communities should expand their definition of community (Norris et al., 2008). To reaffirm their disabled identities and the importance of their lives, disabled individuals experienced a fundamental shift in the way they perceived their disability which centers their and their community's vulnerability. This shift in perception also triggered a shift in behavior where participants demanded that those in their lives compromise their stigmatizing beliefs about disability to remain in the participant's life. When high-risk disabled individuals made these decisions across their relationships with organizations and individuals alike, they employed their negotiation of morality. The study suggests that messages infused with cultural stigma are a form of negotiated morality (Waldron & Kelley, 2008) and that those who are marginalized will participate in that negotiation by the nature of membership in their stigmatized community. The accounts of high-risk disabled individuals reflect the time they were collected. The pandemic has created a context that has heightened the stigma that the disability community faces, but it has also strengthened the community's ability to respond to those messages.

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APPENDIX

Interview Protocol

- Minor demographics at the beginning of the interview will be collected including:
  - How do you identify on the disability visibility spectrum from visibly disabled, alternating visibility, and invisibly disabled?
  - What is your gender identity and pronouns?
  - What is your racial/ethnic identity?
- Can you tell me about your experience being disabled during the pandemic?
- How have other people reacted to you and your disability during the pandemic?
- How have you communicated to others about your disability and needs during the pandemic? Has this changed? If so, can you give me an example?
- During COVID, how did you manage your needs and responsibilities such as those with your family, work, or friends? Can you tell me about a time that stood out to you?
- Tell me about the messages that you noticed during COVID about disability? Is there a particular message that stood out to you?
- How did the people around you respond to messages about disability during the pandemic? How did they respond to you?
- How has the pandemic changed the way you view yourself?
- How has the pandemic changed the way you view your future?
- What are some questions that I have not asked that I should have?
- What are some questions that I have not asked that I should have?

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PROFESSIONAL EXPERIENCE

Graduate Assistant 2020 – Present
Texas Christian University

Taught two courses of Communicating Effectively in Your Community each semester
Facilitated class meetings and discussions with over 20 students per session
Constructed lesson plans for each lab and coached students through public speaking anxiety

Peer Writing and Student Support Services Tutor 2019 – 2020
Texas Christian University

Worked with underrepresented students to assist with their post-graduation needs
Developed and facilitated writing programs to build resilience against academic burnout
Collaborated with subject matter experts to enhance their communication skills

Education

Diversity, Equity, and Inclusion in the Workplace Certificate Jan 2022
University of Central Florida

M.S in Communication Studies 2020 – Present
Texas Christian University

Thesis: "I don't want to be called strong anymore": An exploration of COVID-19 moral messages and high-risk disability identity management

B.S in Communication Studies 2016 - 2020
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Future Presenter May 2022
International Communication Association

"The Audacity of Equality: A Proposal for the Study of Weaponized Civility"
Organizational Communication Committee

Presenter
National Communication Association Nov 2020

"Navigating the Crossroads of Disability and Technology"
The Future of Communication and Technology