

Beyond Better: Undocumented During Covid-19

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Introduction

At the beginning of the Covid-19 pandemic, public discourse was dominated by numbers and statistics. We were introduced to a stark binary: either you live or you die. But what happened to the survivors? What were their stories?

These questions drove Drs. Jessica Martucci and Britt Dahlberg to ask what happened to people who contracted Covid-19. What impact did the pandemic have on their (and other's) lives? What did life look like after a Covid-19 diagnosis? And what did it mean to "go back to normal?" What new forms of dis/ability might emerge from this novel virus?

Historical records show how epidemics continue to affect everyday life as people return to schools and workspaces. One recent example is the polio epidemic of mid-20th century and the emergence of post-polio syndrome that many polio survivors developed decades later (Wilson 2005). What might happen to Covid-19 survivors in the coming decades?

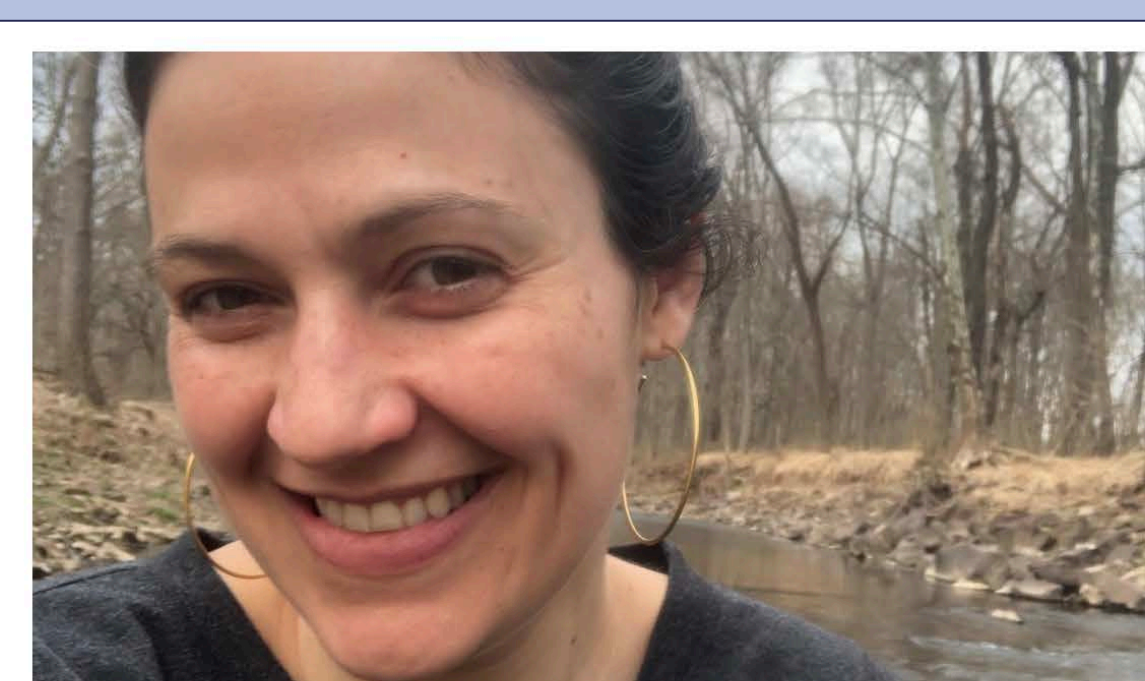


From these questions emerged Martucci and Dahlberg's The Beyond Better Project (www.beyondbetter.org). This public medical humanities project seeks to destabilize ableist narratives in American healthcare through oral history, storytelling, and art. The project's long-term goal is to build a sustainable public medical humanities project that collects and curates people's stories to help advocate for a more caring, inclusive, and community-oriented healthcare system.

Beyond Better's inaugural exhibition (on Instagram @TheBeyondBetterProject) is "Afterlives of Pandemics, Past & Present." This exhibition asks: How do bodies, lives, and societies change in the weeks, months, and years after an encounter with Covid-19? And how might past epidemics help us understand what is happening now and what might happen in the future?

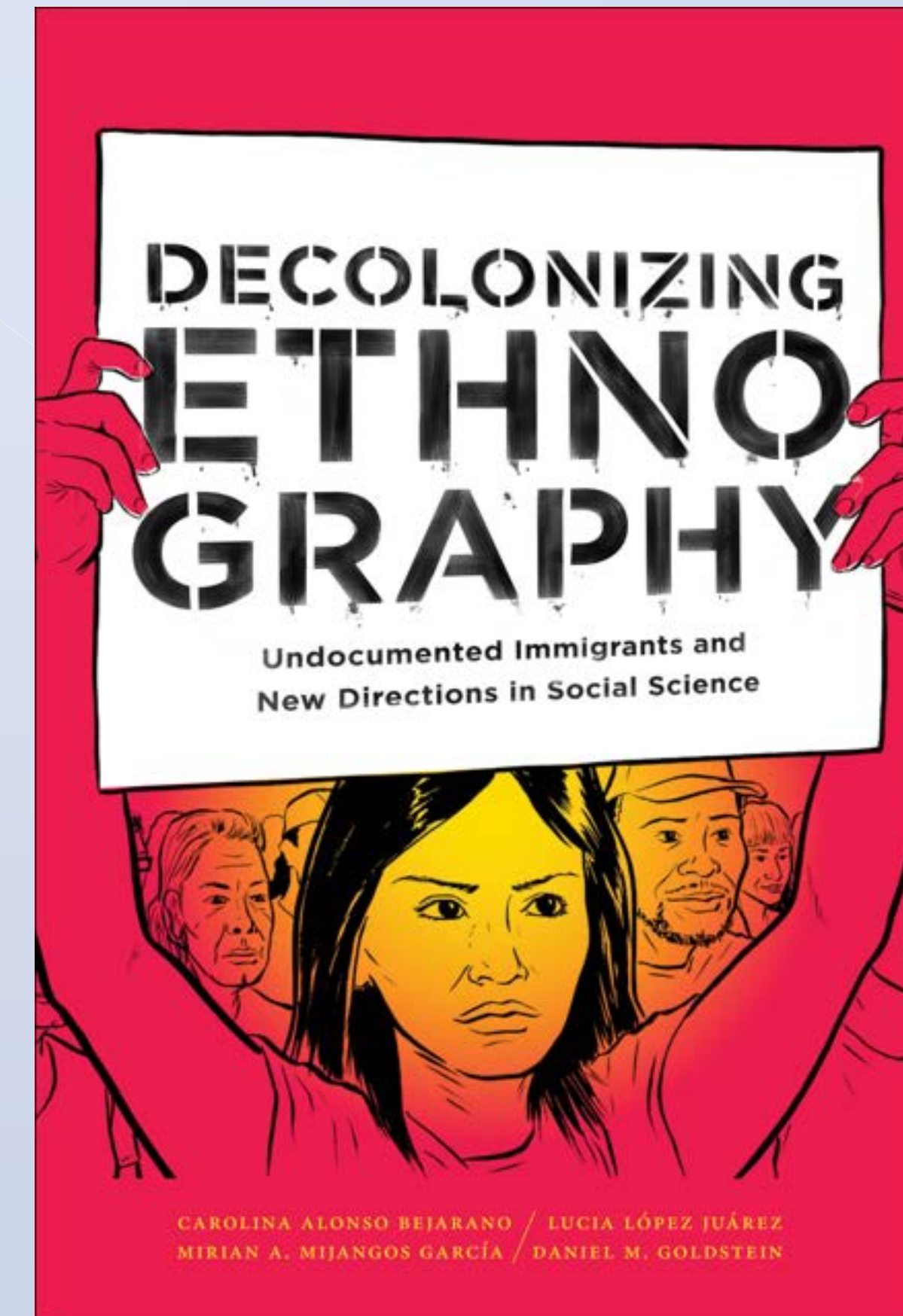


JESSICA MARTUCCI, PHD



BRITT DAHLBERG, PHD

Methods



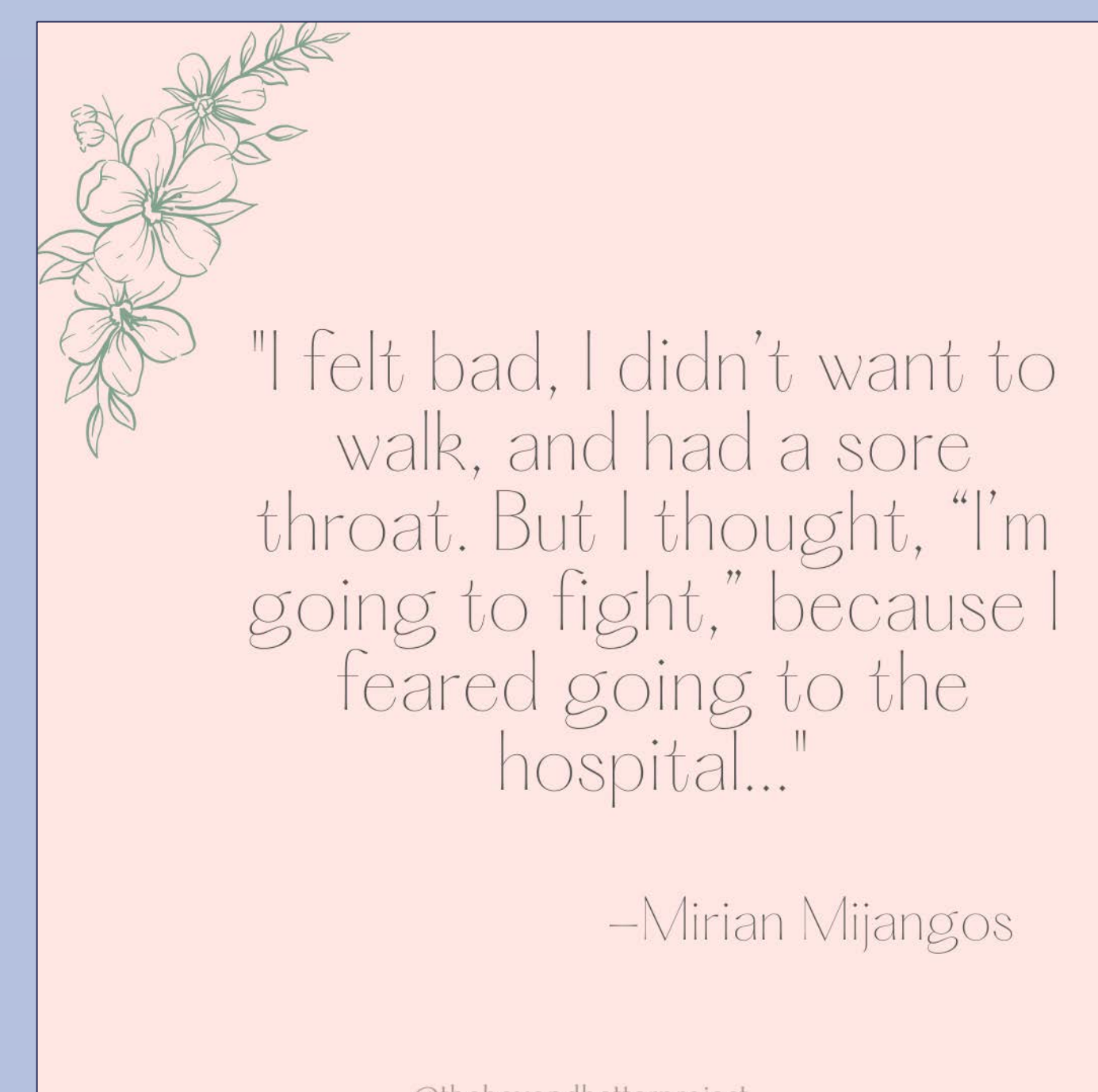
Oral history has traditionally aimed to fill in archival gaps where written documents are not available. Some of the oldest oral history work was done by the U.S. Government's Works Progress Administration, collecting narratives from Black Americans who could remember being enslaved before emancipation. Since then, scholars have theorized what exactly an oral history interview produces, who can claim authorship, and how oral history can be used as a primary source. Oral history is often associated with social and community organizing, as it is a tool for data collection and storytelling that can be easily learned and implemented by people regardless of educational status or background.

As a summer research intern with Beyond Better, I conducted two oral history interviews in Spanish. The first interview was with Dr. Carolina Alonso Bejarano, whose collaboration with the undocumented Latinx community in New Jersey resulted in the publication of *Decolonizing Ethnography*. The second interview was with Mirian Mijangos, an undocumented immigrant and one of the book's co-authors.

During these interviews, I focused on how law enforcement and language barriers disabled the undocumented community by limiting the access to medical care, both during the Covid-19 pandemic and beyond.

Findings

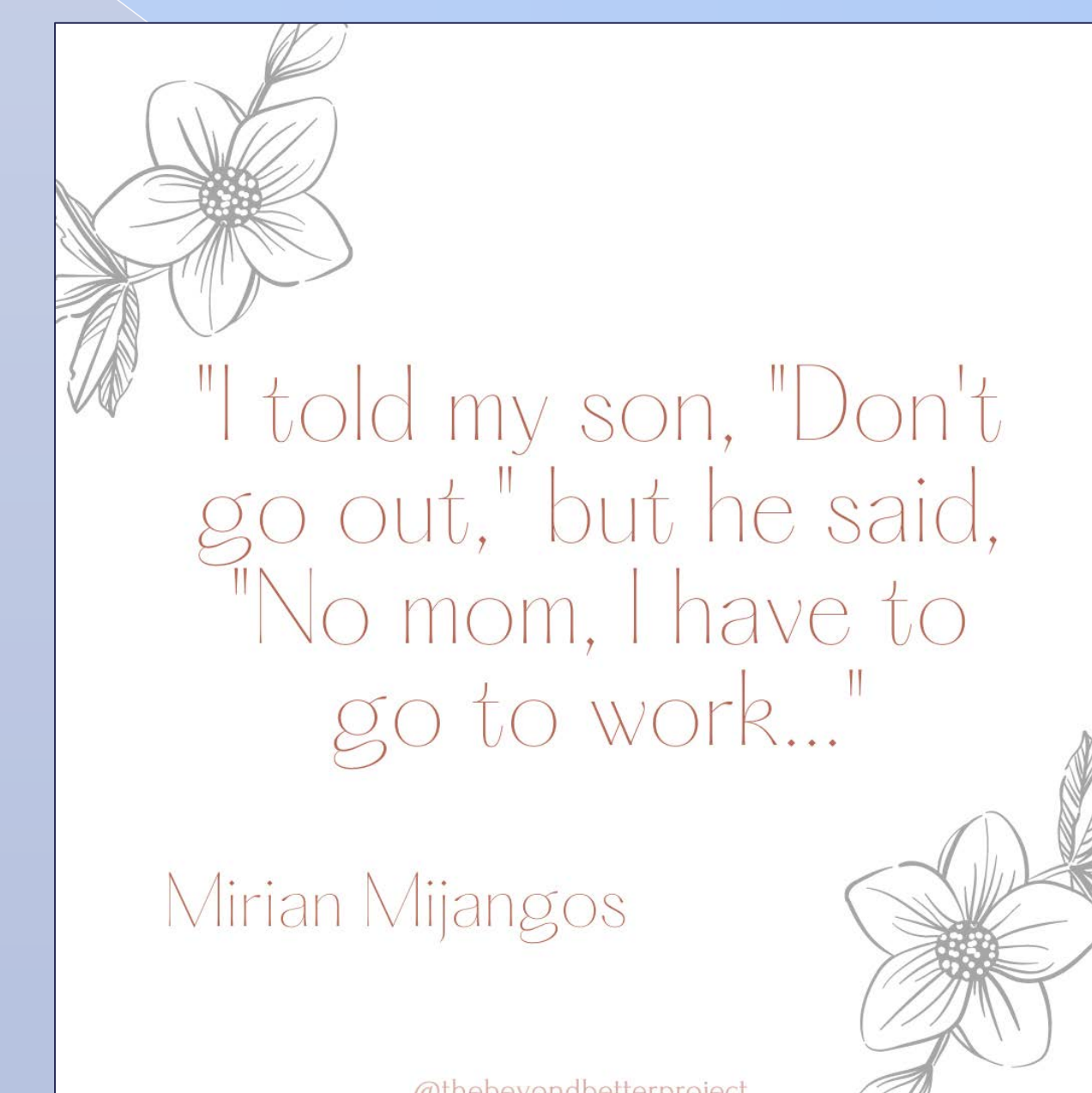
These interviews described the reality that many undocumented people face everyday: the fear that anti-immigration laws will turn a trip to the hospital into a ride to the police station with a deportation order; the decision to use home remedies because of an inability to pay for medical treatment; the language barriers and inadequate communication at healthcare facilities; the pressures of working in a service society while not qualifying for economic relief funds. All these factors have contributed to undocumented immigrants needing to work throughout the pandemic.



—Mirian Mijangos

@thebeyondbetterproject

What would it mean for Mirian and her son to obey the initial public health advice to just "stay home?" For Mirian and her son, as well for many undocumented people, staying at home means having no job or money to pay for food or rent. In Mirian's case, it also meant not being able to send money to her daughter in Guatemala. Many "undocumented immigrants couldn't afford to stay home, even if their jobs entailed traveling in vans with sick people or working without masks in crowded settings. Many people working under informal arrangements and without government protections continued to work while sick, fearing being fired" (Page and Flores-Miller 2021, 5).



Mirian Mijangos

@thebeyondbetterproject

Discussion



I do not intend to generalize and demonstrate that every undocumented immigrant had the same experiences during the Covid-19 pandemic. However, Mirian's story as an undocumented immigrant, and Dr. Alonso Bejarano's experiences living and working with undocumented immigrants, told us about a reality that many of them face daily. The experiences of undocumented immigrants are shaped by structural barriers that disabled them.

My understanding of undocumented immigrants been disabled by society is based on the Ginsburg and Rapp perspective of disability, where they state, "disability is profoundly relational and radically contingent, (inter)dependent on specific social and material conditions that too often exclude full participation in society" (s5, 2020). If we think of disability as social barriers that disable individuals by excluding them from fully participating in society, then Mirian was effectively disabled because her identity and status as a non-English speaking undocumented immigrant prevented her from having access to the information that she needed to protect herself. Unfortunately, this is not only true for Mirian's case, but also for the many Latinx people and immigrants from other parts of the world.

Undocumented community was already oppressed and disabled before the Covid-19 struck. The pandemic just acutely affected their situations and realities. They were forced to work infected, they did not receive economic relief, they had to decide between going to the hospital or paying their rent, but no one seems to care about them. They were forced to treat themselves at home with natural remedies because of the language barrier, the lack of knowledge about medical terminologies, and because of the fear of being deported, and then, people judge them for not seeking medical attention. Those actions are the ones that disabled individuals, those are ableist (inter)actions.

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