'*Se Pesa'*: structural uncaring in the COVID-19 pandemic and caregivers' kinships of care

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Abstract

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The COVID-19 pandemic has exacerbated racial and economic inequities in the United States, intertwining labor and health. This research focuses on immigrant Latina caregivers whose "essential labor" is often excluded from #HealthcareHeroes rhetoric. Building from insights gained working with immigrant-facing community organization in Tacoma, Washington, this research combines artistic portraiture and ethnographic methods to center caregivers as essential workers deserving of respect, attention, and artistic portrayal. Applying theories of racial capitalism and feminist care labor this work contributes to the growing body of scholarship on the ways in which the pandemic has highlighted racialized landscapes of uncaring. This project offers the opportunity to learn how caregivers continue to build kinships of care as they navigate precarity to care for themselves, their families, and clients when the state and their employers fail to care for them back.

Table of Contents

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Introduction: Coming to Care

In many ways I was guided into this research. Not because I don't find it interesting or because I had someone strong-arming me, but mostly because I had never thought much about labor studies, I didn't even know it was a field two years ago. I was trained in my undergraduate studies to be an environmental and political scientist and found my way to a geography graduate program in the hopes of escaping a white discipline[1] and for a critical field in which to engage with questions of settler colonialism and racial capitalism in relation to "natural" spaces. But what I have learned as much as material and theory from feminist and Black, Indigenous and People of Color (BIPOC) scholars thus far in my graduate program has been what it means to conduct research centered in relationality (Moreton-Robinson 2017; TallBear 2014) and the importance of practicing radical vulnerability (Nagar and Shirazi 2019) That is not to say that this research is perfect or pure, I do not believe that pure research exists -- but what it does mean is that is what I am perpetually practicing and inspiring toward and where this research begins.[2]

When the COVID-19 pandemic started in January of 2020, before the first wave of stay-at-home orders came out in March, I was working the front desk at an immigrant facing community organization in Tacoma, Washington. I continued to work this job until late summer 2020 when I moved to Seattle to start my graduate program. During these seven months, as the pandemic shaped our everyday lives, I saw and heard on the phones and through our locked doors every day the impact of COVID-19 on our clients. A lot of our clients were undocumented or had undocumented family in their household which meant they were ineligible for relief resources ("Why Millions of Americans Still Can't Get Coronavirus Relief Funds" 2020). Early on we learned of an experience a

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[1] I know, Geography, too, is a white discipline (Pulido 2002).

[2] You are going to see me use footnotes a lot, welcome to the published subtext, literally. This way of writing has been inspired heavily by Max Liboiron's *Pollution is Colonialism* (2021) Katherine McKittrick's *Dear Science* (2021).

client and their family had at a local food bank while standing in line, a white community member had verbally and physically assaulted our client after asserting that they should be able to cut in line in front of the brown people speaking Spanish because they were, “Americans" and our clients, presumably, were not. This violent experience of asserted unbelonging traveled quickly through the Latinx community in the area and people no longer felt comfortable at the foodbank, a space that many were depending on heavily to meet basic food needs. My core group of Latina coworkers, who welcomed me in and centered me during my time at the organization and still to this day, quickly started to figure out a way to get our community food. We were scrappy; hand drawn signs and the four of us and a couple of our partners giving food boxes out the back of a rented box truck, that I clumsily drove way under the speed limit to the foodbank and back, in our work parking lot. The need was immense. People lined up around the block and our food boxes were gone before we had even been open 30 minutes. When our community needed help, we figured it out. This was supporting each other to meet needs, not charity work. This work of mutual aid is not new, but the pandemic has seen an increase in community efforts identifying and using such language to describe their efforts (Spade 2020).

These mutual aid efforts grounded in meeting community needs were how I started the pandemic and in some ways my transition to a graduate program has been challenging to my ethos of community centered work. I have felt the pull on my time and priorities as my school load increased and the physical distance to these relationships furthered, not least of which was the risk inherent in gathering physically. This project, and my time spent with caregivers was directly driven out of my experience seeing the ways that the COVID-19 pandemic impacted the Latinx community I am in relation with and was shaped by the conversations I had during these early days with caregivers and former caregivers who had contracted COVID-19 at work. These conversations shaped my research questions, the grant applications that funded the project and my continual relationships with the caregivers as I write this today impact how I understand, frame and articulate this work.

Being able to produce research during a global pandemic is due to a type of privilege that I am afforded as someone who is not an essential worker. To have been lucky enough to maintain steady employment and to have a family that was able to for the most part stay safe at home means that the devastation of COVID-19 has stayed relatively buffered from my life. That is not the case for the caregivers of this project and I recognize the power imbalance inherent in this work, for this, and on many other axes. The caregivers in this project witnessed, experienced and cared through firsthand the exacerbation of failed social systems during a global pandemic. They bought themselves personal protective equipment (PPE) out of pocket when their gloves were rationed. They went into homes of those who were actively ill with COVID because they knew they were those people's only source of life-extending services. They were put in unsafe situations that risked their families and their personal health when clients lied, their agency lied or they just had no choice but to work.

Taking the racial dynamics of low-wage care work within the larger healthcare sector seriously, this research adds the layers of pandemic and the resulting discourse of heroism and for many workers, a discourse of disposability, to look into how caregivers understand and navigate their work. To do this, this research asked: how does racial capitalism shape HCA work in the South King County- compensation, language/immigration status barriers and COVID-19 safety? How do HCA's understand their work as "essential" in the COVID-19 pandemic? And, to what extent, if any, do they identify with the #HealthcareHeroes rhetoric? These questions are what I started the project wanting to ask and even reading them back reminds me of the ways the project has taken its own shape. From labor studies and a pandemic analysis to interdependence and embodied care. The following chapters move through the generative friction that came from my thoughts and training colliding against caregiver experiences and articulations as I write about the testimonio interviews, observations, emails, phone calls and conversations that I had with caregivers in the Summer, Fall and early Winter of 2021.

My goal with this work is to show the ways people negotiate with risk and engage in everyday practices of embodied care. What I mean by this is not an over intellectualization of care. By embodied care I mean the physical acts and moments that center other's needs, person and feelings. I believe care to be an embodied practice, a set of things caregivers do and feel. Like bringing in coloring pages, dancing to *corridos* in kitchens and crying in their car after work. What I really want to draw out is how they see themselves as expressing agency through the ways they do this even though they know that clients do not always disclose all their information, they know that employers lie to them and they know that the public does not value their work. What I have learned is that regardless of whether other people see them as "healthcare heroes" or essential workers, they, even before the time of COVID, have seen their practices of care as essential to community and they are happy to be recognized, but they are not relying on other people to recognize the importance of their work. They have known that their work is essential because of the ways in which their *care* makes other people's lives possible.

the case for caring

The spread of the novel coronavirus has amplified the stark inequities that persist, and I would argue are a function of our current social and political system in the United States. With unemployment reaching 14.7% in April 2020 ("Unemployment Rate Rises to Record High 14.7 Percent in April 2020" 2020) and more families than ever needing support to meet basic needs such as affording rent and feeding their families, the pandemic has played out across our deeply capitalist nation revolving around illness and work. Where many found meaning and perhaps even newfound respect as 'essential workers,' no sector was more lauded on the national stage than

#HealthcareHeroes.

As the pandemic restructured daily lives and led to surges in hospitalizations and deaths, the media praised the heroism of healthcare workers using the hashtag #HealthcareHeroes. Military symbolism was deployed (Khan, Iwai, and DasGupta 2021), companies offered discounts to "Heroes," and bells were rung to acknowledge and pay tribute to those on the "front lines" of the global pandemic. The rhetoric of #HeroesDeLaSalud did not circulate as well in Spanish media sources, though some caregivers had seen some posts on social media and heard about the acknowledgment from friends. There have been some mid-pandemic publications on the problems with this media focus (Cox 2020; Khan, Iwai, and DasGupta 2021), but even within the critiques the focus is on doctors and nurses. This discourse of #HealthcareHeroes implies sacrifice and bravery, heroizing and glamorizing terrible working conditions without naming or seeking to transform the structural conditions that undergird them. The discourse, albeit problematic in content, often excludes, sometimes quite viscerally, home care aides altogether.

My research centers on the intersection of "essential" and made disposable, Latina[3] caregivers who are often excluded from #HealthcareHeroes rhetoric. What about those who just have to go to work to live? What about those who have no interest in being heroes, but show up to work because that is what they did every other day? How do they understand and navigate COVID-19 precarity and their labor? This is particularly crucial for Latino workers, as the US Centers for Disease Control (CDC) have found that "Hispanic or Latino persons" have some of the highest rates of cases and deaths of any ethnic group (CDC 2022).

Working within networks I established from my time spent at a community-based resource

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[3] Out of 15 interviews, I had one caregiver who identified as a man. Heteropatriarchal Spanish language customs would have me switch Latina to Latino because of that one man. I have chosen not to do that to emphasize the gendered nature of this work and of the caregivers I spent time with.

center focused on serving immigrants in Tacoma, I conducted 15 *testimonios*, that ranged from thirty minutes to an hour and thirty minutes. *Testimonios* are a type of knowledge sharing that is based in relational storytelling and used to raise awareness and excite social change, challenge colonial academic knowledge production and allow myself and the caregivers the space to think about our whole being- mind, body and spirit (Cahuas 2021). Through these *testimonio* interviews I began to understand caregivers' work histories, moments of pride and workplace challenges and experiences of, and in, the pandemic. I wanted to give caregivers a chance to share about what it was like to bear the brunt of an incredibly challenging year and to begin to understand how they theorize the experiences of this year in relation to their past experiences of being part of a care labor industry. In addition to *testimonios* this project also drew inspiration from the work of Bronx based artist Aya Brown[4] and commissioned collaborative portraits of the caregivers by PNW BIPOC artists. These portraits, in culmination with the stories and perspectives collected through interviews and participant observation offer a centering of caregiver agency, place-making and care.

I wanted to flag that I may bounce between the language of home care aides and caregivers. I will try to use home care aides when I am speaking about caregivers' formal job role but use caregivers more expansively to think about the care they give beyond the scope of their job. These workers' formal job title is home care aides and sometimes, community aides. I use caregiver predominantly in this research as the term that these workers use for themselves and to encapsulate the caregiving, they give both to clients and to the various roles that they hold beyond their paid labor, as mothers, grandmothers, daughters, granddaughters, wives, neighbors and community members.

This work is situated at the intersection of racial capitalism, gendered care labor and Latinx

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[4] Aya Brown's "Essential Workers" Series features incredible colored pencil drawings meant to highlight Black women essential workers in NY. http://ayabrown.com/series/Essential%20Workers

geography. These interviews and portraits were done with a sector composed of predominantly immigrant women of color, often precariously documented or undocumented. This research highlights an invisible sector of our region and larger nation, those who do the complicated and challenging work of care-labor for our elders, disabled people, and others needing support meeting their daily hygiene and care needs. This work builds toward a more nuanced understanding of how COVID-19 impacts (or exacerbates) the lives and labor of everyday workers and offers a unique critical Latinx geography approach to the work and lives of our local #HealthcareHeroes.

converging crises, the landscapes

> Racism is a practice of abstraction, a death- dealing displacement of difference into hierarchies that organize relations within and between the planet's sovereign political territories. -Ruth Wilson Gilmore (2002, 16)

For many low-wage immigrants of color, many undocumented or precariously documented,[5] the COVID-19 crises may have amplified or exacerbated the violence of racial capitalism, but it was a crisis compounding on an already established landscape of unbelonging. It is not possible to understand the nation making projects of the Americas without the Black radical tradition's articulations of racial exploitation, imperialism and slavery. Ruth Wilson Gilmore's articulation of racial capitalism, which builds on the term coined by Cedric Robinson (2000) is fundamental to my understandings of power. Gilmore, along with Black studies thinkers such as Stephanie Smallwood (2017), Simone Browne (2015), and Katherine McKittrick's (2011) clarity and skill at unraveling the strangling threads of racial capitalism and exposing the centrality of race in structuring social and labor hierarchies in capitalist economies shape how I understand the complex economic and social

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[5] Like many colonial binaries, documented/undocumented binaries do not reflect the lived realities of immigrants. Many people transition between documented/undocumented times in their lives. Immigrants live in mixed status households, where some family members are documented but others are not. The feeling of undocumentation, the skills and way of life learned to negotiate an undocumented existence can persist after adjustment. The condition of perpetually assumed undocumentability of brown bodies speaking Spanish (or non-Spanish indigenous language) in public space challenges previously articulated notions of binary documented/undocumented existence. For more on this, see Menjívar's "Liminal Legality: Salvadoran and Guatemalan Immigrants' Lives in the United States."

systems within which my research takes place. The backdrop of racial capitalism creates the interlocking and intersecting oppressions that caregivers experience and are situated within.

Where a racial capitalism analysis rooted in Black theory is where this begins, I also hope this work challenges the Black-White binary that racial capitalism is often framed within. The violence I am naming is a broader system of racial capitalism that takes essential workers and makes them disposable on the basis of race, class, immigration status and language. Megan Ybarra writes, "While US courts demand animus to prove racism, critical race theory demonstrates that White supremacy more insidiously devalues the lives of people of colour (Harris 1993; Pulido 2015)" (2020, 4). It is this devaluation that caregivers feel amplified in their daily lives, at work and beyond. In making the case of environmental racism as state sanctioned violence, Laura Pulido elaborates on the system's reliance on "a vulnerable supply of low-wage workers" (2017, 528). The US immigration system creates and maintains this supply by structurally marginalizing workers. This "racialized rightlessness" (Cacho 2012) allows for the exploitation of immigrants in service of the production and flow of capital. In fact, it necessitates it.

Theories of racial capitalism rely on racialized rightlessness to produce capital. Settler-colonialism constructed border boundaries that settler logics maintain and militarize to "(re)produce categories of vulnerability" that racial capitalism depends on (Freshour and Iniestra Varelas 2022). Harsha Walia articulates borders as, "productive regimes concurrently generated by and producing social relations of dominance" (2021, 78). Carrie Freshour and Iniestra Varelas work with undocumented youth in the south shapes their articulation of immigration and racial capitalism as:

> Viewing immigration through the lens of racial capitalism helps us understand how and why some groups are made exploitable through racial myths with material consequences, but also how competing ideas about racial difference rooted in culture, language, and visions of "progress" move through and construct differently racialised people and places (2022).

For caregivers in south King County racial capitalism and immigration interact in their everyday lives, in their job as home care aides and in their roles beyond its scope as caregivers. In racial capitalism Latinx immigrants are only ever workers, laborers who produce capital. They can never be heroes for risking their lives at work because their disposability is essential, the risk is inherent, exploitation is expected.

The US President's "Coronavirus Guidelines for America" issued during the first few months of the pandemic deemed low paying jobs in which Latinx (and Black) individuals are overrepresented as "essential" (Centers for Disease Control and Trump White House 2020; U.S Bureau of Labor Statistics 2020). The Washington Dream Coalition, a network of undocumented and formerly undocumented professionals of color, recently published a report called "Community Provides: Undocumented Communities in Washington State During the COVID-19 Pandemic" which acutely analyzed that "undocumented people are actively exploited into risking their lives every day during the COVID-19 pandemic, as well as the active climate crises across the country, in the name of 'keeping our economy moving,' which is upholding the system of capitalism in the country" (2021, 4). The caregivers this project is centered on are included in these stats and situated in these contexts. It is in reading racial capitalism with feminist care politics that allows us to understand the experiences of immigrant women caregivers during (and before) the COVID-19 pandemic.

Though racial capitalism is a larger theory of economic and social structure it functions though specific geographically contextualized mechanisms. For caregivers in the state of Washington the organization of their labor between contracting agencies and state structures shows how racial capitalism impacts their lives. The public/private care scheme in the state of Washington follows similar patterns to national and international neoliberal care markets. Notably, the State of Washington's uniquely regressive tax structure, means that social services in the state are woefully inadequate in addition to it being challenging to reliably fund those that do exist. Enshrined in the state constitution, Washington has no state income tax and thus is dependent on sales and other excise taxes to generate a majority of state revenue (Washington State Senate Ways and Means Committee 2020). In Washington state this tax structure overtly challenges unfounded claims of undocumented immigrants not contributing fairly to tax revenue. Because taxes are levied when people buy things, undocumented immigrants in Washington state contribute to the tax pool just like everyone else– though they do not benefit from the services funded through taxes at the same level as other Washingtonians. This is also true when federal income taxes are pulled by employers or filled via ITIN number, a state process that does not happen in Washington though it does in other states. In fact, families in which anyone filed taxes with an ITIN number were intentionally excluded from pandemic stimulus under the CARES Act (Gellat, Capps, and Fix 2021).

Home Care Aides in the State of Washington have three options for employment: hired by an agency or facility, hired by the person needing care and paid by them directly or hired by the person needing care and paid by the state to provide services as an independent provider (IP). Most of the clients who the caregivers in this project care for are Medicaid eligible (financially and functionally), which means they receive care through the Department of Social and Health Services' Aging and Long-Term Support Administration (DSHS/ALTSA) who then contract with the local agency to administer care via caregivers the agency hires and pays. Agencies must apply to be home care Medicaid providers, submitting documentation, meeting qualifications and paying initial licensing fees in addition to twenty-four month renewal fees (Department of Social and Health Services 2020; "WAC 246-335-990:" n.d.). DSHS/ALTSA uses an assessment tool called CARE- the assessment is said to be comprehensive, looking at needs for assistance, informal supports available, unmet needs, etc. – a built in algorithm determines the number of hours a person can receive in terms of care ("Chapter 388-106 WAC:" n.d.). The caregivers then work for the agency in caring for the client for the set number of hours, and delineated tasks, decided on by the assessment completed with the client by DSHS prior to the start of care. This structure creates many of the challenges for caregivers, not least of which is no guaranteed hours and a situation in which clients are allocated the fewest possible care hours (to save money), often insufficient to meet the quality of life and care that caregivers feel is needed. The state's refusal to fund caregiver services adequately is not unique to Washington (Piepzna-Samarasinha 2018). With no real ability to work overtime[6] caregivers are put in a situation of; work unpaid hours to support their client, either because they feel like they need to, because they feel like the client needs it or because the client or the client's family is demanding it OR stick directly to the set hours and tasks delineated in the care plan and risk losing their client and thus hours/pay. Caregivers are time and time again put in this challenging situation where they bolster and hold up the shortcomings of our social systems with their care- this was only amplified in the time of COVID, but more on that later.

Most of the caregivers in this project worked in homes through a local agency that facilitated the state program, but many worked through multiple employment structures, which often meant they were working over full-time, including directly through the state (IP's), contracted directly through a family, via an out of state agency, or in an assisted living or behavioral health facility. For some, dual employment was chosen for the flexibility the state offered in caring for family members, something the local agency had stopped allowing a few years back. Though working directly for the state as an IP was not possible for many caregivers due to their lack of legal work authorization. Agencies offered employment for caregivers who did not have work authorization, at least for those who began work prior to the widespread use of E-verify, a federal process through which employers verify workers ability to work in the United States. Caregivers, or Home Care Aides, as identified by

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[6] Caregivers can technically be paid overtime, though in my interviews it was made clear time and time again that they were not to work more than their set hours. This becomes complicated by the nature of the work, set hours pieced together across various clients adding up to a "work week."

DSHS, must undergo a certification process which includes seventy-five hours of training and the successful completion of an assessment exam (Washington State Department of Social and Health Services 2019). In addition, caregivers must complete twelve hours of continuing education yearly (Washington State Department of Social and Health Services 2019). Many caregivers spoke with pride about their ongoing growth and learning in their jobs and used these continuing education hours as an opportunity to take classes on conditions their clients may be experiencing (e.g. memory loss, diabetes). The caregivers are also members of unions, SEIU 775 and OPEIU Local 8 were represented in the group with some concurrent enrollments for those that were both IP's and employed by an agency. Caregiving unions in the PNW have a history of strong and often overlooked mobilization efforts (De La Cruz and Bussel 2018). Washington state caregivers were the first in the nation to win a $15 minimum wage (National Employment Law Project 2015). Though the caregivers had varying levels of engagement with their unions, many commented on the important buffer the unions provide and advocacy at the state level, as well as their role in salary negotiations, not that any felt they were being compensated fairly. The temporary hazard pay of a couple dollars that had been negotiated by SEIU 775 during the pandemic was recently extended, at a slightly lower rate, until March 2022 ("COVID-19 Updates: Hazard Pay, PPE, and Caregiver Funding – SEIU775" 2021). The union continues to fight for a $20 minimum wage ("Time for $20 – SEIU775" n.d.). Caregivers work in a labor market devalued through racialized risk and gendered care.

the work of care

These caregivers work inside others' homes, depended upon for the labor of outsourced care work. They are entangled between the dynamics of the cared for, the cared for's family, the state of Washington and private and non-profit agencies contracting them. As with most social reproduction, this work is feminized and when outsourced, as it is often, carried out by low-paid women of color and immigrants (Chang 2016). The caregivers I worked with were all immigrants that migrated as adults, all spoke Spanish as their first language[7] and identified as Latina and/or Hispano.[8] Though their context was specific to their clients, agency and personal experience they work and exist within a politicized space shaped by structures of power. This connection between the personal and the structural is what I hope this research can elucidate.

Gendered care labor interacts with the immigrant experience for the caregivers and their labor is systematically undervalued, unnoticed and unappreciated. Feminist geographer Victoria Lawson's 2007 Presidential Address to the Association of American Geographers charged the field of geography with the need to build a robust feminist care ethic. Lawson makes clear:

> ...these shifts have both made care a more pressing concern and have simultaneously marginalized care from view. Geographers are well positioned to draw attention to these twin trends and I urge us to think about our responsibility to care about these issues, and the geographies that they make. I ask us all to think about our responsibilities as geographers to pose questions in the face of (i) market extensions, (ii) currently pervasive discourses of personal responsibility (for poverty, inner city decline, unemployment, etc.), and (iii) the withdrawal of public support from many crucial arenas (2007, 2).

The need to care and the responsibility to pose questions that Lawson articulates continues to ring true, some fifteen years later. In the context of the COVID-19 global pandemic, my feminist care ethic further asks, how do we make sense and understand what it means for caregivers to have their work systematically serve as a pre-existing condition for infection?

In her book, *Children of Global Migration: Transnational Families and Gendered Woes*, Rhacel Salazar Parreñas explains "care resource extraction" as a system of migrant labor that props up the failed neo-liberal state (s). In writing about migrant Filipina domestic workers, she brings an

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[7] All research communication with caregivers, including the semi-structured interviews was carried out in Spanish.

[8] Self-identification around ethnicity, language and/or race is politically fraught in the anti-Black settler-colonial states of Mexico, Honduras and El Salvador, the countries from which the caregivers I interviewed had migrated from, as it is in the US. In conversations around identity caregivers used Latino, Hispano and the country they were born in to identify themselves depending on context and how I framed the question. For more on complex Latinx identify and naming see,

international lens to understanding racialized landscapes of care that is important in the context of the immigrant caregivers in this project. Salazar Parreńas writes, “Care resource extraction enables richer countries to ignore the social inequalities of care caused by inadequate public services, low wages, and insufficient employee benefits" (2005, 29). Geographer Geraldine Pratt, also working with Filipina caregivers, this time in Canada, articulates a theoretical adjustment that this needed when thinking through care labor as a neoliberal byproduct/necessity, “First, a focus on the vulnerability of Filipino domestic workers to the arbitrary exercise of the sovereign power of the Canadian state not only repeats a familiar tendency to begin and end stories in the metropoles of the global North; it obscures the geographical complexity of the power relations in which domestic workers coming to Canada are immersed” (2012). Though less structured of a program than the recruitment schemes both Pratt and Parreñas study, the care labor market in south King County is tied to structural vulnerability through gendered and racialized immigrant care workers.

what is to come

This is more than empirical research; it is also an epistemological project. This master's thesis is the first independent[9] research of this scale that I have worked on. As I thought about the form it would take, I knew that I wanted it to be first and foremost a project centered in community and responsive to the needs, wants and desires of those I am working with. To do this I build on the foundations that Indigenous and feminist scholars of color have sown before me. The myopic portrayal of dispossessed communities’ brokenness in hopes that documentation will somehow initiate change is what Eve Tuck has termed, damage-centered (2009). I hope the following pages move past damaged-centered narratives to think beyond violence, and to instead think through what it would mean to be desire-based – “desire-based research frameworks are concerned with

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[9] I struggle with the idea of this being independent because this project has been anything but something I completed without endless others’ time, support and input.

understanding complexity, contradiction, and the self-determination of lived lives" (Tuck 2009, 416). This project takes the political economies put on our bodies seriously while thinking through desire-based work and embodied practices of care in research. This work invites and creates relationships with people and communities to which I have responsibilities and obligations. It is the messy evolving work of engaged research based in reciprocity, what Black queer ethics has termed "accountable relationality" (Young and Miller 2015).

I situate this research in theoretical grounding and structural analysis and yet, that is what I hope to caveat in many ways. The studying of systems, racial capitalism as a main one, can often leave its 'subjects' in reductionist narratives of passivity. Katherine McKittrick pulls on this intentionally in her piece "On plantations, prison and a black sense of place," writing "We might think hard about the meaningful challenge that intellectuals such as Gilmore have put in front of us, and think about how we can and will re-evaluate the commonsense workings of violence and death and re-think analyses of injustice that re-solate the dispossessed" (2011, 960). McKittrick clarifies the "dangerous analytically teleological linearity of our intellectual work and spatial politics" (ibid, 953). This fundamental idea that a framework for analyzing racial violence in which "the dead and dying black/non-white body becomes the conceptual tool" means that this, "analytical logic can only 'end' with black death" (ibid, 953). This is *important.* If those rendered 'without' are only ever dead/dying, we, in using this analytical linearity, at best ignore and at worst, ontologically murder, all that others imagine, create and are. We can never "'fix' (repair) the plight of the other by producing knowledge about the other that renders them less than human" (ibid, 955). This challenge McKittrick poses of re-imagining geographies of dispossession and racial violence as "sites through which 'co-operative human efforts can take place and have a place" (ibid, 960) is where I hope this work begins.

As such, the following chapters do a couple things, they start by explaining how I approached this research and my process through the project. I devote a large section to my methods because they matter that much. I am a process-oriented person. I think all researchers should be process oriented people. How I come to make the claims I make matters. In the first chapter on methods, I take the time to share the evolution of the project and to elaborate on feminist and Indigenous methodologies that I ground my work in. In doing this I reflect on my role as a researcher, positioning myself and sharing some of the challenges I had as I navigated an inside/outsider evolving dynamic present through the project. Talking about the relationships and friendships I made through the project I discuss what it means to center listening and care in the methods of a project about care and uncare. Through this I also talk about language and translation in research and the role of iterative consent, its constraints and opportunities, throughout the project. The methods section also integrates creative work and artistic expression through portraiture as a way to engage in a more collaborative approach to working with and engaging in dialogue with caregivers. I then take time in this chapter to talk through the methods of the portraits, as collaborative, as supporting young BIPOC artists, as originals that are returned to the caregivers themselves- as intimate versions of likeness that were not always enjoyed.

The middle three chapters, 3, 4, and 5 are shorter chapters centered around lessons learned from the caregivers' work experiences. Chapter 3, "*Se Pesa*" thinks about the ways in which caregivers' care is embodied and the different ways they feel and understand their care. This chapter looks at the mental, physical and emotional toll of the work on caregivers as well as the whole body care they give their clients. In Chapter 4, I center a desire-based framework to think about caregivers' structural constraints (which are not static overtime) and the ways they find and express agency within their workplace regardless of the often-challenging situations they are placed in. In the third and final lesson, Chapter 5, I think about the ways that family and kinship are deployed in care work. I think about clients and caregivers' use of kinship and family in their work- both in meaningful and exploitative ways. I reframe cultural expectations of care as gendered and as "familial care" instead of the often theorized separately elder and childcare. And then I use queer theory to help see the ways that gender is made through caring. These chapters narrow in on specific caregivers' stories to try to avoid reductionist abstractions that happen when quotes are pulled out of context. As such I have tried my best to write around the testimonios, allowing what was shared to shape the chapters. I also hope this type of situated, long-form, in depth, structure offers a more embodied portrayal of the caregivers themselves and that my analysis offers a scaffolding from which to draw patterns and see connections and departures.

Both things are true, structural power and violence plays out and on caregivers' lives and work opportunities and experiences, and yet, if there is one thing that I hope you take away from this project it is that caregivers are the most life filled, affirming, tenacious actors creating meaning and making space for the care they radiate regardless of if I write this thesis and whether or not you read it. My hope with this work is to use the power and resources that I have within an academic institution to draw patterns and connections with other conversations to stand with them (TallBear 2014) and shout their worth, meanwhile, they will be at work and at home and in their communities, doing the good work.

Chapter 1: An Epistemological Project

understanding research

My understanding of research is shaped by the feminist scholars of color who have come before me and the colleagues and friends I learn from and with today. As a geography student who is also in the American Indian and Indigenous Studies certificate program and who has taken classes across a variety of social science disciplines this means that I am learning not only new readings and theories but also HOW the work in these disciplines is coming to be. As UW Cultural Anthropology Professor Radhika Gonvindrajan continually reminded me during her Field Techniques in Ethnography course in Autumn 2021, the methods of your work cannot come second to the material. Your research questions are inextricably entwined with the methods you use, or create, to find their answers. How do people understand research? How do people understand themselves in their research? What do peoples' relationships to their research look like? To echo an idea that I learned from Dian Million in my first year and that I come to often, what are peoples' formations?

When I say I learn from Feminist and Indigenous methodologies I want to be clear what I mean because what may have been new and sparse fields fifty years ago are now large swaths of literature that include many lessons to be learned, and some to be left. There are also plenty of tensions between disciplines and within them. I want to be careful that what I am not doing is practicing extractive reading and merely pulling theories out that I find useful (Liboiron 2021). Instead, I think about this as Dian Million taught me, as my formations, as those I have learned from and with. The following methodology are those that I am engaging with in this project and that I continue to learn from.

What is most salient from feminist theory in this project, and how I think about research more broadly, are the need for me to reflect on myself in the research and the need for me to subjectively situate myself in its context. In referencing this labor of reflexivity, D. Soyini Madison writes:

> The aesthetic/epistemic double bind is no longer a double bind, but a fluid horizon that is expected and necessary. Poetics, knowledge, dreams, repetitions, and even our mistakes and stumbles are all reciprocally linked now to constitute a kind of reflexivity that is willfully about the social—about the self made gloriously and ingloriously through Others (2011, 136).

This being said, I also think through the critique of this reflexive turn that Audrey Kobayashi addresses writing, "Reflexivity thus opens us to the charge not only that it is a selfish, self-centred act that is the very antithesis of activism, but that it can even work actively to construct a sense of the other, to deny the reflexivity of others, and to emphasise the condition of detached alterity" (2003, 348). Richa Nagar and Susan Geiger ask to this accord, "How can we take positionality, identity and reflexivity out of misplaced struggles over legitimacy and transparent reflexivity, and turn them into more meaningful conceptual tools that can help us advance transformative politics of difference in relation to our own research agendas?" (2007, 6). Not only is understanding myself in this research meaningful in the reality that I am part of it but also for the generative space that is created in the reflexivity it invites. More than that, I hope to show in this section the 'meaningful conceptual tools' that this reflection allows.

Centering the lived experiences of First Nations women, Dian Million writes about the power in theorizing from self in her articulation on felt theory and critiques the gendered dimensions of its invalidity. She writes, "It is also to underline again the importance of felt experiences as community knowledges that interactively inform our positions as Native scholars, particularly as Native women scholars. Our felt scholarship continues to be segregated as a "feminine" experience, as polemic, or at worst as not knowledge at all" (Million 2009, 54). Though this context is clearly different- Million is writing about the ongoing generational trauma of settler colonialism and specifically sexual violence and residential boarding schools - the idea of felt experiences as community knowledges is important to a project centered around care through a pandemic. Talking with caregivers I thought often about the ways their affect, and thus insight, was disregarded or deemed not valid. As caregivers shared experiences they often resonated with one another, or referenced things that they knew, but I had yet to catch up on (I got better at reading between the lines), Million's articulation of 'community knowledges' was apt.

Learning from Feminist and Indigenous Methodologies, not as separate but as intertwining, this project takes reciprocity and accountability to and with the caregivers seriously. Richa Nagar offers "two interrelated and complementary approaches to reflexivity: A 'speaking-with' approach that treats both reflexivity and positionality as processes evolving over space and time; and crossing borders to build 'situated solidarities' rooted in our specific (multiple) contexts and place-based locations" (2014; Nagar and Geiger 2007). I find this reflection especially helpful in thinking through this project because my relation to caregivers and my position as insider and outsider changed over the course of the project and with different participants. In her piece, "Standing With and Speaking as Faith: A Feminist-Indigenous Approach to Inquiry," Kim TallBear builds from the work of Richa Nagar is elaborating on her ethics of accountability:

> Part of doing this is broadening the conceptual field— thinking more expansively about what counts as risk (ontological harms?) and rightful benefit (institution building and community development?) in the course of building knowledge. It is also helpful to think creatively about the research process as a relationship-building process, as a professional networking process with colleagues (not "subjects"), as an opportunity for conversation and sharing of knowledge, not simply data gathering. Research must then be conceived in less linear ways without necessarily knowable goals at the outset (2014).

As you will read about below, this project was one that evolved with the input and guidance of caregivers themselves and in which the relationships I was building mattered. I also elaborate on the ways that this project fell short or wasn't able to reach the goal TallBear details as "standing with." Though TallBear and Nagar address relationality, it is Aileen Moreton-Robinson's articulation that most clearly shapes how I understand relationality in relation (ha) to this project. She writes, "Methodologically, an Indigenous social research paradigm offers new approaches to collaborative and participatory research by seeking to make visible our connectedness with the earth and with each other" (Moreton-Robinson 2017, 75). Though I am not Indigenous and want to be careful to not co-opt research paradigms that are not mine, the methodological clarity that Moreton-Robinson offers regarding relationality has been essential to this project. I hope to make those connections visible below.

In the following sections I explain the process of the research, the how of coming to understand the caregivers' experiences as I have and the details of my project. I feel like these details are often missing from research. Mainstream academia is so driven to make claims, that they move quickly over the methods. For me, that would not be practicing feminist accountability in my methodology, it would be forgetting that we are building theory together through dialogue. "Indigenous and feminist research demonstrates that bodies do matter in research and knowledge production and that these processes embody specific orientations towards the social" (Moreton-Robinson 2017, 75). In order to be held accountable to the caregivers, the power imbalances that I aim to challenge and, in some ways, though it feels a bit preemptive, to a larger academic community I need to make clear the details of the project. The following pages are me practicing these methods. The how matters. This is an epistemological project.

evolution of the project

This project came about from a conversation with a former coworker and now friend who had worked as a caregiver and who had family members who still work as caregivers. Her family had gotten sick with COVID-19 through work, and we were reflecting on the risk that caregivers were faced with at work. I talked to her family members first and was told there was interest in them being interviewed and trying to bring light to their work and experiences. They were surprised that someone was interested in hearing from them, especially a young person.[10] The project evolved from there as I applied for funding and started to solidify how I would approach understanding their experiences. As a qualitative researcher I knew that interviews would be a form that this research took. Interviews were legible to my participants as a way to learn more about their work and are considered a valid approach to academic research.[11]

I knew that this research would benefit me, it is being written into a thesis that serves in partial fulfillment of Master's Degree requirements. I will hopefully publish an article in a peer-reviewed journal from this work. That is an undeniable part of research, it benefits the researcher. But, beyond compensation for their time, which participants also received, I wanted to think about what it would mean to engage in reciprocity through this project. As I worked on grant applications and started to solidify the shape of the work, I quickly realized that I wanted to incorporate a creative piece to the project both to offer an aspect of the work that was more legible to a broader audience, to push back on historical research methods and to create a tangible return to the caregivers. After consultation with the first caregivers, I had floated the early project to, this creative piece of the project ended up solidifying as a portrait of the caregiver, completed collaboratively between two artists. All but one interviewee, who maintained a low profile due to personal safety concerns, opted to participate in the portrait project as well as the interview.

the testimonio process

I completed *testimonios* with 15 caregivers and spent time informally in the homes of caregivers, and the home of one cared for, on various occasions beyond that, usually around the

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[10] Surprise at my interest in their work, especially as a young person, continued to come up in nearly every interview. This speaks to not only the invisibility of this work but also longer standing patterns around ageism and an ignorance/ignoring of elder care.

[11] Though many scholars have done meaningful work to push back on this, as a young scholar finding space in a discipline there are expectations and constrained options for research form. cite?

kitchen. I was fortunate to already have connections with some caregivers and was able to expand from there via word of mouth. The interest in being interviewed seemed to come in waves. At some points I was being inundated with calls from random numbers saying, so and so told me you are interviewing caregivers, I want to be interviewed or getting texts from people I had interviewed saying, so and so is free tomorrow, can I bring them to my interview? and you can interview us both? This was juxtaposed with times of more active searching as I sent out texts and called to those I had already interviewed and asked if they knew any other caregivers who would be interested in being interviewed. I had a couple participants who were really committed to gathering others for me to interview and I am grateful to them for the work they did to facilitate connections. The hardest part of this process was finding caregivers' free time. All the caregivers were balancing super busy lives and I often caught up with them in parking lots after work, parks before appointments or playgrounds while kids hung out nearby. I was and continue to be so grateful for the time caregivers gave to me out of their full days in the middle of a pandemic.

My questions for the testimonios were open ended but I wanted to think about work history and how caregivers came to be caregivers. These questions focused on how work changed during the pandemic, how the caregivers were supported or not by their employer through the pandemic, what caregivers liked about their jobs, what was hard and how they understood their work or thought others did and how they wished others would understand their work. This also meant questions around cultural practices of familial care in the home. I use familial care to address the reality of mixed caring that happens in homes between elders and kids. *Ancianos* care for *nietos* and kids are tasked with elder care in the home as they get older, not to mention to support the family through interpretation and bureaucratic paperwork. In literature, these two realms of care, child and elder, are thought of as two separate practices, through my interviews with caregivers, and personal experience, it was clear that this distinction is not true in many Latinx households. Chapter 5 explores this more. The interviews took on a direction of their own as caregivers brought their lenses and focus to the conversation, as well as their energy and mood about work at the respective moments.

The interviews were all unique, but there were commonalities that started to become clear and specifically anecdotes and experiences that I came to anticipate. I also found assumptions that I entered the interviews with challenged readily. Notably, as talked about a bit in the introduction, the framing I started this project with was around how caregivers thought about themselves and their work in relation to "healthcare heroes," rhetoric that I felt had been used to justify exploitation and had been applied unevenly across various classes of workers, where doctors are heroes (as they were already?) and caregivers were left unmentioned. I structured my interview questions accordingly.

During my first interviews, I asked questions about whether the caregiver identified themselves as a healthcare worker and then followed with a question about if they had heard about "healthcare heroes" o "*héroes de la salud*" and if so, did they think others identified them as part of the rhetoric. I was met with a lot of blank faces. I got better at giving context to the question series, but it rarely was met with someone understanding what I was talking about. Was this because they had really heard little about healthcare heroes? Was it because they had never conceptualized the term in relation to their jobs? Was it because I was asking the question poorly? Or was I attuned to the wrong Spanish language media; I couldn't find it talked about anywhere? I still don't have a good answer, probably all the above. I never removed the question from my list as I continued interviews with different caregivers, but I did start to both explain it more and to focus less on it, realizing it was not going to offer the succinct point of contrast or evidence that I thought it might. What this allowed me to do, which ended up being more meaningful, was to explain the assumptions I was coming to the research and questions with and ask them what they thought. It gave me the space to say "I feel like you have been left out of 'healthcare heroes' rhetoric and are not acknowledged for your work in the pandemic and beyond, which is why I am doing this work. What do you think?" This transparency in asking questions and prompting conversation proved much more generative than my flat question that I tried to leave all assumptions out of could ever have.

As I approached the 15 semi-structured *testimonios* that I completed with caregivers in the south King County area I had the weight of what I thought academic research "should be" looming over me. I felt the internal dialogue creep in. I kept getting this during interviews. I couldn't decide if I should respond to the things people were saying while they were talking to me. The recorder was on, and I kept having *the* voice in my head say 'stay still and be quiet, stop emoting so much with your face- you are the researcher, the interviewer, don't taint their thoughts or analysis.' Like who I am had not already come into the space in front of me. Like the way I wore my hair, my shoes, my life hadn't already preceded me. Not to mention that they had a sense of my ethical and political commitments just from the way in which I framed the questions and project. As if I was some omniscient being, the researcher (Haraway 1983). I felt the legacy of colonial research manifest and creep into this space, but I also felt deeply present when I was able to set that aside and to remember that I was approaching this work as a process-oriented experience that mattered, in the doing. The act of listening has value in and of itself. As do the relationships I created with people through giving them space to talk, making them feel heard. These moments were an act of intergenerational sharing and documenting of broader work histories shaped by gender, family obligations, language and documentation status. They were also a space to have a deeply personal connection as a frontline healthcare worker was able to share and release some of the pressure of the last year to someone who had capacity to listen and hold that weight, if only for a short while.

hablame de usted

The caregivers varied in age, but most were broadly between the ages of 30 and 60. All those I interviewed were women, minus one man who I convinced to talk to me after finishing an interview with his ex-wife, also a caregiver who he still lived with. Most of the caregivers worked through multiple employment structures over full time which meant they were currently or had in the past been working incredibly challenging schedules. The caregivers had diverse household and familial constructions and responsibilities, but almost all were balancing work with responsibilities as mothers and some, grandmothers. Most lived in the area they worked in (commutes under 30 min), though many shared stories of long commutes they have had as caregivers in the past. In fact, one caregiver shared directly that one of the main reasons she puts up with her current toxic work environment is to be close enough and have hours that allow her to pick her kids up from school. All my interviews were conducted in Spanish, the native language of all the caregivers I interviewed.

The title of this subsection, *hablame de usted,* draws attention to the language of the interviews and the interpersonal negotiations that happened as I moved through the space with participants who were all older than me and spoke better Spanish. *Hablame* is the informal Spanish language way of saying "talk to me," *usted,* the formal "you" used to converse with someone older, in a position of power, and/or unknown to you. Thus, *hablame de usted* is kind of like saying "tell me what's up, ma'am/sir." Me titling this section grammatically incorrectly was originally unintentional. When my advisor, Megan, noticed, I was embarrassed. My Spanish is far from perfect, I have a good accent because I am a native speaker, but my vocabulary is not advanced and my grammar is poor- the further I get from home and the more years of advanced English only education I have does not help it. Most of my family speaks English now and my Mexican grandparents, when they were both alive, never went to enough school to speak "good" Spanish. My grandparents struggled so much with not knowing English enough, or at least being perceived as not knowing, that they refused to teach their kids Spanish, in hopes that it would allow their kids to have an easier time than they did. Little did they know that it was more than an accent that haunted them.

All this being said, completing the interviews in Spanish was fine - caregivers were kind, helping me find words in Spanish when I stumbled and looking to me for English words or context when they were talking about work procedures or bureaucracy. I leaned on my former coworker who first introduced me to the project to check my translations and to proof Spanish things for publication, she is highly educated in both languages and takes pride in her proper Spanish. I often find my insecurity around language to be a personal problem, a sense of imposter syndrome that is exacerbated by identity struggles around being mixed-race, though such is the case with most insecurities it seems. I decided to lean into my grammatical error because though improper, I am sure that is what I really said during interviews. I decided to keep it in and to use it as an opportunity to talk about the slippages and realities of multi-lingual research and the ways that research relationships shift over time often in and out of formality. Sometimes I was addressing caregivers formally and sometimes we were talking like friends by the end of the project after I had picked fruit from their garden and helped them make tamales. Sometimes formality would shift depending on conversation and what group I was in, and I am sure there were also times when the slippages happened because I messed up and defaulted to a more casual conversation. This is me practicing radical vulnerability (Nagar and Shirazi 2019) and thinking through family histories of language erasure (Anzaldúa 1987).

Most caregivers I interviewed were from Mexico, but they also included caregivers from Central America. All had migrated to the United States as adults. I did not ask directly about documentation status, though many caregivers shared personal and family histories shaped by a spectrum of un/documentation and a couple disclosed that their current work options continue to be profoundly shaped by their lack of legal employment documentation.[12] The caregivers are navigating along this spectrum of un/documentation, some are new citizens, some are legal permanent residents, some are awaiting U-Visas, some do not have documentation to work, many have statuses they did not disclose and that I did not push them on. This was intentional. Though temporality of status' shape people's approach to their jobs / career/ lives and, in the case of the pandemic, unemployment and other benefits were doled out intentionally to exclude many immigrants, I am cautious to reduce people's caregiving experiences and lives to their immigration status. So often research with Latinx communities is centered on un/documentation and often labor, the latter of which I am clearly engaged in, though hoping to expand. These are reductive single narratives that I am tired of. Immigrants do not gain value or need to plead their case for deservingness through labor. They also do not only exist as documented/undocumented, the spectrums and shifting of statuses helps illuminate this.

For this project, the caregivers, through a refusal/disinterest to disclose their status, even when I asked questions that would offer the opportunity, emphasized the fact that their status did not affect whether their caregiving mattered. Except for a caregiver who had been pushed out of work and without documentation was trapped waiting for hours (that were not being given) from the agency, caregivers did not want to talk about status. They wanted to talk about their work, the care they gave, the situations they had to navigate and the lack of support they had. In talking about them and their work, I continue to follow their lead.

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[12] Documentation as non-binary, as a set of experiences, a spectrum. Indocumentability as a way of navigating the world, as a body that is classified as undocumented (racialized) regardless of papers. See Ybarra, forthcoming for more on the profound disjuncture that permission to live is delinked from permission to work in the US and the temporality of status.

Though immigration status was not the focus of this work, it was made clear that work authorization was complex in the caregiving field. After talking with Tabatta, a caregiver leader involved with union organizing, I was offered the rough assessment that 65% of home care aides are undocumented. She emphasized that in the age of social media they all kind of knew who did not have legal documentation. She said in a phone call to me in March 2022, "we know who never travels, never goes on vacations, never goes home." Not only do colleagues know, but she made it clear that so do supervisors. This was only amplified as undocumented caregivers, unlike their documented counterparts, were unable to receive state and federal support during the pandemic and are ineligible for things such as Paid Family and Medical Leave (PFML). Tabatta made it clear in our conversations, and it was clear in my interviews, that being an undocumented home care aide meant you are at a higher risk for exploitation and with less options, are often placed in the riskiest of situations at work.

after the testimonios

One of the things I took seriously through this project is what consent is in context and how it evolves. This meant that consent was much more than a checkbox to be dictated by an Internal Review Board (IRB). Under the purview of IRB this research project did not even constitute research at all. Instead, consent was an iterative process. A process that I worked, and will continue to work on, defining. It is contextual and unique within my relationship with each of the participants. It is shaped by the different caregivers' interests, time and capabilities. Some caregivers continued to offer feedback through the writing process, others offered lots of thumbs up emojis. We all have different engagement levels. Where some trusted me to convey their experiences, many were happy to be interviewed but didn't hold their breath for the impact of the research. What this iterative consent process looked like during the project was lots of emails, phone calls and texts. When the portraits were completed, it meant checking in with the caregivers about if they still wanted their portrait to be public now that they had seen it. When the University of Washington asked to do an article, it meant I checked in to see if it was okay to use their portraits for this purpose, even though they had "formally" already given permission. This part of iterative consent meant that the caregivers were not only saying yes you can use what we talked about but, yes you can use what we talked about in this context that you are trying to talk about as it has evolved over the life of the project.

Though I practiced iterative consent where possible, that doesn't mean that the entire process was as centered in the co-production of knowledge as I wish it could have been. There are very real constraints that I had on my time and academic timelines that I had to abide by. Some of the ways that I could have built more accountability into the process would be to have provided the caregivers with the full transcripts of interviews for their revision in addition to having them each review the whole thesis before publication. This would have meant a lot of intermediate translation work that I did not have time or capacity for. All can be true, that type of engagement with the project would have made this more of a co-production of knowledge AND most caregivers did not have the interest or capacity to engage with the project on that level AND I did not have capacity to work through some of the barriers that would have made that type of engagement easier.

That doesn't mean that I did not build accountability and consent into steps continually through the project. During interviews I talked to caregivers about the next steps after the interviews and I had a couple of people who were really interested in being involved and willing to answer questions throughout the project. One caregiver specifically who was really involved with a labor union had a lot of knowledge around caregiver challenges over time and offered a sounding board as I thought through framings and helped me put things into temporal context around union negotiations and struggles with the state and agencies. This meant throughout the writing process as I had questions or had heard multiple people hint at something I could call her, or email and she would clarify and share her perspective as a leader who is in contact with lots of caregivers.

In addition to a couple caregivers who acted as continual reference points through the writing process this project was made possible by my former coworker, who my early conversations with conceived the project itself. Stteffany, who had worked as a caregiver with her mom before working at the non-profit with me, served as an interlocutor and reference point for understanding caregiving, making connections that started my relationships that allowed interviews and conceptualizing the work through the academic writing process. She reviewed my translations, helped me make sense of job jargon that went over my head and where I was not able to have every caregiver review all writing, she served as a community reviewer. This became especially salient as I was approached by the university wanting to do an article on me and the research project to run on the college of arts and sciences, and later, university webpage. Instead of the article being only reviewed by me I made sure that I would have time to have her review it at least and help fact and framing check the piece. It was also thanks to her questioning if I was going to have a Spanish language version of the article that I was able to advocate for a translated version to be embedded within the article. Correspondence with the university made it clear this was an uncommon practice, granted I provided the translation for them.

This negotiation of language has been something that I have continually navigated through the project in a commitment to accountability and reciprocity. What does it mean to produce work that is not only inaccessible in academic terms (behind paywalls, filled with jargon, in a specific esoteric style) but also in a language that those who are in the project don't speak, at least not as comfortably as they would Spanish? Questions of language in some ways helped make clearer the distinctions in research of the audience. This was the reason it was so important for the article written about the caregiver's and project to be translated, not only so that caregivers could feel comfortable reading it, but also so that they could share it within their networks and feel proud of seeing themselves depicted. I still aspire this thesis being translated, but I will hold that as aspirational for the moment.

the portraits

The portrait aspect of the project evolved out of a desire to offer something concrete to the caregivers and my desire to make the project multi-modal. As I worked on grants to fund the project, I floated some ideas around creative aspects with the first caregivers I talked to. Inspired by the incredible portraits of frontline workers hand drawn by New York based artist Aya Brown[13] and sharing some portrait examples from Brando Martin, the artist I first envisioned doing the caregiver portraits, we settled on portraits. These portraits were conceptualized as a way to center the lives of these workers; as people, as community members, as those who are deemed artistically worthy of being rendered and as #HealthcareHeroes. Beyond this, and reflecting my intentional collaborative methods, the commissioning of these portraits was a collaborative endeavor between multiple BIPOC artists, allowing a generative creative space in how different artists portray those who are unseen and ignored.

The process of the portraits was both embedded within the interviews and separate. Before the interview as I described the project, who I was, what my plan was with the interviews, what they could expect from the questions, I offered them an example of a portrait and explained my vision for them to be in their "uniform," which for some was scrubs and most an apron over clothes they had allocated as work clothes. Because I knew that someone's likeness being included in this project, even if abstracted from their name or experiences, brought increased risk, I was clear to offer the caregivers options in the iterative consent process. Caregivers could participate in the interview, to the extent that they wanted and they could opt into the portrait too, if they so wished, they were not

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[13] Aya Brown's "Essential Workers" Series features incredible colored pencil drawings meant to highlight Black women essential workers in NY. http://ayabrown.com/series/Essential%20Workers

required to do both. They also had the option of having the portrait commissioned just for themselves and not having it included in any public facing material. They were given this option again, to exclude their portrait from any public material, after they received both the electronic and hard copy. This is what iterative consent looked like in this process.

Caregivers were able to provide the photo they wanted, though some asked that I take it at the end of the interview as not all had smartphones or knew how to use them, and given options around their portrait, some wanted to highlight their colored hair or others wanted to have their apron represent their favorite flowers. In this way, some of the way they were portrayed was put back into their hands and they were able to set the direction of their rendering. With this, the caregivers made political choices in how they were to be portrayed and thus seen. One of the interviewees decided to be photographed with her full PPE not because she wanted to be more anonymous, a reason others did choose to submit a photo in a mask, but because she wanted to "set a good example."

So often academic research abstract words from people, a goal of including the portraits, is to allow multiple modalities of representation, how people see themselves and want to be seen, for a community to set their own agenda. Every single caregiver I talked to was proud of their work and found joy and meaning in caring for others- they radiated this energy, and this comes through in the portrait collages. These portrait collages were done as a collaborative project between two BIPOC artists, Brianna Miller and Brando Martin. Brianna created the color pencil drawing of the caregiver and Brando created the custom collage to pull on their energy and to give the portrait dynamic energy. Creating a portrait of someone is a deeply intimate experience, an artist is deciding how they see a person and translating that through their interpretation into another medium. To see two artists in conversation around this process and portrayal was a unique experience that brought life to the final portrait collage products. This co-production of knowledge not only brought more people into relation with the caregivers and their work but also radiated values of care and inclusion. Brianna reflected on the process writing in an email to me in early 2022, “I believe that portraiture and collage in tandem with the personal stories and your interviews creates knowledge through the engagement in a collaborative process between all of the varied perspectives and skillsets.” This co-production of knowledge was also articulated by Brando when they wrote, “The portraits are an additional layer of visualizing the project and making more visible the workers' experiences and your research. It's another way for people from different backgrounds and communities to engage with the knowledge being shared via this project.”

As mentioned above, the caregivers were given the physical and electronic versions of the portraits to do with them what they wished and they were asked for secondary consent in having their portrait, that they now knew what it looked like, used alongside their words and experiences in published materials. Not all the caregivers liked their portrait. There was one caregiver who was an early proponent of the project and who was involved throughout. When I shared her portrait via email, I did not receive a response but chalked this up to her being busy and not a frequent email user - I knew I would follow up when I delivered the physical portrait so didn’t think much of it. It turned out, I later learned, that the reason for the silence was because she didn’t like the portrait. She felt it didn’t look like her and there had been some confusion due to the hair of someone cropped out of the photo she submitted looking like her hair and thus drawn the wrong color. Your likeness is an intimate thing, and it is challenging for anyone to see that filtered through another person and back to them.

I think this is important to talk about, not because “caregivers: they are just like us” (I mean they are) or because drawing a portrait is hard and getting someone “perfect” is subjective (it is). But because being accountable and thinking about consent iteratively meant I ran into these situations, and I had to navigate them. In managing an academic timeline, a set amount of funding, caregiver desires, and artist schedules things weren’t easy or perfect. It meant feeling sad that I had disappointed someone who I had built a relationship with through the project and who I wanted to love the reciprocal aspect that I was returning to them. And it meant dusting off my color pencil skills to change the hair color of the physical portrait before returning it to her. But mostly it meant realizing and coming to terms, or at least practicing acknowledging that research is an imperfect process in which we try our best. And that sometimes we can’t make everyone happy but that doesn't mean we don’t try. And then we learn, and we try again.

Chapter 2: "Tu Te Tienes Que Valorar:" Agency and Resistance

When I was asked what I was most surprised about during the project my honest response was how much home care aides loved the work they did. It is not to say they all loved their jobs, but they all loved the work, an important distinction. Though I have connections to this community, as a student I am nonetheless coming into this work with an academic framework of labor exploitation via neoliberal privatization of care in a racial capitalism landscape that positions immigrants, especially those undocumented, as intentionally exploitable and perpetually unbelonging. All the theoretical frameworks that I have laid out in the earlier pages swirled through my head as the caregivers' shared hours of often incredibly challenging work landscapes in which they are emotionally, physically and mentally exhausted. And yet as I was finishing up these long *testimonios* and though it wasn't a question I had planned to ask, I would often find myself reflecting to the caregiver, "have you thought about getting a different job?" To which they answered "no," or in a couple cases, "yes, but." It is Geraldine Pratt's work with Live-In Caregivers in Canada that best summarized the dynamic caregivers in South King County also find themselves in, "a mixture of constraint, choice, responsibility, and sacrifice reverberated through interviews with mothers who have migrated" (2012, 62).

Researchers trying to think, write and share desire-centered research, or at least avoid that which is damage-centered, often go looking for resistance or some pure articulation of a theoretical concept or political subject. What are we looking for as agency - in agency? And what do we fail to see when we go looking for "resistance?" It was Kessie Alexandre, in her Black geographies course, that first put words to this for me. It is easy to go looking for things and harder to see what you find. Especially when what you find are the messy, human and confusing relationships and lived experiences of real people navigating real systems in a myriad of ways. I am trying to take the realities of the caregivers' experiences for the capaciousness that they are and the caregivers for where they are at.

This chapter is thinking about agency and the choices that caregivers make to work, in their work and about it. For the intents of this chapter and project I articulate agency in two ways as I write around the stories that caregivers shared. The first is a bit more overt and yet, unpredictable, as a form of resistance and assertion of agency, it is slowness and policy adherence. The ways that caregivers set boundaries and say "no" in situations where they often lack structural power is resistance. I articulate why I understand it as such in the following section. The second articulation of agency that this chapter highlights is a bit more integrated and nuanced; it is the meaning-making and value that caregivers give and find in their own work. To preface these two themes that I am drawing out of the interviews I first give insight into three caregivers' work experiences, describing their work history as home care aides to show the ways that their situations are differently constrained and the options they make and are forced to choose within this. I use this to highlight the varied experiences and understandings of caregivers, which I am cautious to not over-homogenize. I situated these vignettes first because I believe discussions of agency to be "yes, and" work. These are the realities of people's lives AND these are the decisions people have, the landscapes they embody and the meanings they make through them.

Everyone has agency, at least in some form. We make decisions about what we do and do not want to do all the time. We navigate options in our workplace about what we are willing and are not willing to sacrifice, about the pros and cons of our jobs. These decisions, and the agency to make them, are impacted by a myriad of factors. The constraints of this agency also change over space and time and for caregivers the acts of slowing down and meaning making in their work through their choice to stay at their jobs are powerful assertions of agency. Caregivers are not subjects upon which life and work happens, they are dynamic actors navigating and finding agency in the situations and spaces in which they are located.

agency is still agency if it is constrained

Almost all caregivers I interviewed shared the negotiation that they had to navigate when they needed to miss work. The reason for the leave- sickness, family emergency, vacation- differed between scenarios but the precarity and risk of not having a client(s) when they returned was constant. Because caregivers are not guaranteed hours, and the hours allocated to clients do not constitute full time employment for a caregiver, they are normally piecing together multiple clients to get to full-time employment, or at least enough work to support their families and their family's needs. It is important here to note that not all caregivers "needed" the work the same as others. The caregivers' socio-economic statuses varied widely: some caregivers were primary earners in their families, some as single mothers, some as earners contributing to dual-earner families (or more, or less, depending on what kids were living and working in the household). Some caregivers came to the work out of a need to make ends meet, some because they hoped it would offer flexibility other jobs weren't offering and others fell into the work as something they found meaningful through a family member or acquaintance. Regardless, the fact that their work was so variable and non-guaranteed, at the whim of the client's desire for the caregiver to care for them, and the states willingness to pay for care hours for the client, creates a unique landscape.

Reina

Reina, a single mother who cares (unpaid) for her now pre-teen son with "special needs," came to caregiving six years ago after going through a divorce and needing immediate support for her and her young son at the time. When discussing the variability of paychecks due to shifting hours Reina made it clear the importance of her job saying, **"***Bueno, yo soy madre soltera, mi hijo, yo cuento con mi cheque para pagar todo.* // Well, I am a single mother, my son and I count on my check to pay for everything." When the COVID-19 pandemic started, Reina took safety precautions seriously (something I found true across the caregivers I spoke to); her son attended school online, and they rarely left the house. However, Reina found that clients, and the families of clients, did not take the same precautions— visiting with each other on weekends, attending church and other gatherings. She felt that neither the clients nor the agency acknowledged that caregivers themselves might have high risk health conditions. Risk and exposure were a requirement of getting paid. She elaborated:

> *PPE este fue muy escaso. Fue muy escaso. No había suficientes guantes. No había suficientes mascarillas. Y este, y ni mandiles. Entonces, este, la verdad que no hubo la debida a como por protección. Porque uno le estaba sacando el trabajo. Vamos a decirlo así, uno está yendo a trabajar, pero no cuidan al personal, a uno. [Caregivers] cuidan al cliente porque si no le atiende, pues no, no le pagan.*

> PPE this was very scarce. It was very scarce. There weren't enough gloves. There were not enough masks. And um, and not even aprons. So, um, the truth is that there was no way to protect yourself. Because one was doing their job. Let's put it this way, one is going to work, but they don't take care of the staff. [Caregivers] take care of the client because if one doesn't take care of them, well they won't, they don't pay them.

These pandemic challenges echoed the things Reina has experienced at other times during her six years as a home care aide. When she had a surgery and lost her clients after having to miss work. When a client with schizophrenia, who she was temporarily covering, falsely told the police that Reina had poisoned her, and Reina had to endure intense police interrogations that took over three months. She questioned:

> *Pero en ese, en esa transición, yo le pregunto a la empresa si, oiga, y en estos casos ok. El cliente dijo esto sí, eso me acusó de algo y él tiene sus derechos. Ok, estoy de acuerdo, pero yo como trabajadora de esta empresa en que me respalda?...(esto es) el riesgo de trabajo que nosotros tengamos. No nada más con el COVID, ahorita.*

> But in that, in that, transition, I asked the company okay, listen, and in these cases OK. The client said this, yes, they accused me of something and they have their rights. Ok, I agree, but as a worker in this company who supports me?... (this is) the risk we have at work. Not only in COVID, currently.

These experiences that Reina shares makes it clear that home care aides are often left to navigate challenging situations on their own, long before COVID exposure became a requirement of employment. Reina navigates a landscape at work that is fraught with risk, risk that she must assume because Reina needs her job, her and her son's lives depend on it. Reina's agency is constrained at work, that is the power held by employers in situations where workers need the job, but that does not mean that she, and other caregivers, don't find ways to make space and time, as I will discuss later in this chapter.

Lesly

Lesly, on the other hand, came to work as a caregiver after her mom volunteered her to care for the mom of an Argentinian translator she had been assigned at a medical appointment. Lesly had been on extended vacation in Honduras, where she is from, taking time off and had returned to the US with plans to help her sister with her newborn. She explained that she had this flexibility because her husband worked and provided for their small family (just the couple and Lesly's daughter). Though Lesly didn't come to the work because she needed it, her story highlights the ways that choice and agency are not static. Thirteen years after starting work with the home care agency, she contracted COVID-19 from her client in May 2020. The client, who died from COVID complications, was infected by family members who did not believe in the severity of the virus and did not follow safety precautions. Living in a two-bedroom space with her husband and daughter, Lesly's family also contracted COVID, though both had much milder cases than her own. Lesly became extremely ill, unable to move, struggling to breathe, she suffered for three months going as far as to prepare her will and write goodbye letters to both her husband and daughter. She continued to have lasting physical and mental effects through summer 2021, when we last sat down to talk.

Unable to work during the time she was sick, Lesly's family burnt through their savings. She credits family support, notably her mom and sister, with making it through those times. Caught between L&I and unemployment, Lesly did not receive any meaningful financial support for those months she was sick until March 2021, nearly 10 months after she had been infected with COVID through her workplace. Though many caregivers I spoke to contracted COVID through work, Lesly's case was the most severe of those I interviewed. Lesly was sad and serious as she shared the risk she was put in by her client's family, she feels she almost died for doing her job. Though she may have started work 13 years ago as a favor to a new family friend, with the financial stability through her husband to choose not to work, it was her constrained agency, in the summer of 2020, having drained her family savings while sick with COVID, that forced her back into care work after having almost died from a client's family that did not care for her back. Lesly's experience makes it clear that agency is not static, but instead a temporarily dynamic and materially contingent state of flux.

Marcela

Marcela, one of the oldest home care aides that I interviewed, was in the middle of an incredibly challenging year. The interview I did with her was one of the most emotional *testimonios* that I had. At 72, Marcela has worked as a home care aide for 24 years at the same agency or 23 years if you exclude mid 2020-2021, during which she did not work. Marcela is undocumented, she does not have the necessary documents to work legally in the US. Starting work prior to widespread use of E-verify in the state of Washington, Marcela is literally trapped at the whim of her employer. I had heard from other caregivers that undocumented caregivers were vulnerable and often exploited at work and it was my interview with Marcela (and her ex-partner who she lives with and who is also an undocumented home care aide) that I was able to learn directly from someone who was willing to share these experiences. Marcela was caring for two clients at the start of the COVID 19 pandemic, one of whom she has been caring for 15 years. Sadly, one of her clients contracted COVID and died, and having also contracted the virus from the one client she followed protocol and quarantined as instructed. While she was sick and quarantined, her client of 15 years was switched to a new caregiver.

Things declined quickly after her client died and she was left without work. She fell into a severe depression. She was having problems with her eyesight and required surgery. Having worked every day for 23 years she was left aimless. In addition, left without clients and unable to be reassigned anyone due to her struggling eyesight, Marcela's finances spiraled. Ineligible for stimulus or other government benefits like food stamps, unemployment, disability or medical leave due to being undocumented, she struggles. Living in a house in which they already rent out all the rooms for extra income, they rely on the foodbank and other resources they can find. As she put it, "*Yo tengo que trabajar. Necesito mi trabajo. Tengo que pagar mis billes. No se esperan.* // I need to work, I need my job back. I have to pay my bills. The bills do not wait." Marcela's case highlights a growing reality in immigrant communities of larger generational migration patterns meaning we are going to have more and more undocumented elders, who have grinded their whole lives and not had access to social services like healthcare, savings accounts or retirement planning other than hoping an investment in their children will be returned as they age. Undocumented workers like Marcela and her partner pay into social security through the Federal Insurance Contributions Act (FICA) but will not receive benefits. In addition, Marcela was still supporting her unemployed adult son. Cycles of generational poverty, fueled by structures of racial capitalism and white supremacy mean that the upward mobility that many may have been relying on for their care later in life are not realized.

“Let’s check the care plan”

Nadia

Regardless of the ways in which their agency was constrained, caregivers found ways to assert agency, they found space and made time. Nadia knew what her client was doing. She has seen a lot as a home care aid the last 13 years and has had time to practice negotiating situations where clients are asking too much from her, straining the hours which she is not allowed to exceed, at least not if she wants compensation. Overtime is in practice not an option for caregivers. The client in this situation lives with her husband and grown son. The client is particular and quite strict with her expectations of Nadia’s care. She watches the clock every morning and comments when school drop off has led to Nadia being even a minute late. In the kitchen she wants every item to be mise en place, chopped finely and prepared separately in its own dish before being cooked, mixed, or blended into a smoothie. As anyone who has searched out “one pot meals” knows, this leads to a lot of dishes, which in this case must be washed by hand.

Cooking and cleaning for the client they care for is part of the home care aides’ responsibilities, as delineated in the care plan. But the responsibilities in the care plan are for the client, not the entire household. This distinction was something many caregivers articulated as a friction when the clients they care for are living in shared spaces with others. Nadia explains:

> *Y ya de la cocina no salí en todo el día porque es una clienta que tiene familia y que por ejemplo para hacerle el desayuno, un licuado pequeñito solo para ella es, “ponle más, picale más manzana y picale más fresas, picale más de todo y ya no era un licuado pequeñito ya es un licuado grande donde tuve que picar varias cosas, tomar más tiempo y es un licuado grande casi para toda la familia…Entonces yo le digo oiga, para qué tanto si solo es para usted? ‘Usted no diga nada, porque a mí, es mi casa a mando yo y este, y aquí si yo le quiero regalar un poquito a mi familia, es de esas cosas ya mía. Entonces le digo, si yo argumento, y le digo sí señora, pero es que de hacer me tiene parada aquí picando y picando la fruta y hacer un licuado grande. Al estar, este, con una cosa solo para usted, yo ya hubiera terminado y empezar a ser sus alimentos. Eso déjelo para después, entonces ya, ya me ocupo. Si era una cosita, un cuadrito pequeño de 15 minutos, ya me ocupo como 40 minutos porque tenía que ser grande…entonces ahí es donde yo considero que abusan de los servicios, porque una cosa que solo es para una persona hace que hagamos para todos y nosotras por conservar el trabajo y ya no estar discutiendo con ella. Mira, ya se lo, se lo hacemos y yo ya no es que sea mala onda, pero ya me acostumbré a que mejor hago las cosas despacito, muy despacito para que ya no me ponga hacer más extra cosas de lo que le corresponde, pero si con ella solo desde que llega uno hasta que sale la siete horas.*

> And I didn't leave the kitchen all day because she is a client who has a family and, for example, to make her breakfast, a small smoothie just for her is, ‘put more on it, chop more apples and chop more strawberries,’ chop more of everything and it was no longer a tiny smoothie, it is now a large smoothie where I had to chop several things, take more time and it is a large smoothie almost for the whole family… So I say, ‘listen, why so much if it is only for you?’-- ‘You don’t say anything to me, it is my house and I am in charge here. If I want to give a little to my family, it is my decision to make.’ So I tell her, if I argue, and I say ‘yes ma'am, but you have me standing here chopping and chopping the fruit and making a big smoothie. If, um, this were one thing just for you, I would have already finished and started on your food.’ I would have left that for later, then, then I'll take care of it. If it was a little thing, a small about 40 minutes because it had to be big…. So that is where I consider that they abuse the services, because something that is only for one person they make us do it for everyone to keep our jobs and no longer be arguing with them. Look, I already know, we do it to and it's not that it's malicious, but I've gotten used to the fact that I better do things slowly, very slowly so that I don't have to do more extra things than I should, but if with her only from the time one arrives until one leaves, the seven hours.

Nadia knows the stakes and constraints of the work, and though she still tries sometimes, she knows that reminding clients of the scope of work leads to confrontation she tries to avoid at best and losing her hours when the client says she no longer wants her as the caregiver, at worst. She has tried in the past to redirect to and reference the care plan, which other caregivers have also mentioned as a strategy to negotiate workplace exploitation. Seeing as that option in this case was met with a pejorative statement of commandment to obey, Nadia tries something else. She slows down. She makes it so that she can't be asked to run around beyond her scope because she only has a set amount of time. She flips the constraints to help her set boundaries. It helps limit her doing unessential tasks, multiplying foods to feed the whole family, cleaning areas that the client does not use, doing shopping for the whole household. In this way she can stretch her hours to preserve her ability to get the tasks done she needs to and to use the set hours with the client to her advantage. When she has hit the hours, she is supposed to work she is done with the care plan needs and is able to leave, not caught finishing up the necessary tasks she wasn't able to get done because she was doing sink basins full of dishes from a family meal. As many caregivers commented, they are not "family servants", though they are often treated as such. This client is rude, often making comments around her weight and food when she sits to take her lunch break, which is not always the case, but whether intentionally or unintentionally, the scope of caregiver responsibilities and their ability to set boundaries is constrained. And yet, as Nadia shows through her deployment of slowness, caregivers find ways to resist the manipulation. A quiet, and slow, resistance is resistance, nonetheless.

choosing to stay

In many ways choosing to stay is also an assertion of agency. The meaning-making and valuation of their own work is another way that caregivers find and assert agency in their workplace. From the outside people may ask, as I did, why would someone want to continue to do a job for $17 an hour that is physically, mentally and emotionally intense. The answer is people find deep meaning in their work. They find this meaning regardless of if you or I, or society, does or not. It is important to make clear here the difference between the social value (for example, no free coffee on essential worker day) and the financial value (stable benefits and hours) that people place on work. The caregivers find social value in their work, they understand the importance of the care they provide and they wish more people saw the role that they play in their clients lives and our society as a whole. They expressed to me that if more people understood their jobs that as a society, we would respect the important work they do more- this is one of the ways this project hopes to intervene. On the other hand, caregivers do not feel there is commensurate financial value of their work, they will be the first to tell you that they are being undercompensated for their work, both for the labor but also for the risk that they assume, as detailed in the experiences shared by caregivers above.

<u>Griselda</u>

Griselda has on bright pink shoes and wears her hair in a high bun when we meet for the first time at a local park. It is a nice summer day, and we decide to sit on the grass at the base of a tree to get away from the background noise of kids having fun on the playground. She reverberates energy. Her love for her job as a caregiver, a job her husband and niece also do, is clear. Being a caregiver for the last 14 years taught her how to navigate the US healthcare and social services system after immigrating, how to use a computer, and to advocate for her client's needs, all skills she credits with helping her raise her four sons here. She also learned skills and was better able to care for her mom as she aged. She gets excited as she tells me about how she has supported clients to find the joy in life again.

There is one client who Griselda shares a lot about as we sit on the grass and who she is proud of the work she did with. This client was struggling when Griselda first started caring for her, she had little motivation to live and was resigned to wait in bed until her life was over. She refused to have anyone touch her- no showering or other personal hygiene was taking place and she had sores on her body. This situation was tough, but Griselda believes she was called to serve this client and was persistent. She shares:

> *De la experiencia que uno va agarrando en ese trabajo es porque uno dice, no, empiezas a hablar con ellos, los empiezas a tratar pues como lo que son verdad las personas que necesitan ayuda y les empiezas a explicar y entre jugando y no jugando. Y después ella se empezó a maquillar, a peinar, que nada más la pasaba en su casa acostada, la empecé a llevar a programas... programa para personas adultas que lo llevas ahí a desayunar, de comer, hacen juegos, con otras personas más adultos..(antes) Se iba deteriorando su cuerpo, su espaldita tenía como muchas ronchitas, o sea, se estaba haciendo como llaguitas. Entonces yo le empecé a bañar, le empecé a poner pomada, se dejaba peinar y cambió completamente la persona.*

> From the experience that one is gaining in this job, it is because one says, no, you start talking to them, you start treating them well as what people who need help are, and you start explaining them and between playing and not playing. And then she began to put on makeup, to do her hair, that she spent nothing else at home lying down, I began to take her to programs... a program for adults that you take her there for breakfast, for lunch, they play games, with other people more adults... (before) Her body was deteriorating, her little back had a lot of welts, that is, it was becoming like sores. So I began to bathe her, I began to put ointment on her, she let her hair be combed

> and completely changed the person.

She got emotional when telling me about this experience and there was sadness in her voice when she told me that the client had died. She took a break from work for a bit after that to process. This break after the death of a client was something multiple caregivers did, and others wished they could have. Griselda continued to share stories like these, different clients who she had supported in different ways, daily walks, baking cookies for sale with a client, learning to cook something they loved. She finds deep meaning with every client she helps. And though it is hard, and she shared lots of those experiences too, she continues to find and make meaning in her work as a way of not only valuing the work, but also herself in turn. This pride and fulfillment were so beautiful to witness as someone gathering these stories.

In many ways we are socialized to think a desk job is better. We have come to value a job in which someone is on their feet less than that which they work at a desk, what some would perhaps distinguish as blue vs white collar. Lesly, who talked about above, whose mom first volunteered her into care work and who had the most severe case of the COVID-19 virus of those I interviewed, said her sister and brother-in-law often offer to find her an office job and asked why she hasn't changed work. She tells them office work "isn't for her," she says, "*Me gusta ayudar a la gente, amo lo que yo hago… Y mientras yo ame lo que yo hago, lo voy a seguir haciendo.* // I like to help people, I love what I do… And as long as I love what I do, I will continue doing it." Lesly makes it clear to her family, though they may pressure her, that she loves what she does and as long as she continues to love it she will continue to do the work.

Delia, one of the first caregivers I interviewed, and who helped me connect with many others, spoke of the distinction between types of job as she shared her experience as a caregiver. Having been injured on the job she spent some time working in the agency office to get hours. After she was cleared to work back with clients, she was offered a job in the office more permanently. Delia did not like office work. In fact, that time spent in the agency office reassured her of her work as caregiver. She decided, "*Entonces dije yo, no, yo me quiero ir. Yo amo mi trabajo y yo me quiero ir 100 por ciento con mis clientes.* // So I said, no, I want to go. I love my job and I want to go with my clients 100 percent." She liked the ability to work independently and though clients can be demanding, she preferred the autonomy she had in meeting her daily goals.

Though the idea of white vs blue collar and "good" vs "bad" jobs are very clearly classed and racialized, even those who may have the opportunity to transition to an office setting may not choose to, as Lesly and Delia made clear. Caregivers were acutely aware of the devaluation of their work, they articulated to me the ways that they felt that in overt and covert ways, by drive through workers who didn't give then the free coffee on "essential worker day," by agency policies, by clients and clients' families, and by the media. Yet despite this, every single caregiver has deep respect and pride in their work. They know, more than anyone, the role their work plays in making peoples' lives possible and they are finding meaning in it for themselves by choosing to do it. As the caregiver Rosio made clear, "tu te tienes que valorar. // You have to value yourself."

The act of slowness as resistance to neoliberalism has gained traction within academic landscapes in recent years (Mountz 2015; Shahjahan 2015; Adeyemi 2019; Mccutcheon and Kohl, n.d.). This worker tactic, however, is not new (Scott 1985; Kelley 1996). The caregivers deploy slowness as a tactic to resist the exploitation that they face in the workplace, as care work for one is stretched into serving the whole household. This slowness is especially meaningful when carried out by Latinx immigrant workers who have an expectation to grind. Caregivers also find agency in the ways that they utilize the care plan and reference union and work agreements to set boundaries on what they are and are not 'allowed' and thus, willing, to do in the workplace. Beyond this, caregivers assert their agency through the meaning-making that they find, and articulate, in their work as home care aides. Though they encounter family members, employers and baristas that devalue their work, caregivers assert their commitment to being, and staying caregivers, due to the passion and meaning they find in what they do is an act of agency in and of itself.

Chapter 3: "Se Pesa:" Embodied Care Work

Though embodiment is articulated and understood in many different ways. My understanding and use of embodiment draw from the way people frame bodies in space. I understand mental and emotional labor as embodied. More specifically in the context of care work, Monique Lanoix writes, "Although this type of labor does not produce a material commodity, it nonetheless involves materiality. Thus, care labor draws attention to remunerated activities that are imbedded in corporeality… as a thickly embodied activity, care labor is deeply relational" (Lanoix 2013, 86). I use embodiment to frame these experiences that caregivers shared because they, quite literally, feel the care in their bodies.

Even as I use a framework of embodiment to think through the caregivers' work, I am wary of the ways that some people are tethered to their bodies while others are able to exist as talking heads. There is very scarcely such a thing as disembodiment and instead just those we allow to float away from reality with the rest of us. This is without doubt gendered and racialized as white men get to have their actions, labor and impact untethered to their physical selves and as such choices and movement through space. Though a different context, it is Heidi Kiiwetinepinesiik Stark's articulation of settler laws as the creation stories of the settler state that has invited me to reflect on the ways that concepts apply across axes of power (2017). In the article, she uses the story of the Hoof Nation, the opening creation story for the Anishinaabe peoples, to illustrate the ways that stories lay out the foundation of laws, a series of relationships. She "contends we understand settler law as the creation stories of the settler state, as it is through seminal decisions that these states narrate themselves into existence and maintain their fictive authority (Stark 2013)" (Stark 2017, 251). Thus, through her articulation, stories, and as such, law, are in fact embodied relationships. In this account, we all are constantly in relation to others– that does not mean that they are good or accountable relationships or just and fair laws. I hold this to be true for how I understand embodiment too, no one is disembodied, there are just those who are not held accountable to how their actions move through and from their bodies.

I want to be careful here to not over-intellectualize care and the work of home care aides. Instead, I hope in this chapter to show the ways that home care aides experience caring in their positions as whole-body work. Care is physical, emotional and mental work, both by the caregivers and on the caregivers themselves. There is not an articulation of a mind/body/spirit split, for the client nor the caregivers themselves. The Spanish language concept and word, *cariño* (care)*,* holds this meaning. Though directly translated to care, it holds a more capacious cultural understanding (Reyes, Banda, and Caldas 2020). This is articulated through examples of actions taken, situations navigated and understandings of work shared. Caregivers embody care in the food they cook, the physical challenges (COVID as just one) they negotiate and the stress and emotional weight they carry.

doing care

This understanding of care articulated above means that caregivers work shows what embodied care looks like, in the doing.

<u>Rosio</u>

Rosio was one of the older caregivers that I interviewed, and her work situation was unique among those I spoke with. In 2007, she was working at a grocery store and was finding the work of moving boxes too physically demanding. Her friend who was working as a caregiver suggested she apply to the agency. She has cared for lots of clients over the past 15 years through two agencies, often working for one agency in the morning and one in the afternoon. She currently works every day of the week, with some afternoons off. Rosio's current client is a middle-aged woman addicted to drugs who was formerly unhoused and Rosio's care of her, as she puts it, is both similar and very different from other clients she has cared for. Rosio often enters her clients' space, to find her passed out or in various stages of mania while either high or in withdrawal. She had first come to this client to cover for another caregiver who had asked to no longer care for this client. She decided to stay when offered the opportunity as the physicality of the job was less challenging than other clients. This woman can walk and lift her body weight, so Rosio doesn't have to manually lift her around to care for her, something that is important to Rosio as she ages.

Rosio is intentional when she talks about this client and the challenges she faces. You hear her work through the understanding of her client as someone who is sick, though in a way our society often doesn't acknowledge. Mental health has begun to be seen within medical communities, and the broader public, as part of and connected to a person's overall health, caregivers articulate this. In recent years, substance addiction has been increasingly understood as a mental health disorder (S. Robinson and Adinoff 2016). However, despite shifts in articulated medical classifications of substance use disorder, substance users continue to be maligned; with drug and alcohol use often seen as something that individuals have control over. It was unique in the interviews I did for this project to find a caregiver caring for a client for whom substance use and mental health concerns were the primary reason for care; Rosio was the only one[14]. She shares her experience caring for this client as such:

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[14] Sol, another caregiver interviewed, also cares for those with substance use disorder at a local residential treatment facility, which she works at in addition to her work as a home care aide. For the purposes of this project, I focus on her work as a home care aide exclusively- though she does not distinguish the caregiving between the employers, other than to comment on how much better she is compensated at the facility.

Ella dice que ser adicta a las drogas es o es una enfermedad, si no lo sabía, que es una enfermedad y por eso ella calificó para para que tuviera una casa donde vivir. So, con ella es bien diferente, porque cuando aparte de sus medicinas ella usa marijuana, cuando no la tiene, cuando no tiene marijuana en el cuerpo. Es difícil cuidarla porque empieza a llorar. Tiembla mucho o no tiene fuerza en el cuerpo, se levanta de la cama en lugar de pararse, se tira en el suelo unos días que amanece. Se baña y hay días que amanece a un lado de la de la bañera de la tina. Ahí se queda dormida. Pero es cuando o se pasa de drogas o le hace falta droga.

She says that being addicted to drugs is, is, a sickness. Yea, I didn't know that, that it is a sickness, and because of that she qualifies for, to, have a house in which to live. So with her it is very different, because in aside from her medicines she uses marijuana. When she doesn't have it, when there isn't marijuana in her system, it is hard to care for her because she starts to cry. She shakes a lot and doesn't have body strength. When she gets out of bed instead of standing she throws herself on the floor some days when she wakes up. She washes herself and there are days that she wakes up next to the bathtub. There she falls asleep. But that is either when she is on drugs or she is without drugs.

Rosio hasn't been close to a lot of people with drug addiction before. Caring for someone is a negotiation, between where they are at and what you are able, and contractually obligated, to do to support them. This varies between care plans, clients and is different on any given day. This client who Rosio cares for is challenging, she can be mean and unpredictable, but Rosio articulates her work as caring for this client regardless of whether she understands the experience of the client or not. Rosio understands her embodied practices of care as supporting this person through showing up to do her job as caregiver regardless of some constructed hierarchy of deservingness. Her embodied care understands the client as a whole complicated person and she shows up to do care through clouds of marijuana smoke, even though she made it clear to me she would never smoke herself.

Griselda, who I talked about in chapter two, is a woman of action and one of the younger caregivers that I interviewed. She is a ball of seemingly endless energy and prides herself at being able to take the most downtrodden client and instill in them a desire to thrive. This is often an uphill battle for her, but she is persistent. One of the ways she articulates her skill at doing this is through finding things the client likes, or used to like, and getting the client back into them. Through this she 'does' care. For one client this was knowing she had been a crafter earlier in life and after hearing about their local church convening a group to make blankets for those experiencing homelessness taking this client to the group and attending together creating community and finding meaning. Griselda was proud to share that that client had contacted her later to say she had continued attending the group after Griselda was no longer her caregiver.

In another case she shares the care she does beyond the specific scope of her job explaining:

> *Y así me gusta mucho interactuar con ellos mucho. Y hay unos pacientes que les gusta nada más jugar dominó o yo les digo vamos a jugar cartas o que hagan cosa diversión, diversión nada más llegar a limpiar porque pues es nuestro trabajo, llegas limpias pero en el trabajo, se acaba en una hora y media, dos horas. Llegar a limpiar la casa, atenderles la cama, bañarlos, pero día a día. Y si tienes ocho horas con ese paciente, tienes que buscar en qué otras cosas. que cuando, cuando tú te vayas de ahí, ellos se queden ya cansados, ya que quería que se fuera y me quiero descansar.*

> And so I really like interacting with them a lot. And there are some patients who just like to play dominoes, or I tell them 'let's play cards' or 'lets do something fun.' …Showing up to clean the house, take care of the bed, bathe them, but day after day. And if you have eight hours with that patient, you have to look at what else. So that when you leave there, they are already tired, they are ready for you to leave and say 'I want to rest'.

Griselda, who is young and passionate about her job, articulates the embodied care she does through actions that bring her pride in her work and makes her clients life better. She deeply feels that her clients are whole people in which their mental, emotional and physical well-being are wrapped together and she addresses all with her care.

Reina, who I also share more about later, talks similarly to Griselda. When emotionally describing how much the work personally filled her up, she shared that the clients that she cares for live alone, in buildings of senior living. She articulated the care she does as such:

> *Yo siento pues que les alegra el día, no? Porque platicamos, me pongo al nivel de ellos, de sus pláticas, aunque a mí no sepa o no me van a decir, no me interesa, no es que no me interesa, sino el oírlos. ellos se sienten, ya que alguien les escucha, no aún. Y la plática de la tele, de la novela de la que habla, aunque yo no sepa nada, pero es esa, esa, esa parte que a ellos, que yo sé que estoy haciendo un servicio, puede ser. Más allá de que tengo que cumplir con el plan de cuidados que tengo que cumplir con el plan de cuidado de que ellos tienen este. Yo les. Yo siento que mi aporte extra es eso, darle la importancia y. Y sentirlos, ofrecerles cosas como mire como aquí mire, yo conocí un que park porqué no vamos? O sea no nada más estar allí como cumplir con mi trabajo y ya voy, le hago de cocinar, le pregunto si va a bañar lo que séa? …confían en mí y que yo les voy a decir la mejor opción para ellos, no de acuerdo a sus necesidades. Entonces esa es la parte bonita que más allá de que a ellos le guste, a mí me llena de que me voy. Salgo de esa casa sabiendo que tiene todo, o sea que ya le solucioné lo que ellos querían.*

> I feel that it makes their day happy, right? Because we talk, I put myself at their level, their chats, although I don't know or they won't tell me, I'm not interested— it's not that I'm not interested, but listening to them, they feel, since someone listens to them. And he talks about what is on TV, about the soap opera he's talking about, even though I don't know anything, but it's that, that, that part that to them, that I know I'm doing a service– could be. Beyond the fact that I have to comply with the care plan, I have to comply with the care plan that they have. I feel that my extra contribution is that, to give it importance and, and feel them, offer them things like 'look', like, 'here look, I heard of a park, why don't we go?' In other words, it is not just being there, like doing my job. I'll go, I'll cook for him, I'll ask him if he needs to bathe, whatever it is …they trust me and that I am going to tell them the best option for them, according to their needs. So that's the beautiful part– that beyond the fact that they like it, it fills me. For when I am leaving, I leave that house knowing that it has everything– that is, I already solved what they wanted.

This came up with caregivers in various ways depending on the client's personality. For some caregivers it was playing certain music and dancing, for others it was learning culturally specific foods or sharing and adapting foods they cooked at home. Other caregivers did care by working through prejudices they carried and by meeting clients where they were at and who they were. But all the caregivers understand their clients as full complicated people and their embodied care as offering life extending labor.

feeling care

The physicality of care echoed through caregiver interviews. From workplace injuries, COVID, stress-related illnesses and the emotional toll of ailing, struggling and dying clients, the caregivers I talked with all felt their care deeply. The physicality of the work perhaps rang most true for the caregivers that were older as they felt the work in their bodies as it wore on them over time. I interviewed four caregivers over the age of 65, and the toll on their bodies came through in the stories and struggles they shared.

Guadalupe

At 73 years old Guadalupe was the oldest caregiver that I interviewed. She came to home care after a chance encounter with a woman at the pharmacy who recommended she take classes and get certified. She was working at a bread factory after moving to Washington for work after her husband died. His illness and death left her large amounts of debt and sons to care for on her own. She has been a home care aide since 2005 and currently works 250 hours a month, combining work through two agencies.[15] She acknowledges the work as challenging sharing:

Pero a veces también cuando yo, yo veo que a veces no puedo, porque como son personas mayores es tan pesadas para cambiarlas. Si es tan pesada, si luego- pues si luego yo creo que hasta me voy a lastimar y ando batallando para hacerlo. Y sí lo hago. Pero como le digo, a veces dicen la persona ‘ya esta a ganar el dinero” – no. Es duro.	But sometimes also when I, I see that sometimes I can't, because as they are older people it's so hard to change them. If it's so heavy, yes then, then, I think I'm even going to hurt myself and I'm struggling to do it. And I still do it. But as I say, sometimes people say ‘they are in it for the money'-- no. It is hard.

She is tired and recognizes her age, but when she thinks about cutting back hours often feels guilt around leaving her clients who she has good relationships with and who she is concerned will not receive the same quality of care with another home care aide. When her boyfriend tells her to retire and relax, as he is, she says:

No, yo necesito ir a trabajar porque siento que yo puedo y si dejo mi trabajo me voy a sentir mal y… si. Si quiero seguir trabajando y me gusta mi trabajo, aunque a veces se estresa uno, al menos yo me estreso cuando se, se pone muy mala la persona que estoy cuidando y se tiene que ir. Entonces me siento como triste porque llevan cariño– me encariño con esa persona.	No, I need to go to work because I feel like I can and if I leave my job I'm going to feel bad and…yea. I do want to keep working and I like my job, although sometimes one gets stressed, at least I get stressed, when the person I am caring for gets very sick and has to leave. So I feel sad because they have affection–I grow fond of that person.

Guadalupe feels the physicality of the job on her 73-year-old body, and yet, when she thinks of what is most challenging it is the emotional and mental toll of ill clients she cares for.

For the caregivers care is visceral. But the toll of the job on their physical bodies is just part of how they understand their care as embodied. The mental and emotional toll also weighs heavily. In fact, the concept of work weighing on the caregivers, *“se pesa,”* was a recurring theme through the

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[15] 160 hours would be the monthly hours of someone working 40 hours per week.

interviews. Various caregivers navigated caring through long-covid and stress related autoimmune diseases. The COVID-19 pandemic, for the risk, the death and the isolation only exacerbated what was already heavy[16] about the caregivers' jobs and support they gave to clients.

Dolores and Diocelina

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[16] My use of the word heavy draws from Kiese Laymon's memoir *Heavy*, which offers a thoughtful and challenging study in the many meanings of the word.

I interviewed Dolores and Diocelina, two friends who both work as home care aides, together. Dolores cares through an out of state agency and works directly with a private family in caring for their paraplegic son, which she has done for five years. She had been working with a local agency in Washington as well but reduced her care to one family (from three) when the pandemic started, to minimize risk of infection. Diocelina has been a home care aide for 12 years and works through a local agency in Washington State. I felt grateful that Diocelna brought her friend Dolores along to the interview as when we began to talk about the impact of covid on their jobs, Diocelina became visibly overcome with emotion as she talked about her client who died due to the virus. Diocelina shared:

Después de ver a uno de mis clientes falleció y yo también me contagié. Me contagié con él y él me dio el COVID. Pero él falleció, pues yo estaba también, este, en cuarentena cuando así, cuando ya recibí la noticia, pues fue muy, muy doloroso para mí. Pues aunque al inicio no usábamos el face shield, porque era reciente, tratábamos de cuidarnos de usar la mascarilla normal, pero por las condiciones de algunos clientes es muy, muy limitada. Sí, este cliente vivía en un cuartito nada más en un cuartito y pues tenía uno que entrar ahí, ¿no? este a mirarlo, a darle su atención y este tipo es imposible no respirar el aire que él estaba y el que él tenía. No lo sé, era imposible no contagiarse si él estaba contagiado y pues no lo sabía. Entonces este así, así me contagié yo y este y también él estaba y falleció unos, 4, 4 o 5 días de que supimos que tener.

After seeing one of my clients pass away- and I also got infected. I contracted COVID from him. But he passed away. Because I was also, um, in quarantine when I received the news, well, it was very, very painful for me. Well, although at the beginning we did not use the face shield, because it was new, we tried to take care of ourselves using the normal mask, but due to the conditions of some clients it is very, very limited. Yea, the client, he lived in a small room, just a small room and, well, one had to go in there, right? To, to look at him, to attend to him and in this kind- it is impossible not to breathe the air and what he had. I don't know… it was impossible not to get infected if he was infected and well, he didn't know it. So that's how it was, that's how I contracted the virus, and he was also infected and he died about 4, 4 or 5 days after we knew he had it.

She shared that after this client died, she needed to take a break from work for a while. The toll of clients dying was common and the desire, if not ability, to take a break from work after a client's death was shared among many caregivers.

Beyond this, the weight of everyday work was often juxtaposed to the energy they needed to have and spread both at work, to keep clients spirits up, and at home, as they were worried about bringing negativity into their personal lives– in partnerships, family gatherings and in their roles as parents. Diocelina, Dolores and I had a conversation about this during our interview:

Dolores: *Y el más grande desafío es eso, porque cada día no sabemos en qué estado los vamos a encontrar y si el desafío de nosotros es tengo que, tengo que sacarlo y tratar de que el pase un día más tranquilo. Y sobre todo eso cuando se están quejando. Y esto es un desafío muy grande, poder darle ánimo y hacerle ver las cosas o buscar otra, otra alternativa de que ellos se distraigan.*

OO: *eso, como es más del físico, también lo emocional*

Diocelina: *bueno, si es cierto, ese es otro desafío que tenemos nosotros, porque saliendo de ahí, qué haces con todo lo que viviste en el día?*

OO: *No sé- no se desaparece el momento en que cierres la puerta*

Diocelina: *a veces, a veces, no, te lo traés.*

Dolores: *a mí me han preguntado, dice cómo hacés tu trabajo, qué haces? Y siempre estás activa, siempre estás contenta. Sí, cuesta, sí cuesta porque somos humanos, pero de una de las cosas que casi siempre nos capacitan es que nosotros debemos de dejar en la puerta nuestro problema y en la puerta a los problemas del cliente con nosotros salimos porque tenemos que tener una vida propia, pero a veces si se queda como, como, como entré a imagínense, yo ya casi cinco años ya con el niño, aparte es un niño. Entonces yo también tengo un hijo. Entonces es bien, es bien complicado. Y cuando hay momentos que, que el niño se pone mal, porque si se pone mal entonces este y queda malito yo, yo me voy como como con eso pues entonces este. Pero digo tengo que seguir. Y si también este es un desafío para nosotras lidiar con eso y no llevarnos eso en nuestra cabeza o nuestro corazón y hacer nuestra vida porque también para para ayudarlos a ellos tenemos que estar bien.*

Dolores: And the biggest challenge is that, because every day we don't know what state we are going to find them in and yes, that is what our challenge is - I have to, I have to take them out and try to make it a more peaceful day. And above all that when they are complaining. And this is a very big challenge, to be able to encourage them and make them see things or look for another, another alternative to distract them.

OO: that, like- it is more than the physical, also the emotional

Diocelina: Well, that is true, that's another challenge that we have, because leaving there, what do you do with everything you experienced that day?

OO: I don't know- it doesn't go away the moment you close the door

Diocelina: sometimes, sometimes, no, you bring it.

Dolores: I have been asked, how do you do your job, how do you do it? You are always active, you are always happy. Yes, it costs, it does cost because we are human, but one of the things that they almost always train us on is that we should leave our problems at the door and our client's problems at theirs, we leave with us because we have to have a life of our own , but sometimes it does stay with you. Like, like, like imagine, I've been with my child client for almost five years now, apart from that he's a boy. I also have a son. So it's very, it’s very– complicated. And when there are times when, when my client gets sick, because if he gets sick and stays sick, I carry that. But I say, I have to continue. And yes, this is also a challenge, for us to deal with that and not carry that in our heads or our hearts and affect our lives because we also have to be well to help them.

In this excerpt from our conversation, Dolores and Diocelina worry about the impact that their work has on their families. Dolores articulates this as the biggest negative of her job as a home care aide and Diocelina echoes this to ask, "and what do you do with all you saw that day?" This struggle with compartmentalizing work life with what Diocelina calls the need to have her "own life" was recurring. The emotional impact of their job's seeps out of their workplaces and into their bodies as they carry it home with them.

Caregivers feel care in their whole bodies, and they also understand their clients' wellbeing as such. Many caregivers remarked of the impact of COVID-19 on their clients, specifically for the isolation that it made necessary. Multiple caregivers shared about a Latino elder support group that they would take clients to and that they got to know other caregivers through. They shared this support group as an essential place for boosting clients' whole-body well-being, activities that were something to look forward to, get dressed and ready for and be in community at, were invaluable. Understandably, this group gathering space was put on hold due to COVID. Diocelina shared the experience of losing the group space during COVID saying:

(covid causo) Más estrés porque la mayoría pasa en casa y por lo regular los adultos mayores que tengo, pues ellos estaban acostumbrados a, a los grupos de adultos mayores, de edad, de convivir, de convivencia. Entonces dejamos de, cerraron los grupos y la gente se tuvo que quedar en casa a tiempo completo y. Y fueron, fueron meses de mucho estrés, de depresión. (empieza a llorar)	(Covid caused) More stress because most clients spent the time at home and normally, for the elder adults I have, well, they are used to, to adult groups, for older people, of co-living and coexistence. So we stopped – they closed– the groups and the people had to stay home full time and, and it was so many months of stress, of depression (starts to cry)

Diocelina's articulation of this group and of her clients' whole beings highlights communal understandings of *convivencia* and *cariño*, the idea that we exist and thrive in community. This group not only offered a space for fostering communal support for clients, it also served as a space for caregivers to build kinships of care with one another. A space to meet new caregivers and old friends; a time to chat, eat, problem solve, air grievances and process experiences. Though caregivers have long seen care as embodied and thus their role with clients as encompassing of clients physical, mental and emotional well-being, the COVID-19 pandemic highlighted the importance of their role, as caregivers were in many cases clients' sole source of social contact. As poor communities of color were left most impacted by the virus and we as a nation turned to home as a place of safety, those who lived in rented shared spaces were left isolated and alone. Caregivers were left to fill these gaps, risking their lives as they cared for people who had no one else.

being

If embodied care is a way of feeling care that caregivers put into practice, then the final form of this understanding is a state of being or type of person that some caregivers articulated themselves as being.

Juan

Juan, the only man I interviewed for the project, disliked the way that I phrased most of my questions, but especially pushed back on my question about a moment or situation in which he felt proud at work. Here is what he had to say during our interview:

Juan: *(mi) favorito es servir. me gusta. Me gusta que esté contento mi cliente y yo también, porque cuando tienes una buena relación con una persona, ya sea de cualquier tipo. Sí, es bonito, sí.*	**Juan:** (my) favorite is to serve. I like, I like, my client to be happy and so am I, because when you have a good relationship with a person, be it of any kind. Yes, it's nice, yes.
OO: *Qué tal, puede describir usted un momento, una experiencia, en que se da el sentido orgulloso de su trabajo?*	**OO:** How about, can you describe a moment, an experience, in which you felt proud of your work?
Juan: *(PAUSA) Ah, no, orgulloso tal vez no.*	**Juan:** (PAUSES) Ah, no, pride, maybe not.
OO: *Pero por qué? Por qué no orgulloso?*	**OO:** But why? Why not pride?
Juan: *Porque. Porque siento que no es un orgullo, eso. porque dice es una. Es un gusto, pero se puede decir es un… Es algo bonito, es algo bueno que siento en mi corazón y ofrezco. No, no, no, no es orgullo, orgullo es otra cosa.*	**Juan:** Because, Because I feel that it isn't pride, that. Because I say it is a– it is a pleasure, but you can say it is… it is something nice, it is something I feel in my heart and offer. No, no, no, no it's not pride, pride is something else.

Juan was firm that pride wasn't what he felt about his work as a caregiver. Though I think this had more to do with his interpretation of what pride is and deep humility. Juan turned to the word *servir* (to serve) in response, he views his work as service. Juan was saying that his care isn't something that he does or a job that he has, instead it is something he feels in his heart, it is something he is and something he offers to others through service.

Sol

Sol articulated a similar sentiment when she talked about her sons and who she hopes they grow up to be. Sol was the only caregiver I talked to who was working at a facility caring for various people in a live-in environment. The place she currently works at is a 30-day in-patient facility for drug and alcohol treatment. She had previously worked as a home care aid exclusively through an agency but transitioned to this place after her client died, affecting her deeply, and she needed a change in job structure. She still cares for one client at his home on Saturdays, in addition to her five days a week at the treatment facility. Sol talked a lot about the way she feels care for her clients and the emotional toll of the work, as well as the embodied care she provides clients. She shared the meals she has learned to make through her time caring for American clients, spaghetti, hamburgers and pizza. She would even put pizza leftovers in the oven to rewarm them to make sure it stayed crunchy, like her client liked, even though she said if it was her, she would have just microwaved it.

When I asked Sol, who was born in Michoacán, Mexico, about how her culture was connected to care she shared:

> *Tenemos que que, que, que hay que tener el amor, la pasión para hacerlo, y yo creo que también cuenta mucho como te, te, como te educaron tus papás, porque yo siento que mis papás hicieron una buena, me dieron una buena educación porque me respeto, para mi trabajo... Ahorita tengo dos hijos. Les he enseñado lo que yo sé y les he enseñado los valores… Y fíjate que te voy a decir algo, que yo me siento bien orgullosa de mis hijos, porque cuando yo, yo, yo no digo nada, pero yo observo, hemos ido hacia restaurantes y yo veo que vienen personas que tú sabes que no pueden caminar bien y un día mi hijo le abrió la puerta a una persona mayor… Yo me dio mucho gusto que yo vi eso, porque yo digo eso, eso. Las palabras a lo mejor pueden decir mil cosas, pero los hechos son los que cuentan para mí, claro…[starting to tear up] Y yo soy, yo, yo soy bien chillona. Y yo le dije mi hijo, me siento bien orgullosa porque porque tienes lo que yo tengo, que siempre* me gusta ayudar a las personas.

> We have to, that, that, that you have to have love, passion to do it, and I think also it matters a lot how you, you, how your parents educated you. Because I feel like my parents did a good, they gave me a good education because I respect my work… Right now I have two sons. I've taught them what I know and I've taught them values... And look, I'm going to tell you something– that I feel very proud of my children, because when I, I, I don't say anything, but I observe. We have gone to restaurants and I see people coming that you know can't walk well, and one day my son opened the door to an elderly person…I was very pleased that I saw that, because I say that, that, words can perhaps say a thousand things, but the acts are what count for me, of course… [starting to tear up] And I am–I– I am quite the crier. And I told my son, I feel very proud because you have what I have, that I always like to help people.

Not only is care within the body, but in Sol's understanding of care it permeates beyond actions in a workplace to be something you are. It is spread beyond to be something she wants and watches and hopes for her children to embody. And it lights up her heart to know that they too are caring people who want to help others, just like her.

Caregivers move between seeing their embodied care work as a gift and a burden, often within the same anecdotes. While caregivers value the embodied care they give clients, the physical and emotional work of such holistic care weighs on caregivers and they feel that weight seep out of the workplace and into their personal lives. This is perhaps most salient in the stress and contagion related health problems that four of the caregivers I interviewed shared about. The idea of *pesado* (heavy) and *se pesa (*it weighs) offer a succinct analysis of the work as described to me through the interviews. This chapter has shown the ways caregivers work of 'doing care' is embodied in their feeling of care, and in the case of some, how they see care as not only something they are good at, but something they are. I will explore this sense of duty and calling to care through a more structural and cultural analysis in the following chapter.

Chapter 4: Kinships of Care

My questions for the interviews were open ended but I wanted to think about work history and how caregivers came to be home care aides. These questions focused on how work changed during the pandemic, how the caregivers were supported or not by their employer through the pandemic, what caregivers liked about their jobs, what was hard and how they understood their work or thought others did and how they wished others would understand their work. This also meant I asked questions around cultural practices of familial care in the home and the relations that brought them to care work. The reflections caregivers offered during the *testimonios* on the kinship relationships that care work facilitated evolved naturally from conversations. It is with this complicated concept of family that this chapter begins.

kinship in the workplace

This chapter, and the project, is drawing from long established work on gendered labor markets and feminist care ethics, as elaborated earlier. Lisa Dodson and Rebekah M. Zincavage's 2007 article, "'It's like a family': Caring Labor, Exploitation, and Race in Nursing Homes" was especially interesting as I worked through the *testimonios* and started to see themes emerging. Their article looks at the ways in which race, gender and class intersect at a long-term care facility. They specifically identify a "family ideology" that works with care workers ``value(d) fictive kin relationships" (2007, 905) to exploit the low-income care workers. Though this article draws from experiences in a long-term care facility, which my focus of this thesis is specifically not, there are overt differences in the home care aides' experiences within their agency and interesting similarities regardless.

In Dodson and Zincavage's piece the family ideology is encouraged through their employer, the long-term care facility. They write, "In the many discussions about care quality and institutional approach, both management and frontline workers described creating a family as the best model of care for elderly and dependent residents" (Dodson and Zincavage 2007, 912). This was quite different from home care aides working through agencies in Washington State, in fact caregivers were told NOT to think about clients as family and NOT to develop affection towards them. The caregivers in this project are not working in expensive private care facilities, they are caring for clients who receive state benefits and are eligible for state funded in home care support. Where in private facilities the deployment of fictive kinships and imagery that draws reference to 'caring for your loved one like our own' works as a marketing plan, in the state-run program these caregivers work in a bare minimum landscape. That is, a situation where the state wants to expend the least amount of money possible to care for elderly and disabled clients, and thus caregivers are assigned strict and limited hours to do dedicated tasks. Often this results in a situation where caregivers either are exploited in their workplace or are labeled as uncaring.

Marivel

Marivel, who has been working as a home care aide in Washington state for over 20 years articulated this separation between client and caregiver saying:

> *Pero los cambios de clientes a veces es bueno y resulta mucho porque también, o sea, es como te digo, es un trabajo súper, súper difícil porque manejas muchas, muchas–se puede decir ramas, así porque este entonces tanto el cliente como al caregiver en veces un cambio les ayuda a uno. Porque hay veces que el cliente se familiariza o se quiere ver como una familia y entonces ya no es un buen ambiente a veces y entonces es necesario cambiar. Y en realidad, pues si no? Como nos han enseñado, nos han dicho y hemos tomado clases. Nosotros no somos familia, somos trabajadores. Entonces nos podemos ver con ese, de ese tipo al cliente.*

> But changes from clients sometimes are good and it happens a lot because also, I mean, it's like I'm telling you, it's a super, super difficult job because you handle many, many–you can say branches, so because this then both the client and the caregiver sometimes a change helps them. because there are times when the client becomes familiar or wants to see themselves as family and then it is no longer a good environment at times and then it is necessary to change. And in reality, well, yes no? As they have taught us, they have told us and we have taken classes. We are not family, we are workers. Then we can meet with that, that

type of client.

Marivel has cared for a lot of different clients and through various arrangements through her 20 years as a home care aide. When she first started working and her sons were still young, she worked double shifts through two different agencies to make ends meet. She worked from 8am to 4pm and then again from 10pm to 5am – cooking, cleaning, bathing and helping her sons with homework in between. She only slept a couple hours before going back to work every day. She did this for four years. She articulates an intentional un-kinship-like relationship to clients, one she expresses as taught by the agency and important to remind caregivers and clients that at the end of the day, “we are workers.”

The concern of a “no longer good working environment” when clients start to see caregivers as family became intensely personal for one specific caregiver, Rosio. I introduced Rosio through her unique care for a client suffering from substance abuse disorder but reintroduce her here to highlight an experience she shared during her *testimonio*. The first client she cared for was a young man with Down Syndrome; he was only 22 when she first started caring for him. He lived with his grandmother after both parents had abandoned him. After Rosio had been caring for him for a few years, his grandmother was diagnosed with cancer and died, leaving him alone. When the client 's grandma was sick she would beg Rosio to adopt the client, Rosio shared, “*la abuelita, cuando estaba enferma, me decía ‘¡Quédatelo, adoptalo, yo te firmo un papel!* // the grandma when she was sick would say to me, Keep him! adopt him! I’ll sign over the documents.” Rosio continued caring for this client as her and another caregiver along with a case manager tried to find family who would take him in. These efforts failed. The house he lived in, and understood his grandmother to have gifted him, was being repossessed to pay for medical debt incurred while his grandmother was ill. Rosio continued to care for this client, feeling indebted and empathetic, as the case manager eventually found a facility for him to live in. She even started working at the facility to continue caring for him– for a brief period – before realizing it was not for her and feeling satisfied that he was adjusting to his new environment. Though Rosio shared this intense story as an expression of care she was proud of, it is also clear the ways that fictional kinship relationships are stretched, blurred and exploited as caregivers become entangled in those they care for's lives.

I feel hesitant using exploitation here, just as I do fictional – to Rosio the choice to continue caring for this client was not exploitative and the relationship she built with him, and his late grandmother, was not fictional. The structure of home care aides work through state agencies means that they are caring for individuals, or pairs of people, who are receiving state benefits and often low-income and many immigrants themselves. For caregivers the workplace dynamic is complicated by a class and able-bodied to disabled relationship. For those in long-term care facilities, facilities that are prohibitively expensive for most families, different class and racial dynamics are at play. There is a gray area between need and willingness to serve that interacts with kinship and care that can lead to exploitation, but most caregivers did not articulate that.

Though Rosio's story was the most severe case of what could be called fictional kinship being exploited, it was not unique that caregivers often felt indebted to clients who they care for, support and often love. For Nadia, this care even extended to pets. She shares:

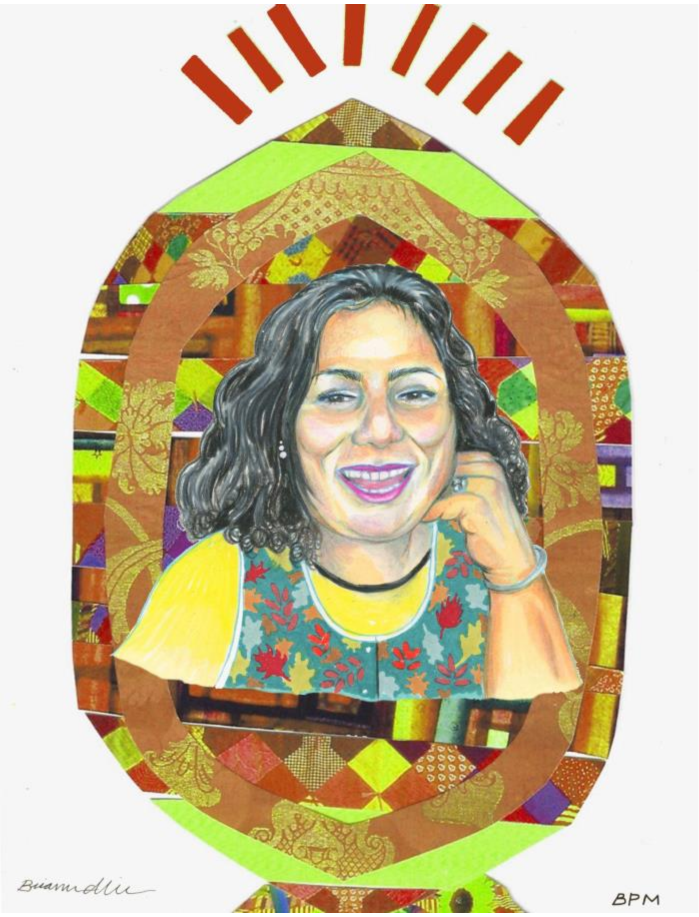
> *Pero nos hicimos amigas y en una ocasión estaba una de sus mascotas enfermas y me dijo– vamos a llevarla al veterinario. La mascota se estaba muriendo, entonces salió el doctor y dijo que si no la operamos en este momento se va a morir porque se había comido un plástico. Entonces volteó a verme y llorando me dijo Por favor, préstame los 700 dólares por tu crédito para salvarle la vida. Entonces, por tener confianza y tener sentimientos, yo con ella, yo le firme.*

> But we became friends and on one occasion one of her pets was sick and she said to me– let's take them to the vet. The pet was dying and so the doctor comes out and says that if they don't operate immediately they are going to die because they had eaten a plastic. So, she turned to see me and crying asked– please loan me the 700 dollars in credit to save their life. So, because I had confidence and emotion, I with her, I signed.

Though in this case Nadia was able to help save the dog's life, the debt her client owed her drug on and on as Nadia begged to be repaid. I share this anecdote because it is a clear example of some of the tensions involved for caregivers in fictional kinship relationships with clients, notably with clients who are often not financially stable or supported themselves. Both the clients and the caregivers are exploited in this system. Because Nadia cared she got stuck with a pet's medical debt- which she will be the first to tell you she made a mistake in being guilted to pay for. She elaborates, "*...me sentí como humillada, usada, porque era Americana la señora. Me rompió mi corazón porque yo realmente la quería. Siento que abusó de mi confianza//* … I felt humiliated, used, because the woman was American. It broke my heart because I really cared about her. I felt that she abused my confidence." What is perhaps most telling and was something other caregivers expressed as a policy that stood out to them from agencies, is upon turning to the agency for help in a situation like this, disciplinary action was immediately initiated. The caregivers are forced to sign a paper taking responsibility for the actions and assuming liability and fault. This assumption of responsibility is just another articulation of caregivers' risk as they care for clients that the agency does not.

From the testimonios it was clear that caregivers struggled with the required separation that the home care agency trains them on and often expressed caring or having "cariño" for clients regardless of agency training and encouragement. Caregivers often felt their clients were "like family." These kinship relations in the workplace, and the tensions around knowing they "weren't supposed to care" were salient in quote a few *testimonios*.

Alicia



Alicia was one of the first caregivers I spoke with and is part of a family of home care aides; her sister was part of this *testimonio* project and her niece and mother, that she cares for currently as an independent provider (IP), have also worked as home care aides. Alicia was especially excited about this project and was responsible for putting me in contact with her network of *compañeras* to interview. Alicia shared the struggle that caring through COVID has been for her, she contracted the virus through her client in November of 2020, who also passed it to their other caregiver and died from the illness. Alicia's COVID-19 case was severe, evolving in pneumonia and time spent in the hospital. Through this she continued to call and check in on her client who was advised to stay home, that she would be okay- despite preexisting conditions that increased her risk of severe complications with the virus. Alicia shares the impact this time had on her and the way she cared about her client:

> *Y a mi me dolió tanto, porque aunque nosotros nos dicen que son personas, que nosotros tenemos que ser como imparciales, no tomar aprecio a las personas, tomar las nadamás como clientes es imposible. Para mí es imposible– porque el tacto directo que has tenido seis años trabajando con esta persona…aunque no queramos, se hace un cariño, se hace una aprecio a las personas, nos preocupamos por ellos, verdad? Nos tomamos, como si fueran nuestros niños chiquitos que hay que cuidarlos y hay que ayudarlos en todo, no? entonces sí duele, sí duele perder en el medio de tanto.*

> And it hurts me so much, because even though we are told that they are people, that we have to be unbiased, not appreciate people, and take them only as clients is impossible. For me it is impossible– because the direct contact that you have had for six years working with this person… though it doesn't become affection, you form an appreciation with people, we care about them, right? We treat each other as if they were our little children that we have to take care of and help them with everything, right? So it does hurt, it does hurt to lose in the middle of so much.

Alicia articulates not only how emotionally hard it was to lose a client to COVID, which many caregivers had to navigate and shared about during their *testimonios*, but Alicia also shares the ways those emotions are complicated by the agency training to not become attached or the directive to maintain a separation between the client and yourself, as a home care aide. She questions, "how could one not care or grow close to someone after caring for them for six years?" She goes even further drawing a parallel to the type of parental care that caregivers give children with the care caregivers show clients as they, "have to care for them and help them (clients and kids) with everything."

Tabatta

Tabatta loves her work as a home care aide, she finds deep meaning and importance in what she does. Tabatta is also an active union organizer and fierce advocate for caregivers. She is a leader among the caregivers I spoke with and graciously spent many hours on the phone talking me through questions and experiences I wanted to know more about after the *testimonios*. She is also a single mother and survivor of vicious domestic abuse, which she shared with me during her *testimonio*. She migrated at a young age with her new husband who quickly turned controlling and violent once she was away from family support networks in Mexico. She was fortunate to be granted a U-visa after the violence, something many immigrants will never be afforded despite the violence or threat they may be under or have experienced. This allowed her the ability to adjust her status and gain legal documentation to work as a home care aide, which she has been doing for seven years. Her ex-husband and his family however are still around. She fears for her and her daughter's safety, because of this she lives under the radar, which means she was the one caregiver who did not participate in the portrait project.

Tabatta shares her understanding of work and family ideology proudly right at the start of the interview:

Me llena de satisfacción saber que yo puedo ayudar a, a lo básico, que ellos ya no pueden hacer, no? Como una simple taza de té o una simple puesta de loción. Llevarlo a las citas médicas, bañarlos, darles compañía, escucharlos y al mismo tiempo somos parte de su familia porque muchos de ellos no tienen familia allá. Muchas veces nosotras, las community aides, somos la única persona que ellos tienen para su vida diaria.	It fills me with satisfaction to know that I can help, at the very least, with what they can no longer do, no? Like a simple cup of tea or a simple lotion application. Take them to medical appointments, bathe them, give them company, listen to them and at the same time we are part of their family because many of them don't have family there. Many times, we, the community aides, we are the only person they have for their daily lives.

Tabatta's relations to clients circles back to the ways that dynamics of community care reverberate through caregiver articulations of their work in ways that are different from what Dodson and Zincavage found with certified nursing assistants (CNA's) in long-term care facilities (2007). Tabatta also articulates a family ideology that is a bit different than that which Alicia identifies in interesting ways. Where Alicia says she is caring for her clients as if they were her family (which other caregivers also expressed), Tabatta, like Marivel earlier in this chapter, is expressing the ways that clients see them, the caregivers, as family. These kinship relationships built from market labor exchange are complex and situational- shaped by understandings of self, positionality in relation to client, the client themselves and the time spent with the client. The family ideology works in dynamic ways and can still lead to worker exploitation, whether the ideology is being articulated through the employer or fostered within the caregiver and client relationship itself.

familial care

I use the term "familial care" to address the reality of mixed caring that happens in homes between elders and kids. *Ancianos* care for *nietos* and kids are tasked with elder care in the home as they get older, not to mention to support the family through interpretation and bureaucratic paperwork. In literature I have found these two realms of care, child and elder, to be theorized as two separate practices, with people studying one or the other. Through my interviews with caregivers, and from personal experience, this distinction is not true in many Latinx households. Not only is the distinction between types of care not siloed, but the white heterosexual middle class family archetype - mom, dad, two kids- is an imaginary irrelevant in many households. Grandmother headed households[17], single moms cared for their one kid, blended families spanned large age ranges, grandparents lived in homes, eldest kids managed homes as those with citizenship and the best English[18], neighbors became family, exes lived in their house together with the woman's new boyfriend and their adult son, friends rented an apartment together and shared a dog… you see what I am doing here. Family and kin are all these things. The white Protestant concept of the nuclear family, upon which policy is often created, is nothing if not a myth.

Delia

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[17] I find LaShawnDa Pittman's work on Black grandmothering to be insightful work and I think there is more to think about in relation to the caregiving Latinx grandmothers of this project. (Pittman and Oakley 2018; LaShawnDa Pittman 2015).

[18] For more on the transnationalisation of families through deportation see, Ybarra & Peña 2017.

Delia, a Mexican immigrant and caregiver in her 50's, came to home care work after a social worker suggested she apply to care for her late ailing father, at a time when state compensation as a certified care worker for your direct family was still possible through the agency. It has since been made against agency policy to care for an immediate family member unless employed as an Independent Provider directly through the state, though caregivers find ways to work around that with broader conceptions of family than the agency recognizes. When asking if she thought care was connected to her culture Delia responded:

Pues está conectado porque en nuestra cultura los abuelitos viven con nosotros e incluso amamos a los abuelitos. Los hijos mientras no se casan viven con nosotros. Eso es cultural? Sí, eso es cultural. Así que eso no me molesta. Yo me crecí con mi nana, o sea, mi nana vivió con nosotros en nuestro hogar. Entonces nosotros la cuidábamos a ella o ella nos cuidaba a nosotros primero ella nos cuidó a nosotros, crecimos, los cuidamos, a ella…	Well, it is connected because in our culture grandparents live with us and not only the grandparents, the children live with us while they are not married. That's culture. Yes, that is cultural. I grew up with my nana, that is, my nana lived with us in our home. So we took care of her or she took care of us. First she took care of us, we grew up, and then we took care of her…

In this quote Delia not only shows the way that care is not contained within child / elder spheres but instead illustrates a familial care network that offers a more cyclical and mutualistic articulation of care. Delia continues, offering another example of care:

…yo no tenía el título de caregiver en México yo cuidaba a mi vecina que vivía al cruzar la calle, ella era una señora sola y yo siempre le asistía, la ayudaba, la llevaba cada noche cuenta que era una caregiver, pero sin título verdad? Y sin paga. Pero no importa. Osea, me pagaba en la manera de que cuando mi esposo me dejaba que yo me quedaba sola con ella siempre nomás cruzaba la calle, miraba a mis hijas como sus nietos. Entonces a veces decía 'Delia ahora vámonos a la comida china'. Y nos íbamos en su carro y yo manejaba su carro y nos íbamos con las niñas como si fuera una familia, porque ella era en realidad con mi familia. Mis hijas le decían abuelita. Entonces, este, ella se pasaba a la casa y comía todos los días en mi casa. Así que sin querer hasta mecánica, a veces le cambiaba alguna pieza al carro o algo. Me aventuraba eso porque no estaba mi esposo, ella necesitaba algo, yo buscaba la manera de como yo siempre ayudarla, asistirla. Entonces pues si es cultural, nosotros como que así somos.	…I didn't have the title of caregiver in Mexico but I took care of my neighbor who lived across the street. She was a single *señora* and I always assisted her, helped her, took her to the market. Given that…I was a caregiver, but without a title, right? And without pay. But it doesn't matter. I mean, she paid me in the way that when my husband would leave and I was left alone, she always just crossed the street, she looked after my daughters like her grandchildren. So sometimes she would say Delia, let's go to Chinese food. And we would go in her car and I would drive her car and we would go with the girls as if we were a family, because she was really my family. My daughters called her *abuelita*. So she would come over and ate every day at my house. So sometimes I was even unintentionally a mechanic, sometimes I changed a part to the car or something. I did that because my husband was not there, she needed something, I was looking for a way to always help her, assist her. So well yea, it's cultural, we kind of are like that.

Beyond challenging child/elder care dichotomies, Delia offers an articulation of familial care networks that expands beyond a colonial conception of immediate blood family. This relationship with her neighbor, a network of care, may have come from the pressure put on communities when men migrate for work but expanded beyond to a deep sense of family where her daughters now refer to this neighbor as grandma.

who cares? women!

As Delia began above, caregivers continued to share about the ways they came to care and their understanding of care as a cultural expectation. Sociologist Evelyn Nakano Glenn articulates this gendered dimension of care as, "What underlies the pattern is the deeply held belief that women 'ought' to care and the widely held expectation that women 'will' care" (2012, 88). In this aspect care work in the home, as care work in the formalized economy, is highly gendered. Glenn refers to this concept of caring as a "status duty for women," a type of coercion, and highlights the role the state has played in "defining and enforcing this obligation" (2012, 9). Care work is women's work because it has been made to be that. It is important to acknowledge that though this larger framing is true, there are many forms of care work that are missed through this lens. In this project this lens is in part due to who I talked with and was in relation to, and the care work valued, undervalued and unvalued by the liberal state (as necessary for social reproduction, though often unpaid). Though the caregivers conceived of care as constituting expansive kinship networks, they still reproduced cis-heterosexual relationships. This type of care work tends to be associated with emotional labor as I shared about in Chapter 3, but not all care work may have this association. In fact, many different types of care and care networks exist outside of formalized economies and the mainstream, which I will delve into a bit in the conclusion (Sandoval 2017; Kafai 2021). It was the case however, in this project, that women– cared.

Rosio, who was introduced above, echoes a lot of the sentiments Delia shared about a type of familial care that is cyclical, though she identifies the way her gender shaped this role. She says, seated across from me in a parking lot near her work:

> *Cuando una ancianita está en casa, los abuelitos, los cuidamos en la casa hasta que se mueren. Y nosotros bueno, en la casa, en casa donde, mi abuelita murió de 104 años. Sí, y creo que murió cuando yo tenía como 18 años. Pero como yo era la niña bonita de la casa, de la abuelita, entonces yo me dormía con ella. Y cuando ella, como a los... yo tenía como 6 años, cuando ella se quebró un pie y ya no caminaba y entonces yo la ayudaba mucho. Cuando para caminar con su bastón yo le iba ganándole un lado, yo le arrimaba su silla o la comida, ella me quería mucho porque yo la ayudaba mucho también. y así yo pienso que de ahí viene como un poquito lo de cuidar ancianos, porque yo más o menos yo tenía experiencia con mi abuelita.*

> When elders are at home, the grandparents, we take care of them at home until they die. And we, well, in the house, in the house where my grandmother died at the age of 104. Yeah, and I think she died when I was like 18. But since I was the chosen girl of the house, of my grandmother, then I slept with her. And when she, like when... I was about 6 years old, when she broke her foot and couldn't walk anymore and then I helped her a lot. When she walked with her cane I was at her side, I would bring her chair or her food, she loved me very much because I helped her a lot too. And so I think that a little bit of caring for the elderly comes from there, because I more or less had experience with my grandmother.

When sharing what she identifies as the roots of her contemporary work as a home care aide Rosio highlights herself as the 'pretty girl of the house.' It is this position that seemingly justifies her role as caretaker of her grandmother that begins when she is just six years old and continues until she is nearly 18 and her grandmother, 104. Rosio's gender matters and she has an expectation of care placed on her that begins when she is only six years old.

Guadalupe, who I introduce more during the discussion of the physicality of home care work, shares a similar articulation of care within her family due to gender, but in her case, class, and geography, play a more overt role. Guadalupe shared with me toward the end of her *testimonio*:

> *Yo creo que eso lo tengo desde muy muy niña porque tenía familia que estaba estudiando medicina. Haya en Sinaloa y yo chiquita – mi padrina era doctor. Pero yo no podía tener los estudios porque donde vivía yo era un rancho y no había escuela. Y cuando me vine a Mexicali, a los 9 años, mi tía no me puso en la escuela. Entonces ya no estudie mucho, no más hasta tercer año, y ya me podía poner en la casa porque me puso a cuidar a sus nietos y no tuve la oportunidad. Pero yo estaba con esa idea de que iba a ser doctor– ayudar a la gente…*

> I think I have had that since I was very very young because I had a family that was studying medicine. Back in Sinaloa and I was little – my godmother was a doctor. But I couldn't study because where I lived was a ranch and there was no school. And when I came to Mexicali, at 9 years old, my aunt didn't put me to school. So I didn't study much, not until third year, and she could put me at home because she put me to take care of her grandchildren and I didn't have the opportunity. But I was with this idea that I was going to be a doctor – help people…

Guadalupe is conveying a lot in this short quote. At age 73, she is reflecting on aspirations she had of being a doctor and the structural- gendered, geographical and economic realities that made this dream impossible. Growing up until age nine in a rural area of Sinaloa, which she identifies as a '*rancho*,' she did not have access to school. After moving when she was nine to be with her aunt in Mexicali, the capital city of the state of Baja California in northern Mexico, she attended school for a few years, until third grade, before being required to stay home and care for family. Guadalupe has a desire to care fostered in her as she watched other family members go to school and become doctors. Though structural constraints meant she was forced to care for family at the expense of any personal schooling to become a doctor, her desire to help people and be a medical professional is what drew her to home care work when we last spoke.

Rosio and Guadalupe's experiences are not unique across the testimonios, half of those I interviewed identified familial care as either the thing that drew them to this work immediately, meaning they were caring for an ill or ailing family member as adults, or that their current job built from experiences they had when they were younger performing familial care. There is a gendered expectation of care that Latinx women experience and articulate. Though there are varied constraints on agency to do this familial care work, it is clear that when familial care work is needed,

it will be women who are expected to
care.

making gender

In thinking about the ways that care is universality inscribed onto the Third World woman's brown body, I have found Martin Manalansan's work on "Queering the Chain of Care" helpful. Manalansan uses the experiences of queer carers to disrupt the neat synchronicity of the "chain of care." They use the documentary film "Paper Dolls," a cultural production that chronicles the travails of gay Filipino men and female transgender domestic care workers who work as unskilled "health aides" and whose charges are elderly Orthodox Jewish men, to question, "Does this mean that these gay men and transgendered women are devoid of 'feelings'? Are these care workers inauthentic because as biological men they are not 'equipped' to fulfill the 'natural' womanly role of caring? Or is it more accurate to say that their feelings are less grounded in normative domesticity and filial attachments?" Manalansan wraps up the piece writing, "as feminist scholars and researchers, we need to think of the chain of care not as a set of discrete relationships between worlds and bodies strung up in a teleological manner, but rather as a series of conflicting and diverse bonds between labor, emotions and corporeality that do not line up neatly in terms of gender binaries and normative familial arrangements."

I am still thinking through the ways that my work with home care aides in south King County is participating in and or responding to the important critique Manalansan's work provides, but Manalansan wraps up the piece writing, "As feminist scholars and researchers, we need to think of the chain of care not as a set of discreet relationships between worlds and bodies strung up in a teleological manner, but rather as a series of conflicting and diverse bonds between labor, emotions and corporeality that do not line up neatly in terms of gender binaries and normative familial arrangements."

I am still thinking through the ways that my work with home care aides in south King County is participating in and or responding to the important critique Manalansan's work provides, but I am cautious of reproducing essentializing and violent gender binaries through my work on care. In interrogating the ways that different caregivers "come to care" and the family structures and relations that require and produce caregivers we can see the ways that if gendered care labor is created through the expectations placed on women, then gender is made and remade through the act of caring.

If we understand gender to be a performance, a set of things we do, or are expected to do, then the performance of care is an expectation of womanhood. The home care aides of this project have experienced various family structures and have found themselves in formal and informal situations in which they, as women, are expected to be the one who does the care work. In this way, families, cultural expectations and for home care aides, a labor market is reifying what it means to be a woman.

CONCLUSION: Thinking with Interdependence

When I first began this project, my scope was relatively narrow. I was mindful of time and trying to be realistic about thesis research during a global pandemic.[19] I was drawn to this project because of relationships, of commitment, care and friendship, in community. As I began *testimonios* and started to learn about the work and experiences of caregivers., they made clear to me that, as in the case of most inequities and oppressive structures, the pandemic only exacerbated existing system failures.[20] To only focus on the effect of the pandemic on caregivers' lives and work experiences would have meant not only to miss the larger landscape they are situated in, but also to facilitate a dismissal (as we are seeing) of said "pandemic problems" after said pandemic was stated to be "over."[21] Instead this thesis has taken a larger scope to think through caregiver experiences in the COVID-19 pandemic and beyond. This is also reflected in the literature I am engaging with and the evolution of my thinking regarding caregiver experiences. While I began the work in labor studies and feminist care ethics, two bodies of thought with long (white) histories, I come to end (and continue) in disability studies with crip-of-color critique (Kim 2017) .

how far we have come

Formed from the 15 *testimonio* interviews that I completed during summer and fall of 2021 in south King County this thesis has built from Feminist, Latinx, Black, Indigenous and Queer

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[19] I began my MA program in the Fall of 2020.

[20] I draw my use of "system failures" from the women of Aileen's. Aileen's is a peer-centered organizing and hospitality space located in Federal Way for women working along the Pac Hwy. I spent time at Aileen's compiling resource zines during the time I was doing this research and the conversations I had greatly influenced how I think, and talk, about intersecting oppressions in people's lives. See more about their work: http://aileens.org/

[21] For more on the eugenics and violence of the state's response to the pandemic read Mia Mingus' recent post, "You Are Not Entitled To Our Deaths: COVID, Abled Supremacy & Interdependence" : https://leavingevidence.wordpress.com/2022/01/16/you-are-not-entitled-to-our-deaths-covid-abled-supremacy-interdependence/

scholarship on racial capitalism, caring labor, migration, and gender. I struggled with creating and ordering distinct chapters with which to organize the experiences because I see dynamism and cyclicity in the experiences and findings over space and time, not linearity as a thesis may suggest (Sandoval 2017). In addition, I have worked through the feminist praxis of understanding the editorial role I played as a curator of these experiences that were shared with me. Embodied care practices weave with cultural understandings of care as gendered obligations creates conditions for exploitation in some instances and profound senses of purpose in others. I opened in the first chapter by detailing extensively my methods and the evolution of the project as a means of researcher reciprocal relationality and accountability. The portraits, a key component of the project and a tool for centering caregivers that has had resonance outside of the academy, then followed. These are intentionally full pages and ask you, the reader, to sit and reflect into the caregivers' eyes. I do this as a building of relation, with who they are, but also to invite a pause from text and an orientation as the writing transitions to the body chapters.

In chapters two, three and four I have used the testimonios shared with me to convey three key lessons from the project. The first of which is shared in chapter two, a conversation on agency. This chapter on agency and caregiver resistance is sitting with Eve Tuck's challenge to suspend damage (Tuck 2009). By centering a desire-centered analysis the chapter finds the space people are already creating within structures that shape the conditions of possibility-- or at least try. The chapter starts by laying out the non-homogeneity between caregiver positionality and experiences, and thus the structural constraints on their agency. It moves beyond this however to show the ways that though constrained in very real ways in the workplace, caregivers deploy tactics of resistance in their turns to slowness and leaning into policy adherence through a care plan to express agency. In addition to these perhaps more overt methods of resistance, in that they are more obviously read as something they are doing "in resistance to" a type of labor exploitation, caregivers also express agency and resistance to the devaluation of their jobs in the meaning-making that they themselves create and find in their work as home care aides. Caregivers see, respect and value the work that they do for others. In community with other caregivers, in union spaces and over shared meals they affirm each other's work and create and center an understanding of care and care work that they want others to see but are not dependent upon.

The third chapter, "Se Pesa" is focused on the embodied care that caregivers do, feel and are. This chapter highlights the care caregivers give as holistic, mind, body and spirit – or put another way, mental, emotional and physical. This kind of support has only become more necessary as the pandemic closed community groups and made other social settings increasingly risky. Caregivers held the threads of failed systems exacerbated by the pandemic together as often clients' main source of social contact- sometimes the only other person they would see. It also shares anecdotes from the caregivers on how they feel their care work in their whole body, as embodied. Their care seeps out of the workplace– into their personal lives, families and bodies, with many experiencing stress related illnesses, injuries and COVID-19 infections (in addition to long-covid symptoms). This is the challenge, reward and toll of embodied care work.

Finally, in chapter four I think through the way that kinship and gender interact in care work. I use previous care research of kinship used for exploitation in caring facilities to juxtapose local caregiver experiences of similarities and differences with home care work. I then offer the concept of familial care as a term that broadens previous care labor frameworks of childcare and elder care as two separate forms of caring and considers the lived experiences of mixed caring, that in which elders care for kids and kids care for elders, that caregivers shared. To close the chapter, I work through the gendered expectations and obligations of caregiving, and the limitations of such a static framework; I use queer critique to touch on the ways gender is thus made, and remade, through caring.

towards an epistemological project of interdependence

As much as this project has been one of learning about caregiver experiences, it has also been an epistemological project in which I have practiced and learned what centering interdependence looks like in the doing. I wish I had a list of "5 Steps to Doing Meaningful Interdependent Research" I could share, but I do not[22]. As a geographer there is perhaps nothing I take more true than the reality that place, and thus context, matters. There are however some ways that I have found were important in this project. I hope that this type of project, one that is grounded in community and centers those whose stories are shared, becomes more common practice. I think of it as a starting place for those who aim to do good research.

Interdependence as an epistemological method meant the project was centered in community need- starting with caregiver interest in sharing their experiences. This meant doing what I could to compensate the caregivers for their time, gift cards given to the place of their choosing, but also my time and support in other ways— picked apples, watched dogs, college counseling for their first-generation high school kids. Interdependence in the project meant understanding consent as an iterative process, check-ins that happened continually throughout the project, and especially, follow ups after the portraits were done about using them in public-facing materials, such as the UW article done on this project.[23] In a similar vein, language justice was an important aspect. To have iterative consent, I needed caregivers to understand what I was writing about their experiences, and to have the work reach audiences within caregiver communities, it needed to be translated. I hope that the entire thesis will be translated but keeping the quotes in their original language first and translating more public facing writings are a good start. These translations and project support also

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[22] Well actually, people have offered a good start: Pulido's (2008) "Frequently (Un)Asked Questions About Being a Scholar Activist" (2008), Waheed and Assil's (2015) "An Introduction to Research Justice," Piepzna-Samarasinha and Park Milburn's (2022) "Disability Justice: An audit," Patai's (1991) "U.S. Academics and Third World Women: is ethical research possible?" and Stacey's (1991) "Can there be a feminist ethnography."

[23] The article can be found here: https://artsci.washington.edu/news/2021-12/covid-challenges-caregivers

echoed interdependence as I was able to compensate my friend Stteffany, whose mom and aunt were the first people I interviewed and who herself has worked as a caregiver. She made the project possible as I depended on her throughout it. In this project, creative methods that fostered the co-creation of knowledge – with caregivers, artists, Stteffany and myself-- allowed the project to center interdependence and to become legible to diverse audiences. In the thesis writing process, which as Osage scholar Jean Dennison reminds me is just the write up of research you already did, I was spurred by a comment from my committee member Vicky Lawson to write around the quotes. This serves in contrast to writing (and coding) methods in which you try to pick and fit quotes into what you had already intended to say. A project centered in interdependence meant though I surely curated the narrative as the researcher, I worked to allow the purview and direction of the writing to be informed by what caregivers decided was important – through statements they explicitly said, what they chose to disclose and withhold and the time they decided to dedicate to certain conversations.

¿Cuáles Cambios Quiere Ver Para Caregivers? // What changes do you want to see for caregivers?

As I thought about wrapping up this piece of writing I sent an ask out to caregivers to see what kind of changes they wanted to see. I had the themes of change I had pulled from *testimonios*, but I wanted to offer caregivers another chance to set the takeaways from this work. Where I may have framed this thesis at a structural level, which is important, there are also pragmatic changes that caregivers had similar desires for when I asked what changes they hoped for. I have organized them into four key changes that caregivers want to see in their jobs:

One: Respect and Dignity

Caregiving is a profession that deserves respect and dignity. This is an ask for a general public's increased understanding of the complex and meaningful work caregivers do, but also a specific reference for a desire for clients and clients' families to better understand the scope and boundaries of caregivers' responsibilities. The following changes build toward a workplace in which caregivers begin to feel this respect materially.

Two: Pay and Benefits

Caregivers are healthcare professionals. They have full responsibility for vulnerable clients and run physical and emotional health risks in their jobs, in COVID-19 and beyond. As such caregivers deserve a commensurate salary and benefits. With hazard pay ending in 2022, caregiver and labor unions continue to fight for a $20 minimum wage ("COVID-19 Updates: Hazard Pay, PPE, and Caregiver Funding – SEIU775" 2021; "Time for $20 – SEIU775" n.d.). Beyond pay, caregivers also deserve paid time off (PTO) that is not only increased to at least equal levels of other positions within the same agency, but benefits that are more robust and flexible. This includes a way to care for themselves and direct family when sick that does not use their limited PTO hours. In addition, caregivers (many of whom are aging themselves) deserve employer contributions to 401k's that respect the physical and mental wear and tear of their job and allow for a dignified retirement.

Three: Work Materials

Though perhaps most overt in a COVID-19 context, caregivers also deserve access to the supplies and materials needed to care for their clients successfully and thoroughly. This means access to PPE such as gloves, masks, aprons and disinfectant that reduces their risk of contracting illness when visiting their clients' spaces. These items should be prioritized for caregivers working in such close contact with clients and should not be something that caregivers must purchase on their own. At the start of pandemic and a scramble for resources PPE was scarce, though the agency may not have been able to procure supplies (which is another problem around which healthcare workers have value) the caregivers could have been reimbursed for the PPE they were forced to source on their own.

Four: Job Security

The final articulated change is the need for a system that better assures caregivers hours, if not long-term contracts. As it currently works caregivers are often trapped in exploitative workplace situations because they are not guaranteed work if the client they are with asks for a change. This means that caregivers' ability to set professional boundaries, speak up about unfair working conditions and seek work that fits their professional competencies is limited by the need to pay bills and keep a roof over their and their family's head. Additionally, in a job that is physically and emotionally taxing the ability to take PTO for vacation, to visit family or even take sick leave and know that you will have hours when you return is essential. Caregivers deserve[24] the ability to rest.

on interdependence

> Because the truth is: we need each other. *We need each other.* And every time we turn away from each other, we turn away from ourselves. We know this. Let us not go around, but instead, courageously through (Mingus 2010).

As I reflect on this project, Mia Mingus' writing on "Interdependence" sits with me. Mingus is a disability and transformative justice writer, educator and organizer. I was only introduced to disability studies at the end of my undergrad when I got to attend a book reading by Eli Clare[25] and am still learning with and from the disability justice scholars and organizers (forever), but I think that seeing caregivers embodied care through an interdependence lens can be generative. This is not to say that I think the current neoliberal state caregiving structure is fostering such interdependence between disabled clients and caregivers - in fact many of the *testimonios* that this thesis is centered

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[24] When using this word, I often think of Lisa Marie Cacho's critique of deservingness in *Social Death Racialized Rightlessness and the Criminalization of the Unprotected* (2012)

[25] The readings from this event were eventually published in *Brilliant Imperfection: Grappling with Cure* (2017).

around shows the ways this is very much unrealized. However, I do think that there can be a powerful reframing of care work when taken from the lens of interdependence. Caregivers know, perhaps more than anyone, the holistic capaciousness of the disabled clients they care for. They see and feel the shifting relations we have with each other and the varied needs we all must get through our days. Caregivers embodied care for their clients is life-extending. This framing of caregivers with disability justice can be a generative space for further work in imaging an interdependent world in which we all thrive.

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