Invisible Outcasts:
How Chemical Exposures Shape Social Life

by

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DISSERTATION ABSTRACT

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This dissertation examines the contested illness multiple chemical sensitivity (MCS), in which individuals developed symptoms, sometimes to life-altering and disabling degrees, to the chemicals found in our everyday lives. Based on ethnographic data, including interviews (n=33), participant observation of online support groups, analysis of online content (websites, reddit forums, and support groups), and enactive practices I undertook in the field, I argue that chemicals are embedded in our social lives in ways that many of us do not see. These potential exposure routes remain invisible to many of us due to our imaginative inability to see each other as connected, take on responsibilities for each other's health, and move beyond dominant ideologies of modernity that see us as discrete from each other and from nature. By looking at how people with this illness practice chemical avoidance, I find that managing this condition displaces a tremendous amount of labor onto them, labor that should be eased by regulatory apparatuses, medical institutions, and proximate others. I find that those with the condition attempt to stay connected to others by redefining risk and relational responsibilities but that this often leads to isolation from the world within both the public and private sphere. Using my own embodied experiences in the field, I trace how embodied, tacit knowledge has been of historical importance to our conceptions of environmental health and how those with MCS are reengaging with these perspectives to chart their own paths through our chemically contaminated world. I

conclude by looking at how relocation is a crucial tool in responding to pervasive contamination. It is not the geographical patterns of harm that are present in this case but the lure of geographical havens that offer the promise of wellbeing and restored health.

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To my parents

They paved paradise and put up a parking lot
With a pink hotel, a boutique, and a swinging hot spot
-Joni Mitchell, “Big Yellow Taxi”

There was a shopping mall
Now, it's all covered with flowers
If this is paradise
I wish I had a lawnmower
-David Byrne, “(Nothing But) Flowers”

CHAPTER I: INTRODUCTION

Matilde is a woman living with chemical sensitivities whom I spoke with over the phone one warm September day. She lives out of her van, which is currently broken down, and makes art and videos advocating for those living with environmental illness. People with chemical sensitivities (also called environmental illness) get sick from small doses of the chemicals found in everyday life. Many people including doctors, believe this illness is something that is psychological, "in their heads," rather than a physical illness of the body. During our interview Matilde told me she was having an identity crisis. When I asked her to tell me more about that, she said:

> Well, I know that I see myself as I don't fit in this modern-day world thing. A casualty of the Industrial Revolution. No, that's not the right word. But I know the word I want to say. I want to say I feel like I'm an outcast. Like I just don't know what to do. I want to participate in the world. So, I try to be and act like I'm normal sometimes. But then that fails. I can't. And then I leave just like 'Crap, I couldn't do it'. But then I also show that I'm positive when really inside half the time, I'm not sure if I'm really feeling that. I just show the outward positivity, which has also proved to be a bad thing. Because of my show [of] being positive, nothing's wrong. How could [it be]? You're just lying. You're not really homeless, you have a house somewhere, you know, how could you be positive? I'm going like, okay, so when I was bedridden, I was exaggerating, they said, but I got out of the bedridden part and now that they show like I'm smiling, well then, I'm lying, so I honestly don't know what to do. I don't even know how to behave. I can't even…So I actually chose a positivity, which is a bunch of positive things. That's also kind of like my…coping measure. Even if it's not like the best thing in the world, that's my coping measure is I just stick to the positive things. And I can't seem to express my real whatever. Because I know there's going to be some kind of judgment and stigma and so I just pretend I'm fine.

Because everyday chemical exposures make her sick, Matilde is excluded from many parts of social and public life. She can't find housing she can tolerate so she lives out of her van. She is bumping up against physical, social, and emotional barriers to participating in the world. This feeling of being an outcast of modern life is what is driving her identity crisis. She is living under a set of tensions; she is excluded from the world, but she forces herself to participate sometimes even knowing this will make her sick. To others, her participation seems to undermine or invalidate her illness claims. This is a common experience within the world of disability and

chronic conditions. Many chronic conditions and disabilities are considered "invisible" because they are basically impossible for an outside observer to detect. As Gibson writes in her work on chemical sensitivity and community access, "because this population is excluded from sight, business goes on as usual, and public venues remain the purview of those whose bodies conform to the modern-day mandate of imperviousness to toxics" (2010:11). In some ways this can benefit people. They may be able to pass for healthy and normal when they want to (Barrett 2000; Grue 2024), but in other ways, this ability further undermines their claims of pain, discomfort, and disablement.

Matilde is in a double bind when it comes to how she expresses not just her body's abilities but also her emotions. No matter how she acts she is seen as being untruthful in some way. There is not a clear way for her to feel and behave to render her suffering legible or believable to other people. If she could crack the code of these feeling rules around sickness and disability, would she be able to break through other's denial and disbelief? Would she find the support and compassion she needs? Matilde is trying to contort herself in order to manage or eradicate the stigma she faces. Other people can't see or feel what she is going through so she is forced to pretend. This illness, and the chemically reactive themselves, are invisible not only because people are unable to see or feel the chemicals themselves but also because they are unwilling to see and believe the suffering they create.

Both Matilde's experiences in the world and the epigraphs at the beginning of this book communicate something specific about our places within modernity and ecological transformation. Modernity seduces us with promises of control over nature, mastery over our bodies, and unlimited resources through technology. Instead, it has undermined our relationship with nature, alienated us from each other, and jeopardized the ontological stability of life itself. What happens when the promises of modernity deteriorate, when the body rebels and people experience a collapse of their abilities to rely on institutions, consumer culture, and even personal relationships? Both songs quoted in the epigraph function as clear indictments of consumerism and our ecological arrangements. Both artists sing about consumption- boutiques, hotels, and shopping malls- and how the ways we consume are inseparable from how we organize our relationships to nature. Indeed, it is within the spaces and practices of consumption that the impacts of chemical sensitivity are most keenly felt. When Matilde talked to me about not being able to participate in modern life, one of her chief examples was how difficult going

into the grocery store is for her. The very conveniences of modern life are what is wreaking havoc on the bodies of the chemically sensitive and their abilities to be in the world.

In many ways the troubles of the chemically sensitive occur at the end point of production processes. Environmental justice cases show us what happens when workers or residents close to polluting facilities become entangled with production. They get sick. They die. Their children are born with birth defects. But we should also be questioning what happens further down the line in the lifespan of these products. How do the chemicals encapsulated within them continue to come into contact with human bodies and the bodies of more-than-human nature? What happens when people claim harm from these occurrences? What happens when chemicals that are known to cause harm now permeate all our natural environments, social lives, workplaces, and homes? And how can we analyze and resolve environmental injustice in a permanently polluted world? Living with multiple chemical sensitivity means living in a protracted environmental crisis.

Background to Multiple Chemical Sensitivity

What exactly is multiple chemical sensitivity (MCS)? It is a condition in which people develop physical reactions to chemicals found in everyday life. These exposures often occur at doses that are below the scientific threshold for toxicity (Coyle 2004). Exposures are frequently linked to petrochemicals, volatile organic compounds, and synthetic and organic fragrances. They come from pesticides, laundry detergents, car exhaust, perfumes, cleaning products, personal care products, and other facets of consumer and industrial life. Other terms for multiple chemical sensitivity include Chemical Intolerance (CI), Chemical Sensitivity (CS), Idiopathic Environmental Intolerance (IEI), Toxicant Induced Loss of Tolerance (TILT), Total Allergy Syndrome (also termed Twenty Century Disease), Chemical Injury, Chemophobia, Toxic Injury, Environmental Hypersensitivity Syndrome (EHS), and Environmental Illness (Zucco and Doty 2021). Due to both its etiological uncertainty and lack of social legitimacy, scholars classify multiple chemical sensitivity as a contested environmental illness (Gibson 1997; Brown et al 2004; Brown 2007). Medical studies and theories about multiple chemical sensitivity exist but are limited, lack funding, and have failed to arrive at a consensus about its etiology. Some researchers believe multiple chemical sensitivity to be provoked by an acute chemical injury that

sensitizes the body to future chemical exposures, often referred to as "toxicant induced loss of tolerance" (TILT), a concept put forth by immunologist Claudia Miller (1997). Others connect multiple chemical sensitivity to mast cell activation syndrome (MCAS), a rare and also understudied group of disorders that function in the body similar to allergies but present with multisystem symptoms (Akin 2017). Like with MCAS, any system of the body can be impacted by multiple chemical sensitivity, including the neurological, endocrine, and respiratory systems and symptoms can include brain fog, nausea and vomiting, laryngitis, sore throat, irritable bowel syndrome, rashes, fatigue, and/or anxiety (Coyle 2004).

So, who has multiple chemical sensitivity? Looking at the demographics of those with MCS is likely less about who suffers in this way and more about who is able to name one's suffering as MCS. Like with other contested illnesses such as fibromyalgia and chronic fatigue syndrome, getting a diagnosis from a doctor often involves years of struggle, travel, and attempts to find appropriate medical care (Barrett 2000; Dumit 2006). It costs money and time to even be able to name what is happening to the body. Once someone does have a name, this doesn't guarantee them effective treatment. In the case of multiple chemical sensitivity, the most prescribed treatment modality is simply chemical avoidance, something many people discover on their own. This being said, the demographics of MCS are also hard to pin down as the prevalence estimates vary considerably (Hempel et al. 2023). This suggests that there are differences in operationalizations of the definition and diagnostic criteria for MCS. Despite this, it is a phenomenon that has been recognized within both the United States and internationally for decades (ibid). It is also regularly reported as more prevalent in women, with estimates that sufferers are between 60 to 88% women (Zucco and Doty 2021). Researcher Anne Steinemann's work has focused on evaluating the prevalence rates and demographics of chemical and fragrance sensitivities in national populations including the United States. In a survey from 2016, she finds that 25.9% of the US population reports being "allergic or unusually sensitive to everyday chemicals like those in household cleaning products, paints, perfumes, detergents, insect spray and things like that" (Steinemann 2019a). Her work also traces how fragranced products impact asthmatics and autistic adults (Steinemann 2019b) as well as what chemicals (often undisclosed) exist in fragranced consumer products and how these contribute to indoor and outdoor air pollution (Steinemann 2009; Steinemann 2015; Steinemann 2017). Her body of

work makes the case that these exposures, often seen as quite minor, are actually a problem for many people and meaningfully contribute to ecosystem degradation.

As with other contested illnesses, multiple chemical sensitivity is primarily viewed by both medical practitioners and lay people as psychological, rather than physical, in origin (Kroll-Smith and Floyd 1997; Zucco and Doty 2021). This explanation is fiercely rejected by those with multiple chemical sensitivity who see it as pejorative. They argue that psychological or psychiatric intervention 1) does not treat their condition, 2) stigmatizes them and their experiences, and 3) reproduces historical hysteria narratives about women's bodies (Gibson 1997; Sebring 2021). The psychological explanation undermines their search for social and medical legitimacy and allows people to dismiss their broader concerns about chemical contamination. Although many doctors and lay people assume multiple chemical sensitivity is a psychological condition, it is worth noting that neither the psychological cause, the psychological disorder that would most closely align with this condition, or a psychological treatment that would treat or cure the illness has been conclusively arrived at. Further, support for the psychological explanation is often mustered through claims that people in MCS samples have high levels of depression, anxiety, and mental distress (Zucco and Doty 2021). It is debated whether these symptoms are a cause or a consequence of this disease, with some researchers arguing these psychological symptoms predate multiple chemical sensitivity and are proof of its psychological nature (Fiedler, Maccia, and Kipen 1992). The tack of these arguments brings to mind similar arguments around unhoused people; that mental illness fundamentally causes housing insecurity rather than produces it (Fischer and Breakey 1985; Padgett 2020). There are similar sociological echoes here; mental illness is used to elide any social responsibility for the production of these problems and is seen as confined to individual bodies (and brains) existing without relation to the other issues in their lives. Indeed, many of my respondents discussed their anxiety, depression, and suicidal ideation with me but without fail they saw these psychological problems as created by their forced retreat from an institutionally grounded life, social connections, and agency over the trajectory of their lives.

Contested Illnesses and Environmental Health

Like with other contested illnesses, multiple chemical sensitivity is a patchwork of contestation and legitimacy (Kempner 2014.) It has failed to gain acceptance as a clinical entity by most medical organizations such as the American Academy of Allergy, the American College of Physicians, the American College of Occupational and Environmental Medicine, the American Council on Science and Health, the American Medical Association, the Royal College of Physicians, and Royal College of Pathologists. Conversely, it has gained partial legitimacy through its recognition by a number of government agencies, including the Americans with Disabilities Act (Zucco and Doty 2021). While people are supposed to be able to receive disability payments under the ADA, my work, and that of other researchers, finds that people with chemical sensitivities have a very hard time getting disability using an MCS diagnosis. Instead, comorbidities are often used to secure disability payments by people with multiple chemical sensitivity who are unable to work.

What makes an illness contested? Contested illnesses are conditions under dispute in the medical community and for which scientific consensus has not been achieved. Though this may sound like a straightforward labeling process- experts either know a disease is real or they don't- social scientists have disambiguated the term and troubled disease boundaries through work on both contested and legitimated conditions (Mol 2003; Brown et al. 2011; Kempner 2014). Contested illnesses have the five following characteristics: 1) their statuses as legitimate illnesses are controversial; 2) their cause is ambiguous; 3) their presence is linked to other comorbid conditions; 4) their remedy or treatment remains uncertain; and 5) their medical, legal, and cultural categorizations are disputed (Swoboda 2005). Researchers have called these "illnesses you have to fight to get" (Dumit 2006) or illnesses with highly subjective components (Swoboda 2005). Phil Brown frames contested illnesses more narrowly as conditions whose existence creates scientific and public dispute over their causal relationship to environmental exposures, thus defining the phenomenon as firmly rooted in the environment (2001).

Many of these contested illnesses are also emergent. In anthropologist Joseph Dumit's work on chronic fatigue syndrome (CFS) and multiple chemical sensitivity he writes: "They are emergent illnesses in the sense that they are researched, discussed, and reported on, but no aspect of them is settled medically, legally, or popularly. They are serious, fraught conditions not only

for the persons afflicted, but also for the thousands of physicians, families, researchers, corporations, insurance, and administrative agencies having to deal with them" (2006:578). These kinds of unsettled illnesses invite skepticism, judgement, and rejection from others. They widen the pre-existing gaps in the social safety network for people with illness and disability causing more and more people to slip through. People with contested or emergent illnesses are therefore denied the sick role (Parsons 2013 [1951]) altogether and with it institutional and relational support. Dumit's work looks at how facts are mobilized by doctors and patients in situations around these emergent illnesses that ultimately are about judgements (2006).

Important to the concept of contested illness is the idea that our body of disease knowledge does not simply reflect a material reality. Avenues of scientific knowledge are not equally pursued. The knowledge that is produced is heavily reliant on what can attract funding and what is deemed socially important. Determinations of what deserves funding are highly subject to existing social hierarchies. Scientific knowledge is also contingent on prominent social ideologies. Littlejohn's work shows how commonsense ideas about bodies are deployed through clinical encounters and by medical technologies, reverberating throughout social interaction in ways that are highly gendered (Littlejohn and Kimport 2017; Littlejohn 2021). She argues this is not due to material bodily differences but rather to how gendered responsibilities (in her case those around pregnancy prevention) are socially constructed. Responsibility for pregnancy prevention is socially placed upon women's shoulders through the deployment of particular birth control technologies (Littlejohn 2021). Thus, ideologies about which bodies matter and how people should be responsible for their health are concretized by the bodies of knowledge that are developed and disseminated.

If this is what makes an illness contested, then what makes an illness legitimate? Legitimation is achieved or withheld through three different pathways: epistemological, moral, and institutional. Epistemological legitimacy is what we primarily think of when we name diseases as real and usually, though not always, relates to some known biological mechanism. This can be a clearly identified pathogen, a pharmaceutical that addresses and relieves the condition, and/or a somatic basis inferred through brain imaging. It can also be won when the economic cost of the condition to society reaches a critical mass, thus leading to the inference it must exist even without comprehensive biological findings. The moral dimension of legitimacy means that society must believe people who are sick are deserving of help (Kempner 2014). This

relates to claims made by feminist scholars that women are seen as culpable for their own illnesses through their behavior, personalities, and fundamentally unruly bodies (Hudson 2022). This marks women as less deserving of help. Feminist scholars argue this is why more women suffer from contested illnesses than men do. The third dimension of legitimacy is institutional. This refers to the devotion of attention and resources to treating the condition. In Kempner's case study of migraines, she argues migraines exist in a legitimacy deficit whereby the biological mechanisms causing migraines are underdetermined and the institutional legitimacy they receive is lacking (2014). While doctors agree migraines exist, their physical intensity and their social importance are contested. There is also a gap in how they are funded compared to their economic and social costs in productivity. Headaches are estimated to cost the economy $31 billion per year but their public funding by the National Institute of Health averages $20-25 million.

Epistemologically, multiple chemical sensitivity suffers from uncertainty, leading to its relegation as a psychological disorder. In terms of institutional legitimacy, my respondents certainly felt like there were not enough resources devoted to research from either federal institutions or universities. We also see this deficit in institutional legitimacy in terms of disability payments. While on the one hand, multiple chemical sensitivity is supposed to be a condition that entitles someone to social security disability, in practice almost all of my respondents who were on disability received it for other conditions like depression, as it was too challenging to prove their case using MCS. What about moral legitimacy and multiple chemical sensitivity? Kempner writes, "Symptoms are never just reported- they are reported from particular people, who may belong to social groups that are more or less likely to be believed. Likewise, the public perception of a disease - and its relative importance- may hinge on the stereotypes of the social group with which it is associated" (2014:12). But why aren't people with multiple chemical sensitivity believed? My respondent Nancy told me that they were an undesirable group, but I spoke with a population that was white, highly educated, and often came from professional class backgrounds. Being white and middle class is certainly a status that gets you taken seriously in most matters. Is it because the majority of sufferers are women? Is this a feminized illness? Kempner's work, which looks at the gendered politics of migraine, would certainly suggest that. Even the biomedicalization of migraine is not enough to ensure treatment and institutional gravity, as migraine remains plagued with gendered stereotypes and images. Or are people seen as undeserving because they are disabled and can no longer work? Or is it

because their illness makes political claims about our chemical dependency that remain unthinkable to most people? Is it the environmental piece of this illness that directs it away from the moral high ground?

Contestation when it comes to illness fundamentally revolves around a struggle to define reality and this struggle involves power differentials. Whose reality should be believed? Elaine Scarry writes about this tension in her book, *The Body in Pain.* "For the person in pain, so incontestably and unnegotiably present is it that 'having pain' may come to be thought of as the most vibrant example of what it is to 'have certainty,' while for the other person it is so elusive that 'hearing about pain' may exist as the primary model of what it is 'to have doubt'" (Scarry 1985). One person's experience hinges on certainty while the others' is defined by doubt. But how do these two perspectives collide? And what consequences does this have for each actor? One place these collisions occur is within institutional settings like medicine, science, and the law. But they also occur interpersonally, within interactions. Whether institutional or interactional, power is being wielded through contestations. Who gets to define the reality of what the body experiences? The person in the body or the person outside it? Patients themselves understand their experiences living with contested illness as a form of "medical gaslighting", whose power relations are especially rooted in gender imbalance (Au et al 2022; Sebring 2021). While used in primarily psychological contexts (Sweet 2019), gaslighting as a term carries more cultural and moral weight than contested does. It calls out the ability to define one's own experiences in one's body as a form of power.

While there are clear political economic incentives for not addressing the saturated nature of our chemical reality, it is hard to draw a straight causal line between the chemical industry and medical practitioners (as opposed to say, the pharmaceutical industry and opiate over prescription). In the case of multiple chemical sensitivity there are many interactional, institutional, and ideological factors at play. One such factor that other writers gesture to is gender (Gibson 1997). Contested illnesses are gendered phenomena as they are primarily reported by women, including in the case of multiple chemical sensitivity (Coyle 2004; Barker 2005). The exception that proves the rule is Gulf War Syndrome, a contested environmental illness affecting veterans of the Gulf War, who are almost all male (Brown et al 2001; Brown et al 2019). These veterans were also told that their illness was psychological and endured doubts, intensified stigma, and lack of credibility (Shriver and Waskul 2006). This suggests that all

sufferers of contested illness may be subject to gender contamination, regardless of any one individual's gender identity. Contested illnesses are explained further through the concepts of "undone science" or the "non-production of knowledge". In her work on endometriosis Hudson calls non-knowledge "the choice to accept gaps in a field of knowledge" (2022:21). About whose bodies and social identities does science see fit to accept gaps in knowledge? Scholars argue that these are predominantly conditions that impact women like endometriosis and fibromyalgia due to the moral legitimacy that women lack (Barker 2005; Kempner 2014). Contestation provides us with a conceptual link to think about how environmental injustice is gendered. There is a parallel contestation taking place between environmental health claims and conditions that primarily impact women.

Dusenbery's book, *Doing Harm: The Truth About How Bad Medicine and Lazy Science Leave Women Dismissed, Misdiagnosed, and Sick,* explores why women's health exists in such uncertain and contested terrain (2017). She reports that these issues stem from the inception of medicine as a professional practice and are made possible through dual, mutually reinforcing gaps in our medical system: the knowledge gap and the trust gap. The knowledge gap about women's bodies and systemic health experiences begins at the most basic level of biomedical studies where male cells and animals are overwhelmingly used in preclinical research. It continues upwards through the clinical research process, including which issues are even seen as researching at all. This means that conditions that primarily impact women, even those well documented as biomedically real like migraines and endometriosis, receive little scientific scrutiny. This results in doctors who simply know less about women's bodies and health experiences than that of men. This is especially ironic to consider when you realize that women are more concerned about their health and more proactively seek health care than men do (Bertakis et al. 2000). The trust gap refers to the fact that women's accounts of their bodies and of their symptoms are not believed and have for years been relegated to the psychological realm. The terms used to describe this shift - from "hysteria" to medically unexplained symptoms- but the basic idea - that women's problems are in our heads remains stubbornly pervasive in medical research, treatment, and care (Dusenbery 2017).

While multiple chemical sensitivity is an illness explicitly marked as contested, contestation is at the heart of all cases of environmental injury and harm. How much do the health claims of the environmentally injured align with known science? How can specific

pollution sources be proven to have created particular manifestations of harm? How much do environments actually affect our bodies, versus genetics or lifestyle choices? How do we disentangle those factors to discover and label the etiology of diseases? These questions hang in a political economic system that actively shifts blame away from polluters- whether corporations or the state- and onto individuals. As Brown et al. (2000) explain, "Virtually all diseases and conditions that can be attributed to environmental causes are highly contested and the source of considerable confusion, anger, and resentment. Precisely because environmental diseases are often linked to the production and consumptive practices of modern societies, acknowledging these diseases, and taking actions to reduce them is more often the result of political action than routine medical intervention" (p. 9). How much more convenient for breast cancer to be an individual matter of "preventative"[1] early screenings rather than a corporeal manifestation of pollution (Brown 2007). How much simpler for asthma to be the responsibility of mothers rather than the consequence of trucking routes (Sze 2007).

At the same time as environmental and gendered illnesses are contested, there are thousands of chemicals we regularly encounter that have not been evaluated for human or ecological safety. Therefore, we live with many known unknowns about the cumulative effects of polluting industries. Polluters are well aware of this, taking advantage of these uncertainties and the structure of current laws by clustering in the same locations. One such place is the River Parishes of Louisiana, a stretch of land by the Mississippi River nicknamed "Cancer Alley" because of the alarmingly high rates of cancer among residents. Although not explicitly remarked upon, the tradition of environmental justice scholarship and activism is to believe the health claims of the environmentally ill as rooted in pollution and counter the dominant narratives put forth by corporations and the state.

Sociology of Chemical Pollution

Synthetic industrial chemicals have proliferated in society since World War II and now saturate bodies, products, and ecosystems in novel ways (Russell 2001; Langston 2010). Everyone on

[1] Many activist scholars have pointed out that early detection is fundamentally not a preventative strategy as it detects cancer once it has already arisen in the body (citations)

earth, even newborns and people in geographically remote communities, has a chemical body burden of industrial chemical residues within themselves. How saturated in chemicals is the world? How much are we interacting with potentially hazardous chemicals in our daily lives? How does this tie into political economy? How have chemicals been socially and culturally problematized or failed to be problematized (i.e., secondhand smoke)? Concerns about chemical exposures have often merely led to the development of tiered markets rather than regulations, like with organic and conventional food. Another two-tiered market is that of scented versus fragrance free options. In this way consumers are tempted to manage their exposures at the level of the individual and the family, an unsurprising choice given the sustained role neoliberalism has played in politics and how it has conditioned our responses to social problems.

Culturally, chemical pollution and exposures are both problematized and treated as unavoidably entrenched within modern life and our economic system. They are problems that can be appropriately remedied at the level of the individual. Taken broadly, chemical pollution can be implicated in most environmental crises, from the burning of the fossil fuels causing climate change, to the disruption of nitrogen and phosphorus cycles by artificial fertilizers, to the mass deaths of pollinator species, to the poisoning of Black, brown, and poor communities around the world. Structurally, these chemicals have been induced into our lives by racial capitalism (Pulido 2016) and colonialism (Liboiron 2021). Synthetic chemicals create both ecological and corporeal rifts that threaten the world's ability to remain intact and our own health (Clark, Foster, and York 2010). Air pollution alone is linked to childhood asthma, cancer, cardiovascular disease, and other health conditions (Sze 2007; Manisalidis et al 2020; Kim 2021; Kashtan et al 2023). Additionally, the cumulative and interactional effects of toxins are understudied despite this being the reality of how our bodies are exposed to and experience chemicals. While site-specific risk assessment considers multi-chemical, multi-pathway risks, risk assessments conducted for the sake of regulating specific chemicals are conducted almost entirely in isolation (Lewis et al 2011). Even as scientists regularly uncover new information about the ways chemicals in our lives are harming our health (i.e., Kashtan et al 2023; Knox et al 2023; Smalling et al 2023), this information is resisted, contested, and unevenly applied. Not all illness and health claims are seen as validly related to chemicals or environmental hazards (Brown 2007; Cable, Shriver, and Mix 2008; Jacobson 2016) and in some instances there is strong reason to think otherwise, like with the anti-vaccination movement (Offit 2015; Reich

2016). Relatedly, chemical avoidance can be overvalued and overdetermined such as when it is work mothers perform to ensure their children's safety at an individual level (Bryson, McPhillips, and Robinson 2001; Cairns, Johnston, and MacKendrick 2013; MacKendrick 2018). This knowledge brings up empirical and normative questions: Should we as individuals be worried about chemical exposures? How much are we interacting with potentially hazardous chemicals in our daily lives? How can and should we manage our own chemical exposures? What are the right political strategies when it comes to resisting toxics and promoting good health? What kinds of expertise are accurate and trustworthy? What valid concerns might science be dismissing?

Environmental sociologists challenge the power relations governing chemical production and the contestation of environmental illness (i.e., Cable, Shriver, and Mix 2008). My work builds on this tradition, revealing the non-consensual relationship we all have to industrial chemical production by looking at a population experiencing corporeal effects from low-dose exposures. These chemicals are produced through numerous pathways: the synthesis and disposal of fossil fuels, creation of commodities with embedded chemicals, generation of waste from commodity production, application of pesticides and fertilizers in agricultural production and the spritzing of aerosol products used in home and personal care routines. Industrial chemicals enter our bodies through inhalation, ingestion and/or dermal contact. These chemicals are comprised mainly of synthetic organic[2] chemicals (SOCs), a class that includes petrochemicals, and volatile organic chemicals (VOCs), which break down faster than SOCs and are emitted as gases (US Environmental Protection Agency 2022). Heavy metals and nanoplastics[3] are often referenced alongside chemical pollution as they have similar body-environment relationships. The term "chemical body burden" now exists to capture how all humans have hundreds of chemicals residing within our bodies including pesticides, bisphenol A (BPA), phthalates, and brominated flame retardants (MacKendrick 2014). Some of these chemical compounds are proven neurotoxins, carcinogens, endocrine disruptors, and asthma exacerbators (Sze 2007; Dodson et al 2012; Chiang et al 2017; Rashtian 2019). Most others have

[2] This means carbon-based, not that they are naturally occurring

[3] Technically a petrochemical, making plastics a specific form of synthetic organic chemicals

never undergone rigorous testing or regulation and therefore pose unknown health and environmental effects (MacKendrick 2018). Some of these chemicals are eventually excreted while others bioaccumulate in fatty tissue (ibid). While health impacts of chemicals are now being routinely scientifically discovered, when people attribute health conditions to environmental exposures they are regularly challenged in their claims-making by medical professionals, the state, and corporate actors (Brown 2007; Cable, Shriver, and Mix 2008). Sociologists argue that by contesting environmental illnesses, the state, workplaces, and chemical corporations effectively deny monetary compensation as well as social and health services to the environmentally ill.

Chemical pollution is a legacy issue in environmental sociology, which emerged as a disciplinary subfield in part due to the environmental justice (EJ) movement. The EJ movement is renowned for organizing around issues of chemical pollution, although contextualizing EJ historically to the onset of settler colonialism challenges the narrative that EJ was born in response to chemical harms (Gilio-Whitaker 2019). More recent EJ work widens the scope of the field by considering other unevenly distributed environmental arrays like green space (Gould and Lewis 2017), police violence (Pellow 2017), and relationships between humans and more-than-human nature (McGregor 2018). Therefore, while chemical pollution is not the full extent of environmental justice, it constitutes a focal point of organizing and academic work, evident in the ongoing Flint lead crisis, anti-toxics movement, and continuing concerns about water and air pollution. Note-worthy environmental justice activists and cases like Rachel Carson's work on DDT, Hazel Johnson's advocacy for clean air and water on the South Side of Chicago, and Lois Gibbs' activism at Love Canal all pointed to the dangers of acute chemical poisoning coming from unchecked polluting industries.

While most sociology on chemical pollution focuses on environmental justice cases, work is being added on the dangers posed by consumer products, food, and indoor environments (Adamkiewicz et al 2011; Cordner 2016; MacKendrick 2018). As industrial chemical production soars, consumer awareness also grows regarding the dangers posed by these chemicals (Szasz 2007; Cordner 2016; MacKendrick 2018). Embedded in products and buildings, these industrial chemicals are normalized in their production, consumption, and disposal processes. They are not furtively buried beneath schools or targeted for disposal in racialized, low-income communities as in environmental justice cases. Instead, these synthetic organic chemicals saturate all our lives

and are embedded in the very products and spaces we use to care for ourselves, our families, and our homes; beauty and personal care products, fresh produce, canned foods, domestic cleaning products, and medical facilities. Even health promoting behaviors like flossing are linked to higher chemical body burdens depending on the brand used, with Oral B-Glide dental floss associated with higher exposures to per- and polyfluoroalkyl substances (PFAS) (Boronow et al 2019). Our chemical body burdens are driven by the extremely profitable role that chemicals play in our economy in both war and peacetimes (Russell 2001). Pervasive chemical pollution is a hallmark of modernity and of our continued quest for control over nature (Beck 1986). Aware of the scientific evidence gathering around the health impacts of chemicals (i.e., cancer, endocrine disruption, neurological harm, impairment of metabolic and thyroid function), civilians attempt to curtail the risks chemicals pose to their bodies and the bodies of their children through changes in consumption. These consumer protection strategies are termed "precautionary consumption" (MacKendrick 2018) and "inverted quarantine" (Szasz 2007). Both concepts highlight the ways collective risks are promoted in society as having individual level solutions. Szasz argues that by focusing on their own exposures people create an "inverted quarantine" around themselves whereby they attempt to live in an uncontaminated bubble within a polluted world. He argues such strategies lead to political apathy, what he calls "political anesthesia", as consumers become convinced that they can successfully protect themselves from hazards through consumption alone.

Precautionary consumption is related to inverted quarantine but is a slightly separate phenomenon. The idea of the "precautionary principle" states products should be proven safe by industry before they are released rather than proven harmful after the fact. This framework has not been legally enshrined by the United States government. In light of state inaction, consumers are left to manage exposures themselves, conducting an analogous behavior to the precautionary principle at the level of the individual. This is seen in how individuals define environmental hazards, respond to them, and try to control their exposure to them. This largely takes the form of non-toxic shopping and food preparation, labor that, along with the related management of family health, is still primarily women's responsibility. Thus, motherhood inflects ubiquitous chemical exposure with a sharply gendered edge (MacKendrick 2018).

Prior research on individual responses focuses on the element of cognitive risk assessment that undergirds consumption choices as people try to produce the nebulous condition

known as "health" or at least stave off disease and illness[4]. This is a subtly different phenomena than the practices of those with multiple chemical sensitivity. While both experiences involve mitigating chemical risks, multiple chemical sensitivity is characterized by somatic responses to chemical exposures. Additionally, while consumers are validated for their precautionary consumption through the messages, they receive from environmental health movements and in green marketing campaigns, the chemically reactive are often discredited for their symptoms and protective behaviors by not only medical institutions but also friends and family. This is a compelling tension. Why is acting on cognitive scientific knowledge socially validated while responding to physical sensations is delegitimated? Is this an example of the social binary between rationality and emotionality, in which physical experiences are translated as emotional because they rely on subjective feelings?

Chemical sensitivities have not yet been classified as an environmental justice issue, likely because this condition does not traverse clear racial or class lines. Conversely it often affects, or at least is diagnosed in, middle class professionals more frequently (Alaimo 2010). Yet responding to chemical sensitivities goes much further than precautionary consumption or inverted quarantine strategies do. The chemically reactive claim an illness identity, attempt to marshal support, and sometimes must extensively isolate themselves from the social and material world. While rigorous consumption strategies may be one aspect of coping with this illness they are not enough. Other people permeate their chemical boundaries, causing them somatic distress, and they must navigate unfriendly built environments and medical contexts as they seek the material support that they need to function.

While chemical pollution is a material issue, how is it socially constructed and navigated within everyday life? Chemical pollution is socially constructed as an issue that people must manage as individuals in modern risk society (Beck 1986) under the ambivalent gaze of the neoliberal state (Bryson et al 2001). Ford writes that within liberal democracies the public sphere is being increasingly defined as the marketplace, narrowing public participation in politics into consumer choices (2020). Practically speaking she says that "conducting daily life and performing quotidian practices of care operates via consumer choices" (Ford 2020:5). Regardless

[4] See also vaccine scholarship: Berezin and Eads 2016; Reich 2016

of the efficacy of chemical pollution avoidance through consumer choices, people are often drawn to them as strategies of self-protection (see Cairns, Johnston, and MacKendrick 2013; MacKendrick 2018). The material ubiquity and relational nature of chemical pollution married with this tendency towards individualizing the problem creates what Ford calls a "double bind of environmental toxicity". How do those with chemical sensitivities navigate this double bind? How do they view their responsibilities towards chemical pollution and the responsibilities of others, be they individuals or institutions?

Overview of Chapters

In my first chapter I bring us into the world of chemical sensitivities by detailing the physical and emotional labor that comprises this illness experience. I tease out the emotional and physical labor of chemical avoidance to build a case that chemical sensitivity is a matter of environmental injustice. In my second chapter I trace how chemicals are constructed as present in social life, paying close attention to claims about risk and responsibility in interactions. Those with multiple chemical sensitivity reinscribe the spaces of everyday life as hazardous to their health due to the proliferation of chemicals and the chemical dependency of others. My third chapter looks at how olfaction becomes a crucial tool of chemical avoidance, one that drives new practices of embodiment. Those with chemical sensitivities then try to socialize others into these practices in a process I call embodied resocialization. My fourth chapter looks at how the spatial politics of this illness experience often involve relocation, as people seek environments that will match the needs of their bodies. My work links meso- and macro-sites of social power to the micro-dynamics of the body and everyday life, advancing the literature in environmental sociology and environmental justice in three ways. First, I show how chemical exposures are a dimension of power within relationships, making the case that health and environmental harm can be embedded within social interactions. Second, I examine how illness and disability co-exist with ongoing environmental harm, rather than in the aftermath of acute poisoning events. Third, I reverse the customary geographical considerations of environmental justice, looking at how relocation is a crucial tool in responding to pervasive contamination. It is not the geographical patterns of harm that are present in this case but the lure of geographical havens that offer the promise of wellbeing and restored health.

CHAPTER II: METHODS

When I first set off to write about Juniper and the people relocating there to avoid chemicals, I imagined I would be able to conduct an ethnography in the vein of sociologists of the family. I wanted to spend time with people inside their homes, watching how they went about their daily routines without toxic chemicals, and sometimes Wi-Fi and electricity. I wanted to go run errands with them and see how they navigated the built and social world living with this illness. I was hopeful there would be some informal community events that I could go to and socialize at. I knew I could be a vector of risk, but I planned to make myself as clean as possible, to not use scented products, to do whatever people told me to do so that we could share space together. This did not turn out to be possible. Like many other field researchers before me, my plans changed due to circumstances I could not foresee. For one, my body and belongings were seen as far too contaminated for me to be welcomed into most people's homes. I would have had to live out in Juniper for far longer, under conditions I was not prepared for to be able to be safe enough to come into space with the chemically sensitive. For another, people didn't really run that many errands. Delivery services like Amazon and pick-up services at grocery stores, instigated in large part by the COVID pandemic, have wiped out a lot of these daily routines. And lastly, I did not expect the amount of suspicion with which I was viewed. My contact (the community liaison) was so friendly and welcoming I (naively) assumed everyone would share her attitude towards me, my work, and my intentions. Unfortunately, the chemically sensitive, and particularly people living in communities like Juniper, have been covered by the media in ways that exoticize and stigmatize them. For me, a large piece of this project was learning how to work with a stigmatized population and not reproduce this stigma while still analyzing what I saw and what I think is happening in this case.

Although I did not conduct the ethnography I envisioned, my work is still ethnographically informed rather than a straightforward interview project. My learning was deeply informed by my physical presence amongst the chemically sensitive and how we navigated the chemicals on my body and belongings. Despite reading materials by multiple chemical sensitivity sufferers in preparation for my field work, many of these practices only became clear once I was in the community, visiting with people, and attempting to manage my own chemical exposures. This methodological practice is what Wacquant calls an "enactive

ethnography" (2003; 2015). Wacquant defines this as "immersive fieldwork through which the investigator acts out (elements of) the phenomenon in order to peel away the layers of its invisible properties and to test its operative mechanisms" (2015:5). According to Wacquant we are not merely creators and wielders of symbols but rather "situated corporeal creature[s]" (2015:2). I did not understand the interactive dimensions of chemical exposures in social life and our built environments until I was in the field practicing this embodiment myself.

I began this project by visiting a multiple chemical sensitive community in the Southwest I call Juniper. The Southwest is a favored place for many with multiple chemical sensitivity to relocate. People with multiple chemical sensitivity often also react to mold and the terpenes in wood and the dry desert ecosystem brings relief. As some people lose access to housing and must live out of their cars and vans, the Southwest provides areas that are warm enough to survive throughout the winter while maintaining a distance from polluted areas. People also come to the area with the hope of forming relationships with others with multiple chemical sensitivity based on shared experiences, tolerances, and proximity. I drove out in a small RV in September 2022 and spent almost a month living near the community. I stayed at an RV park nearby so I could access a power hookup, but I regularly visited community members at their houses and even camped out in my van for two nights on someone's property. I interviewed nine people who currently lived in or near Juniper and one former resident who lives elsewhere in the Southwest. I was put in touch with these residents through my key contact in the community and then through the others I spoke with there. In this process, I found that my respondents connected me to the people they thought were in a better position to be interviewed without becoming distraught. These were people with relatively greater emotional and material resources amongst their friends and acquaintances. This meant I did not interview many people in more precarious positions. For example, many of my respondents reported knowing people living out of vehicles but I only spoke to a couple people who were currently living out of their vans. One of these women had financial and emotional support from others around her and one of these women was an activist who was willing to be outspoken about her experiences with being unhoused. I also suspect I was connected to people who seemed more "normal" and who could represent environmental illness in less conspiratorial ways, itself a form of stigma management.

After this trip, I continued snowball sampling from my respondents in Juniper while I began data transcription and coding. These new interviews were conducted primarily over Zoom

but occasionally over the phone. I was then invited to attend a regional online support group over Zoom based in a mid-size Southwestern city I refer to in my work as "Desert City". While I initially planned to focus on multiple chemical sensitivity sufferers in the Southwest, because this support group now meets on Zoom due to Covid, people tap in for support from around the country. Therefore, some of my remote interviews took place with people not currently living in the Southwest, including three people in Canada. Though the Southwest remains an important symbolic and material place within the social world of multiple chemical sensitivity, the challenges, and realities of connecting to a "hidden population" (Watters and Biernacki 1989) forced me to adapt my methods in the field and to prioritize increasing my number of interviews.

In February 2023 I went on a second fieldwork trip, this time to Desert City. I spent a week there and interviewed eight people. This area is significantly more urban than Juniper, which is rural. Most of the people I interviewed here did not live particularly close to one another but rather were scattered throughout the city. As chemical sensitivity is a spectrum, people who live in Desert City are often assumed to be on the less severe end as they can tolerate an urban environment that many people with multiple chemical sensitivity are unable to withstand. However, I found my respondents in Desert City also experienced significant disruption to their health, work, relationships, and lives as a result of multiple chemical sensitivity. Overall, I conducted thirty-three interviews, participated in observation of two online support groups, and read through newsletters, websites, and online forums created by the chemically sensitive. I used testimonies I found on the subreddit r/chemicalsensitivities to confirm and add nuance to some of my most common themes (relationships and embodied resocialization in particular). Twenty-nine of my interviews were with people who are environmentally ill and four were with their family and friends. All people and places are anonymized.

I used Atlas.ti to code my interviews. Authors don't often detail coding beyond citing grounded theorists or using vague terms like "open", "inductive", or "thematic" to describe processes which can be frustrating and obfuscate the analysis process (Deterding and Waters 2021). I employed a coding method developed by Deterding and Waters (2021). This strategy involves beginning with indexing large sections of the data based on interview questions and then utilizing broad codes, rather than the line-by-line coding that grounded theorists suggest. In the third stage finer grain details are sifted through and conceptual relationships are verified. Equally useful were the insights I had while transcribing interviews, re-reading them, and

creating memos for each interview (Gerson and Damaske 2020). For every interview I memoed on the questions "What did this interview teach me? How had this interview aligned with or diverged from others?" (Fielding-Singh 2021:275). Through my process of analysis, I was able to understand the importance of social interactions for understanding multiple chemical sensitivity, the relationships chemicals created between bodies and spaces for those with multiple chemical sensitivity, and how the recruitment of others into chemical protection strategies differed from our existing theories of personal protection.

Methodological Hurdles

Three main methodological hurdles occurred in my research. The first was the issue of physical proximity which led me to change my ethnographic strategy as I discussed. The second was that privacy concerns were paramount. To address this, I use pseudonyms throughout and changed some non-essential details within data when using quotes or descriptions. A few respondents didn't want their interviews recorded and one asked to not have any direct quotes used. For those interviews I took detailed notes. The third challenge was researching a stigmatized population which I discuss in more detail below.

Researching a Stigmatized Population

In doing this research I was told many times that I should strongly consider the possibility that this illness has psychological dimensions and focus my attention on the social construction of purity and the ways people "become" chemically avoidant. Many of the people I spoke with in my daily life who weren't sociologists also seemed most interested in knowing if this illness was "real" or not, even though my data and my training cannot prove that. What I find interesting about this is the readiness with which so many people draw the line at the claims of those with MCS as being "too much", as being obviously informed by a psychological imbalance, at the implicit belief they therefore demonstrate about the safety of chemicals in the world, the knowledge that medicine has of the human body. Why are some claims about chemical harm easy to believe and some are easy to dismiss? Why are the same people who filter their tap water and buy their children organic food asking me not to take chemical sensitivity at face value? Why is it so hard for people to believe this could be real? How did we decide where these

boundaries lie? Under which circumstances are we quick to question medicine and under which circumstances are we quick to defer to science? It's odd to me, not that the claims of those with MCS may be real, but that so many people seem to find them unfathomable. My respondents are telling me they have been disabled by environmental injury and explaining to me the lengths they must go to live in the world under these circumstances, to support themselves, and to maintain relationships with others. I choose to take their disablement seriously and to use this case to consider our environmental entanglements with each other and the ways none of us are protected from potential chemical harm. I want to demonstrate how easily dismissed embodied knowledge is and the material and emotional harm that does to people even if they were to be wrong about their bodies. I want to show the ease at which environmentally based illnesses and gendered illnesses are contested and minimized, as a contemporary theorizing of ecofeminism. I want to show how neoliberalism has placed the social responsibility for health solely on the individual and how impossible these demands are to live up to (stunningly visualized in Todd Haynes' film [*Safe*]).

Here is a conversation I had with George about stigma. George had been reluctant to speak with me until he met me at a friend's house and heard reassuring things about me from his other friends. I asked him about this and the stigma their community had faced.

> Isabella: I was hoping we could start with what you were saying to me when we met at Keith's about how the experience with previous journalists and researchers that have come out here and kind of the way that they have portrayed people.
>
> George: Oh yeah, they totally abused…the people who live here…They want to sensationalize this problem whichever way they can, so they can sell a book. That's their main purpose. So, they get bizarre stories and there are a lot of stories in the Naked City. And…they are bizarre…the people that become allergic to things are yet to be determined. There are - people are allergic to strange things…they become allergic to the sun, or maybe become allergic to things that are in the air and they become allergic to I mean, there's a lot of them that, you know, food obviously. But clothing materials, fabrics can be any number of things that make people react.

In writing this project I try to hew close to the banal details of daily life, rather than focusing on the sensational details of how people make their way in the world with this illness. It is my goal here to "strange the familiar" rather than familiarize us with that which seems strange and unusual (Berger 1963). It is all too easy to exoticize people who cover their walls in aluminum foil. But to me, someone who immersed herself in the world of environmental illness, aluminum foil has become less symbolic of the conspiratorial thinking many associate it with and more representative of knowledge and economic status. Aluminum foil is a relatively cheap material

that can be used as a sealant on walls. But there are more expensive options out there, like clay paint. Clay paint looks totally "normally" when applied, as I saw on a house tour of one of my respondents. It is also very expensive. This choice though isn't only about how much money you have at your disposal but also about the underground knowledge of chemical reactivity. Because people are living with a disability that is not medically established there are little formal resources for treatment or management. Even with sympathetic doctors who tell them to practice avoidance, this avoidance labor sprawls over the totality of daily life. This is just to say, not everyone I talked to knew about clay paint. I even told one of my respondents who was worried he might have sensitized himself to aluminum that he might want to consider it if he was looking for a different product.

Throughout my research it was very important that I presented myself as someone trustworthy, who took the concerns of my respondents quite seriously (which I did). I emphasized my perspective as a feminist researcher, as someone who would and did take people's learned knowledge of the world very seriously. I also let many people that I spoke with know that my mother has fragrance sensitivities and that I saw parallels between their experiences in the world. I tried to be as forthright as possible about what sociology could and could not offer as a discipline when it came to this illness. I told people that I was not a medical researcher and could not offer them that kind of proof about the reality of their illness. As a sociologist researching an illness experience, I do have to be attendant to the multiple ways social construction is at play in this case regardless of the material reality behind it. This sociological perspective emphasizes the cultural, political, and historical aspects of phenomena thought to be exclusively natural (such as illness, disease, and disability). Conrad and Barker trace the three overarching ways in which social construction has been productively employed in the case of illness and disease (2010). First, some illnesses have particular cultural meanings. This is seen in cases of stigmatized or contested illnesses as well as disabilities. Secondly, all illness experiences are socially constructed. Individuals come to understand and live with their illnesses in particular ways that reflect the world in which they live and act. For example, Barker looks at illness identity formation in the case of fibromyalgia, another contested illness (2002). She traces how self-help literature on this condition helps individuals to organize dissimilar experiences into a unified illness identity. And third, medical knowledge is constructed,

developed, and deployed by claims makers and interested parties as Kempner makes clear in her work on migraine (2014).

Social constructionism lets us examine how social reality and knowledge is produced. In this case we can imagine that there could be people suffering in similar ways who for various reasons do not categorize these experiences as multiple chemical sensitivities. My research is based on the illness experiences of people who are able to organize their, often dissimilar, experiences into this illness identity and marshal particular forms of recourse to it (such as moving to the Southwest as Chapter 4 details). In my work I pay attention to the meaning making my respondents do around their illness experiences and how these inform what they see as solutions to their problems. The way they see these solutions themselves are deeply informed by political, historical, and cultural forces. In this case, dominant ideologies of individualism and personal responsibility for health shape their experiences profoundly and are at least in part why this experience becomes disabling. Admittedly, I am more concerned in the cultural construction of illnesses as contested and what this implies about the limits of what we are able or willing to perceive as valid knowledge of the world than I am in how MCS is coalesced into a meaning illness category by the sufferers themselves. Especially in a case that is seen as environmental origin and intimately connected to chemical pollution I think it is dangerous to dismiss the material concerns that these sufferers raise.

In doing this work I still feel uncomfortably caught between two worlds - the world of the academy and the world of the chemically sensitive; the world of the people who suffer and the world of the people who have been deemed worthy and righteous to make sense of that suffering. There is an inherent discomfort to abstracting people's lived experiences of the world, especially when these experiences are painful, fraught, and contested by so many[5]. It is my hope that this project reveals the unseen burdens that many are forced to carry and can help us to deepen our empathy towards others' experiences even if they do not match our own. I also hope to add to the disability scholarship that makes visible the invisible work of illness and disability and as a result renders these practices "culturally legible" (Grue 2024:87).

[5] Thanks here are due to Shannan Lenke; our conversations inspired this piece of my reflection

CHAPTER III: “LIVING IN THE SOUP”: CHEMICAL AVOIDANCE, EMOTIONS, AND EVERYDAY LIFE

In my interviews with the chemically sensitive, I always asked people to tell me about how they avoid chemicals. I wanted to understand what differentiates the experience and labor of multiple chemical sensitivity from the chemical avoidance that many consumers practice. Healthy consumers are practicing chemical avoidance as well, through non-toxic shopping but also by avoiding thinking about or noticing the ways that toxics permeate all features of modern life. Instead, they take back control by weaving “contingent boundaries” around themselves (MacKendrick and Stevens 2016). Understanding this, and communicating it to other environmental sociologists, will help us see gaps in how we have socially problematized chemicals and how they are structurally and interactionally induced into our lives. I wanted to know if individual management of multiple chemical sensitivity was possible. The conditions of multiple chemical sensitivity changes people's ways of relating to the world (Alaimo 2010), the body (Kroll-Smith and Floyd 1997), and other people (Gibson 2010; Gibson et al 2011). It shows us another way that problems that are social, but also environmental, impact our relationships with others. It also makes visible the vast amounts of labor displaced onto individuals as they struggle to manage a condition for which the world is not prepared and has not prepared them. Can a person really carve out a space in the world away from chemicals? How would this work? What would they have to give up and leave behind? How would this impact their social life and relationships with non-chemically reactive people?

The impacts of this labor were particularly clear on both a practical and emotional level in my interview with Danielle. Over a Zoom interview, Danielle explained how she does laundry every morning in her bathroom sink because she has so few clothes left that she can tolerate. She told me that after all the rewarding intellectual labor she did in her former job it was sad how much energy she has to put into finding a shirt that she can wear. This is a process of trial and error that involves researching companies, tracking her reactions, and losing money when she buys things she ultimately cannot wear. It requires her to subject her body to products that may ultimately make her sicker. What struck me most in this interview was how frustrating and

depressing it is to live with the feeling that your talents, abilities, and energy are being wasted on something as banal as buying a new shirt. This is a task the non-chemically reactive take for granted as achievable. Everyone I spoke to with multiple chemical sensitivity exhausts a tremendous amount of mental, physical, and emotional labor on simple tasks that go largely unnoticed in the lives of the non-chemically reactive.

This labor is an example of what Daniels calls "invisible work", the work that disappears from view but is essential to the social construction of daily life and the maintenance and development of institutions (1987). The imposition of a social burden through invisible work perpetuates inequality for disabled and ill people, similarly to how gendered invisible work perpetuates gender inequality (Grue 2024). Grue writes,

> To use the domains of work and labour as tools for understanding the efforts associated with illness and disability is… an act that both stresses their ongoing and ultimately unresolvable nature, and one that illuminates the way in which these efforts are structured by the neoliberal economy. This operation develops both a political-economic and a cultural analysis. To speak of the invisible work of illness and disability is both to point out the literal requirements made of disabled people and to reconceive their experiences—to make them, in Snyder and Mitchell's terms, culturally legible (2024:87)

Scholars of disability urge us to detail embodied invisible work (Pritlove et al 2019) in order to counter the deeply embedded but inaccurate cognitive metaphors wherein illness and disability is equivalent to passivity (i.e., "wheelchair bound").

In our interview Myles told me that "coping with multiple chemical sensitivity is like a full-time job" and detailed at length the many surprising ways in which chemical concerns permeate his world and make it difficult for him to find enjoyment in daily life. He can't surf because he is worried about tracking sunscreen-soaked sand into his car. He can't meet up with his long-distance girlfriend at a hotel without having to seriously modify the hotel room, a process that takes most of a day. The toll chemical pollution takes on his life goes beyond physical health ramifications. Chemicals make an already complicated, stratified, and varied consumer landscape even more fraught with complexity. They intensify the already strict requirements around domestic labor and health practices (Bryson et al 2001; Sze 2007). And they permeate social relationships and interactions in ways that demand increased emotional labor from people living with chemical reactivity. The emotional labor done by the chemically reactive is a manifestation of the power wielded in personal relationships and the way that

structural problems infiltrate our relationships with others. Emotion work is thus done to mitigate power imbalances and attempt to create a shared reality within these relationships.

In this chapter I explore the work of multiple chemical sensitivity. This work includes chemical avoidance strategies, domestic labor, and emotion work with family, friends, as well as organizational actors like doctors and salesclerks. While many scholars address the work of managing and treating chronic illness, known as "illness work", in the literature (Corbin and Strauss 1985), the bulk of illness work for multiple chemical sensitivity is chemical avoidance. Chemical avoidance is part practical strategy, part emotional navigation of interpersonal relationships, part drastically increased domestic labor, and part the creative seeking of new ways to be in the world in order to withstand the emotional and physical aspects of this illness. Although alternative treatments exist and some people find sympathetic doctors, my respondents all expressed to me that avoidance is central to their illness work. Other scholars confirm this writing, "with neither medical treatment nor accommodation, chemical avoidance remains the only survival mechanism for persons who become ill/disabled from these exposures and reportedly helps over 94% of persons with sensitivities" (Gibson, Elms, and Ruding 2003). While chemical avoidance certainly helped my respondents have fewer symptoms and reactions, very few people I spoke to felt that this reduced their reactivity over the long run.

Chemical Avoidance and Personal Protection Strategies

Chemical avoidance is not solely the purview of those with multiple chemical sensitivity. Under risk society even people who aren't chemically reactive work to keep chemicals out of their bodies as they are cognitively aware of the health risks they pose. Beck explains how the risk society is organized around the deliberate introduction of hazards created by industrial production technologies in order to achieve modernity (1986). Central to these hazards are synthetic organic chemicals known to cause adverse health effects. Individuals must therefore work to first assess and then protect themselves from ongoing conditions of risk such as chemical exposures. MacKendrick's work details how consumers navigate their everyday chemical exposures from food and consumer products (2014; 2018). These everyday exposures are the ambient material conditions of chemical pollution. MacKendrick explains how chemical avoidance adds additional contours to the work of domestic labor and how, like with domestic

labor generally, this work is predominantly done by women within the family. In fact, pregnancy is usually the time in which consumers become aware of and concerned about widespread chemical pollution and exposures. She finds that consumers practice a form of "precautionary consumption" named in reference to the precautionary principle, a form of environmental legislative orientation that has not been enshrined within U.S. law. Under the precautionary principle, the onus would be on corporations to prove chemicals were safe before they could be released into the air, water, or consumer products. Without robust legislation like this, consumers are instead left to calculate risks from untested chemicals and protect themselves through the market. In their work on exposure experiences Altman et al refer to this as the "consumption fallacy" (2008). Even research participants who have been tested and told of their chemical body burdens adhere to this, asserting physical and symbolic boundaries between themselves and chemical risks. These scholars label this a fallacy because it supposes that consumer choice is limitless when in reality there are finite ways in which consumers can "shop their way to safety" (Szasz 2007) and products are frequently unlabeled, unregulated, or prohibitively expensive. Within the family, this consumer labor is predominantly done by women working to protect their children from the risks of chemical harm (MacKendrick 2018). This unequally gendered labor is created and reinforced by public health authorities (Bryson et al 2001; Kukla 2010; Mansfield 2012) and consumer advocacy groups (Scott, Haw, and Lee 2017).

The work of precautionary consumption is done almost exclusively in response to future health risks like cancer and reproductive health problems and not in response to immediate embodied impacts from chemical exposure (hence why it is "precautionary"). In the data MacKendrick uses in her book, only one of her respondents talks about feeling better physically after implementing a precautionary consumption routine. This is quite unlike how chemical risks permeate the lives of those with multiple chemical sensitivity. Those with multiple chemical sensitivity have a different temporal frame of engagement with chemicals. They know that being exposed to low doses of the chemicals in everyday life can cause immediate, physical reactions. Harm is not a future event, but rather ongoing. The labor the chemically reactive undertake is also more extensive, permeating all arenas of daily life. While mothers that practice precautionary consumption conduct significant food work and buy personal care products that are free of particular toxins, those with multiple chemical sensitivity must also fortify their homes against chemicals, seek accommodations at work, and navigate the chemical usage of

others. Additionally, while consumers get their information on chemical exposures from environmental health organizations like the Environmental Working Group, people with multiple chemical sensitivity come to know chemicals as harmful through the reactions of their bodies. Kroll-Smith and Floyd detail this "practical epistemology" in their work on multiple chemical sensitivity (1997). This practical epistemology involves using senses and embodied experiences to theorize and bring into existence a "new body" of transcorporeality that is in constant, dialectical relationship to its environment and the bodies of others (Alaimo 2010).

Domestic Labor

Feminists both inside and outside the academy assert that unpaid labor is as legitimately a form of work as paid labor and equally important to understanding and analyzing political economy (Waring 1999; Bhattacharya 2017), gender inequality (Hochschild 1989; Lachance-Grzela and Bouchard 2010), and the social organization of relationships. Feminist scholars have teased out how household labor is cognitive and emotional as well as physical and shown that women in heterosexual families bear a disproportionate burden of all aspects of these tasks, serving as captains of households and doing the bulk of routine tasks (Hochschild 1989; Daminger 2019; Ciciolla and Luthar 2019). While men's contributions to household labor have increased over time, the division of unpaid labor has proved a sticking point for gender equality especially in heterosexual couples with children. Studying unpaid household labor thus has clearly significant sociological insights into gender inequality. However, does household labor only take on sociological significance when it takes place within the family unit? How can we sociologically understand the labor that takes place by individuals who aren't embedded in families, especially families with young children? Theorists of social reproduction theory offer one avenue, arguing that unpaid labor has a significant relationship to capitalism for all workers. All workers are compelled to labor daily to reproduce themselves as workers, but what about people who don't work- who have been out of the workplace by illness or disability? What does their domestic labor "count for" (Waring 1999) and mean? What does it tell us about relationships between individual experience, social structure, ideology, power, and inequality? Feminist scholars argue that these forms of unpaid labor are not simply natural parts of life, nor are they universally conducted. Rather this labor mediates relationships with institutional and economic structures

and unveils much about the ways inequality enters our daily lives. It is where the unpaid work that sustains capitalism is captured. If looking at domestic labor within the family shows the patterns of gender inequality that persistently structure our lives, what institutional and interactional patterns does the domestic labor of the chemically reactive reveal? It unveils ideologies of personal responsibility for health and the ability of medical and state institutions to totally write off some people's concerns and not provide them with adequate redress for what is happening in their bodies.

Fortifying the Home

Fortifying the home against chemicals is imperative to creating a safe space and protecting oneself from toxins. Finding a safe home that doesn't induce sickness is believed to be the most important need for people with multiple chemical sensitivity. This was a significant challenge for all but one of my respondents, is discussed thoroughly in online spaces, and was frequently mentioned in my interviews as what people need the most from the state, beyond medical care or more stringent chemical regulations. Home is the central space in our lives, known as the “first place” (Oldenburg 1989) within sociology. This makes the home pivotal to ontological security, “the confidence most human beings have in the continuity of their self-identity and in the constancy of the surrounding social and material environments of action” (Giddens 1990:92). Loss of the home as a safe space is one of the most devastating impacts of this illness and a factor in suiciding. At least two cases in Canada have been reported where chemically reactive women were able to achieve medical assistance in dying (MAiD) for multiple chemical sensitivity (Alberga 2022; Favaro 2022). Fundamental to these cases was the inability of both women to find a safe place to live. Samantha also shared with me how her inability to tolerate her home led her to multiple suicide attempts. Coyle’s work on environmental illness finds that her respondents create a materially safe space to “stabilize corporeal chaos” (2004:71), through both body-centered and environment-centered techniques. Environment-centered techniques focus on making the home impermeable, improving the air quality within it and prohibiting guests who might contaminate their spaces. Coyle argues that,

> Any space that is to be conceived as safe for environmentally ill women should not merely be free of chemicals but provide a sense of emotional buffering, characteristic of therapeutic landscapes (Gesler 1990, 1993). Namely, it should be communicative. Whilst not all women explored these

> interconnections, as I stated earlier, many respondents testify to stressful rebuffs from family, friends and colleagues at work. As Jacqueline asserts, emotional stress increases the reactivity of her body, changing her brain chemistry and magnifying the physical reaction she experiences. Consequently, any safe space has to be one of trust, confidence and cooperation, in order for environmentally ill women to openly communicate their experiences (2004:69).

Coyle draws our attention here to the emotional contours of "safe space". My respondents didn't draw attention to these intersections the way hers do, but they did make it clear the emotional toll that multiple chemical sensitivity takes on them and the emotion work they must do to maintain relationships with others.

The built structure of the home can cause reactions that must be mitigated. These reactions come from paints and carpets, which off-gas volatile organic compounds, residual chemicals left by former residents like insecticides, and wood cabinets which contain terpenes. In Evans' memoir of his quest to build a healthy home he talks about the difficulties of finding or building a safe home. There isn't a set standard for what an "environmentally safe" home is. Since multiple chemical sensitivity exists on a spectrum, and people have different exposure triggers, a house that makes one person feel better may pose a risk to someone else (Evans 2019). Kelly told me about getting sicker in a supposedly healthy home:

> [The landlady] had said, "Oh, I healed in that house. And so have other people. And this will be good for you." And then I called her. I'm like, "You know, there are leaks in the sliding glass door. There's mold growing. And will you please address this?" And eventually, she said, "Oh, yeah, my builder just didn't do a good job. And I've had several leaks." Oh, really? So, this is a healthy house. So, you know, and another thing I think of is, how can you have a brain injury, be sick and manage having a house built? You just can't, you're really...someday, I hope that there will be full on construction companies where they know what materials to use, they know how to build it. So, you don't have the water intrusion or the excessive - use no VOC materials and such.

Kelly points out how difficult it is to do complex cognitive labor while ill. This quote makes it seem like the landlady may have knowingly put Kelly at risk, since she admitted to knowing about the leaks and it is well known within the environmentally ill world that mold is a health hazard. However, even well-built homes may be incompatible for someone with multiple chemical sensitivity. Evans estimates he has visited 50 different healthy homes and only believes he could live in a handful of them (2019). Because of this, whenever possible, people with multiple chemical sensitivity rent homes for a very short timeframe in order to test them out. Chemically safe houses are more expensive than normal housing because they must be built from scratch or significantly retrofit and there is a small market for them. They are also a risk to build because there is no guarantee someone with multiple chemical sensitivity will be able to tolerate

them, as we saw with Kelly's experience. Sometimes these homes are built and then sit empty, their specialty modifications making them unappealing to healthy people and their standards insufficient for someone with multiple chemical sensitivity to tolerate. If the windows are left open and they are aired out long enough (think years), they may eventually off-gas enough to become proper housing for the chemically sensitive (Evans 2019).

Not everyone can afford a house designed to be chemically safe or lives in a place where they are a part of the housing stock. These people must modify their existing home or rental to the best of their abilities and budget or keep moving to new properties hoping they find a better fit. Some people with multiple chemical sensitivity are so impacted by existing paints that they coat their walls with aluminum foil or repaint them with very expensive clay paints. Ceramic tiles are the preferred flooring material. Another issue of the home is the close proximity of others. What neighbors and building custodians do to their own spaces or to communal spaces can enter a chemically reactive individual's home and compromise their safe space, like using scented laundry products or applying herbicides and pesticides. While buying a house can be a huge improvement in comfort, a great deal of work goes into making even these homes livable for those with multiple chemical sensitivity and cannot totally protect against the choices of neighbors or nearby developers. In Juniper, many of the rural homes are owned by those with multiple chemical sensitivity, mitigating some of the common issues with neighbors. However, the people living there are well aware of their ultimate vulnerability. They don't have zoning protections, so businesses could theoretically move into the area, and they are at the mercy of some farming neighbors to keep choosing to grow organically and without pesticides.

If the home cannot be fortified, then people are forced to sleep in their cars, with family or friends (though it is rare to tolerate their homes), or outside. Kelly talked to me about the trauma of having to leave her home to go sleep in her car, "When I realized I wasn't tolerating my apartment in Tulsa and having to- [go sleep in her car]. I mean that was very traumatic for me. And the first night that I slept in my car, you know, just think about that, being away from your comfortable home". For Kelly, as with other unhoused people, being forced to sleep outside or in a car was a traumatic experience. It represented a complete rending of the life she had known, the comfort, stability, and ontological security she had been able to count on up to this point. We will see more about this erosion of comfort and identity in the next section on forced

minimalism. Similarly, Keith and Martin were both driven out of their homes and onto their porches or into the local woods. Keith said,

> I bought a house, and I didn't really tolerate the house. So, I spent two years, basically living on my porch. There on a cot. So, I was really almost desperate to just live indoors again, you know, not being a camper. I wasn't enjoying that very much. I mean, literally, I was up in the mountains in North Georgia, sleeping on a porch kind of like this with a rifle next to me, because there are a lot of black bears in the area. Just in case.

Martin also had stories like this of sleeping outside and being disturbed by coyotes or seeing scorpions around his cot. For men living outside, nature was the dominant threat but for women sleeping in their cars or on rural lands, nature was not the issue, men were. Matilde described to me her experiences traveling to different remote parts of the Southwest during the winter in her van. She often camps on Bureau of Land Management public lands, which offer free campgrounds known as "dispersed camping" (BLM website). These areas are a popular place of retreat for people with multiple chemical sensitivity but also for people "running" from other things. At one site in Utah the first thing she was asked was, "What are you running from?". She went on, "My answer was 'well the environment'. And they would tell me, they're running from this and that and I'm like, oh my god, this is the Wild West." She explained further that many of the people were running from the law or were freshly out of jail and couldn't find employment. Then she said:

> And the biggest thing isn't just jailbirds but people in general, guys. Oh, my goodness, there was one. I needed help with my van. They said they'd help. It's the most remote area you could possibly think of. And they said, basically… I'd have to take everything out of my van. Put a tarp over it and if they deemed my vehicle unsafe, I have to sleep in one of their vehicles. Are you kidding me? So, I made sure that I kept, I did not put my back to them. Because I did not know what they were up to. And I joked around and pretended I was fine. Never went back.

As a woman living out of her van, Matilde was vulnerable to violence from men. Kelly deals with this by bringing a gun with her car camping but Matilde didn't have a weapon, a partner, or a dog (all things recommended to her by fellow campers for safety reasons). As many women do, she attempted to manage her emotions and the emotions of the men in the situation (Schwalbe et al 2000). She controlled her emotional display- "pretended I was fine"- and used humor to get the men in a good mood and not seem perturbed by the situation. It's also noticeable how little the men seemed to care about *her* emotional experiences. Whether this was a deliberate way to subtly threaten her and assert power over her, or whether these men just didn't need to think about the way their actions would make her feel (demanding she sleep in one of their vehicles), it

was an assertion of power, nonetheless. The situations that the chemically reactive are backed into demand these sorts of emotional performances as they navigate chemical avoidance in social life and through relationships with others.

One of the last questions I asked when conducting interviews was "what do you think the government could do for people with multiple chemical sensitivity?" The need for housing was mentioned at least as many times, if not more, than the need for regulations on chemicals or better health care. As Nancy, a Juniper resident, put it, "We need housing. We need housing. Terrible bad. Not all of it here. And it's, it's wonderful to have this neighborhood. And then it's lasted us for 30 years. That's amazing. It might not last forever. I know that somebody could move in next door with a laundry product problem and drag us off? In which case we're going to have to sell our stuff and try to buy yurts or something. I don't know what they have. Because we could get run out here real easily." As many people expressed to me there is a desperate need for housing that is safe for people with multiple chemical sensitivity. There have been two state funded projects through the Department of Housing and Urban Development (HUD) to provide low-income chemical free housing, one in Arizona and one in the Bay Area called Ecology House. These have had mixed success. On the one hand, they demonstrate that with enough activist pressure, it is possible to get the government to build chemically safe housing. On the other hand, they contribute very minimally to the housing supply and some respondents felt like Ecology House in particular was not actually chemically safe. This was in part due to bureaucratic restrictions by HUD that mandate access to bus lines and therefore prevented the property from being in a preferred location that was more rural and prevented as much community chemical exposures from things like car exhaust or nearby auto body shops. Even the collective agency of environmental health activists who got this safe housing built is entangled with limitations.

Forced Minimalism: Getting Rid of Belongings

Environmentalist critiques of consumption make it easy to dismiss the role possession play in our lives (i.e., Elgin and Mitchell 1977). Our possessions, however, do have power. They connect us with our families and personal histories through heirlooms and mementos, help us craft our identities (Stillerman 2015), and shelter us in comfort and certainty. While choosing minimalism

can be a powerful way to underscore the toll capitalism is taking on the earth and push back against dominant social norms around consumption, being forced to live a minimalist lifestyle can be degrading. Many journalists and cultural commentators have pointed out the aesthetic similarities between poverty and minimalist culture, noting the irony that while people in poverty have minimalism thrust upon them, the aesthetics of minimalism have become an indicator of extreme wealth. Likewise, many gurus of minimalism are fleeing what they see as a high-figured but spiritually empty past and stringently avoid making critiques of capitalist production preferring an individual approach (Tolentino 2020). For those with multiple chemical sensitivity being forced to get rid of belongings is not an act of empowerment or a manifestation of a sustainable lifestyle, but rather a condition of their illness. Surrendering possessions means surrendering the past version of themselves and their vision for a healthy future. As Keith said to me about the years he spent camping trying to find a safe space to live with multiple chemical sensitivity,

> The biggest thing is just, I love modern life. I like the comforts of home and I had to haul all my own water and propane and we did laundry by hand for seven years…I'm really not a bohemian type person. I'm very conventional, kind of bourgeois, I guess you'd say, by nature. And that's the life I would be leading if I weren't here. So, I mean, it was cool. It was an experience, but I'm really happy just to have the comforts of home, climate control even.

As Keith shares, his lifestyle is not one that he chose voluntarily for himself. He specifically speaks to the discomfort as well as the labor that went into living a simplified lifestyle and trying to escape from consumer life. Although Keith still lives a minimalist lifestyle by many standards, he does now own a home and is able to have more creature comforts than when he was living in a van and camping. This is a qualitative improvement in his life. Nancy shared with me what it was like to have to get rid of her belongings:

> When I first realized that I wasn't going to get the capacity back to wear stuff I liked, two of my girlfriends came over and I stood outside the bedroom window, and I watched through the glass and they took all my clothes out of the closet. I had some kind of swanky stuff. And lots of it was things I bought in different countries that I really loved. Anyway, they took all the stuff and the knee high, high heeled leather boots and all my stuff that so I could be like a city person…and they'd try it on and say how's this? Trying my stuff on and then they'd carry it out of that house and take it all away. And it wasn't anything else [that] could be done but I was maintaining as much of my spoiled middle class United States person outfits as I could...And there were a couple pieces I wanted to keep really badly. They were kilims, woven pieces from the Mid-East. And some good, some good rugs that I liked…And some of the rugs I was still trying to hang on to I had rolled into what you call a coil, like a newspaper, leaning against the front door of the apartment where I was. And there were several of them out there. And I've been hanging on to them. I kept thinking well, they're ancient, they're wool. You're gonna air out. I think I can hang on to these. And it got stolen in the middle of the night. Oh, well, you know, this is answering a lot

> of questions. No, you don't get to live in that neighborhood in [Big City] in a conventional apartment and have new stuff or beloved stuff and put it on the porch to save for a few years till you maybe get better. And things like that happen so often, you know that some chord or some tie would just "click"- cut. No more to think about it. That's gone. Other stuff I hang on to. I still have dolls from when I was three. Oh, ragdolls my mom made me things like they're in a hermetically sealed box there's a lot of stuff that may not see the light of day for some time. But I love knowing that they're in there.

In this excerpt we can see how Nancy's belongings exist in a matrix of identity, history, and personal memories. Her clothes marked her as a "city person" and denoted her stylish femininity while her interior decor showed her to be someone who had traveled the world and appreciated the art of other cultures. Although she let these possessions, and this part of her identity go, and moved away from a major city to the rural Southwestern desert, she couldn't part with the dolls from her childhood that her mom made her. Our possessions can connect us to our families, our personal histories, and our memories and being forced to part with them is a sacrifice made necessary by chemical avoidance.

Forced minimalism can impact relationships as well as personal identity. Myles got sick around the time his wife was graduating medical school and embarking on a new chapter of her life.

> She resented how many things she had to give up in our space, because she'd just become a doctor. And she finally could afford all this nice stuff. And I was like, "No, we can't have any of that. And we have to spend a lot of money on raggedy looking things because just this one couch I can tolerate. And we need to trade out our gas stove for electric and all that stuff." So, at that point, I moved. I still had the idea that like, "Okay, I'll try one more place. And if that doesn't work, then we'll reassess our marriage".

The ability to indulge in aesthetic consumer objects that create comfort and denote wealth was important to Myles' wife as it is to many of us. Part of the payoff of working so hard and of sacrificing her time, money, and energy into medical school was being able to have a space that reflected her newfound status. When Myles' illness took this away from her, it led to resentment and deteriorated their relationship. They are now getting divorced, and she is claiming that he is not ill and does not need spousal support. This speaks to the power imbalance between those who are healthy, and have easier access to employment, and those who are sick or disabled. While this problem is clearly at its root a structural problem, tied to the inadequate economic distribution of resources through work alone, it is also clear how this power imbalance becomes manifested within interpersonal relationships.

The Problem of Laundry

Every person I interviewed discussed the problem of laundry with me, including friends and family members of sufferers. Laundry as an issue is multi-scalar. It exists at an individual, interactional, and environmental level. People with multiple chemical sensitivity must resolve how they do laundry, the laundry products others around them use, and navigate airborne laundry exposures. At the individual level, if the chemically sensitive person has their own washer and dryer, laundry becomes straightforward as long as they have found a detergent that works for them. Fabric softeners and dryer sheets were anathema to all the respondents I spoke with and were targeted in a great deal of online materials as well. Without personal access to a washer and dryer however, things become more complicated. People living in apartments usually wash their clothes by hand in the bathroom to avoid contaminating them with detergent residue found in apartment washing machines and laundromats. For people living out of this car or van, clothes must be washed in buckets, often using a toilet plunger to agitate the clothes, and then hung somewhere to dry. Matilde is a dual Canadian/US citizen living out of her van. She splits her time between the Southwestern United States and Canada depending on the season. It is too cold for her to safely live out of her van in Canada during the winter, but she has to live there part of the year to stay on government assistance. Here she explains her laundry routine to me:

> Matilde: I do my laundry with a plunger in a bucket because I can't use fragrance but getting water is really hard.
>
> Isabella: Okay. Yeah, that must be challenging. Do you have water? Is your van an RV or more like a minivan?
>
> Matilde: Well, it's actually- it used to be a road truck that had everything in it. I had to gut the whole thing because I couldn't handle it…And water I mean…if I'm in the desert, I'm trying to figure out where do I get water and sometimes you drive 20 miles to get water and it's not even enough to do a blanket.

In rural areas, where many with multiple chemical sensitivity retreat to, just finding water for laundry can be an endeavor. To strip away chemicals, other features of modernity must be stripped away as well. This is especially true for sufferers with few economic resources like Matilde who are struggling to survive while practicing chemical avoidance. She does not have access to running water, a van with a water tank, or the ability to participate in communal spaces like laundromats that meet the needs of other poor and working-class people. This vastly increases the amount of work she must do to complete this form of domestic labor. Water access

isn't the only issue for those living on rural land. They must be careful that their clothes don't pick up chemicals as they are line drying. Mark lives in a rural area with his wife who is severely ill. He explained to me the issues they have with a pig farm down the road:

> It's a big operation. I mean, it's an industrial pork factory. And it's changed ownership a number of times. And I think what it is, is once a week or so…they run some cleaning operation, right. And a lot of stuff gets pushed out. You know, it's an enclosed factory farm. I think what it is, and if the wind is blowing in your direction, there. It's awful. And it'll last you anywhere from, you know, 20 minutes to three hours. It's like you have to be inside, right? I once made the mistake of having laundry out on. And it's like you have to throw it out. You can't get that stench [out]. You know, I tried washing it a couple of times, and it's like, no, it just has to go.

Finding clothes that are safe and tolerable is also difficult. Danielle lives in a large apartment building and does laundry by hand every morning in her bathroom because she can't find new clothes. Hand washing new clothes releases chemicals and odors that make her sick. Danielle told me that it wasn't always this difficult for her to find fabrics she could tolerate and attributes this to either her condition advancing or industrial changes in fabric and clothing production. How can she know if this increased reactivity is due to her body changing or to widespread changes in production? The body is the beginning and the end of the line in industrial production practices, the last waste sink.

Although labeling is meant to help consumers navigate their choices, Danielle finds labeling to be of intermittent use in determining what her body will or won't react to. This is an example of how multiple chemical sensitivity displaces additional labor onto individuals. A tool constructed to help steer consumer's choices, including those around chemical exposures, fails in the face of this kind of body-material-environmental interface. Alaimo argues in her work on transcorporeality that the chemically reactive experience their bodies as scientific instruments constantly negotiating the "intra-acting material agencies of every place, every stream of air, every food and personal care product that they encounter" (2010:116). Again, this is very different from consumer chemical avoidance, where labeling is relied upon to determine purchases. While these practices also create additional gendered labor (MacKendrick 2018), this case shows us the additional labor created by a neoliberal system that mandates individual responsibility for health.

How does Danielle practically navigate these conundrums? First, she looks for country of origin on clothes, saying that she won't buy anything from China but can sometimes tolerate clothing made in Peru, Vietnam, or the United States. Things that are supposedly "pure" can still

be a problem, most cotton is terrible for her, although she actually tolerates conventional cotton better than organic. This is something she determined through the reactions of her body. Myles also told me that he doesn't have many clothes he can wear and that while he buys undyed clothing from Cottonique, not all of those items work for him. While their experiences with labeling can help them narrow down what to buy, ultimately, they must test products for themselves. This leads not only to physical reactions but also additional expenses. Matilde talked to me about her process of using both labels and her own body to select personal care products:

> Isabella: Okay, so then when you're figuring out what products you can use, a lot of it sounds like it's just using your own senses basically. It's not like oh, I know there's a certain thing on this ingredient list that I can't tolerate or that I can tolerate. How do you figure that out?
>
> Matilde: Well, well yeah, fragrance if it says the word fragrance and other than that, I can't remember and when I'm in a store, I can't think straight. So, I start smelling. Then I'm at a certain point [where] that doesn't even help because you're in the store and you're reacting to everything. It's so hard so now it's really, it's just trial and error so it's a lot of wasted money.

We know that labeling meant to help consumers navigate a complex exposure landscape already leads to more domestic labor (MacKendrick 2018), and that this domestic labor is reinforced by state public health advisories, who "do gender" by putting this burden on women within the family (Bryson et al 2001). But when labeling fails or becomes significantly less valuable, as it does in this case, this increases the domestic workload even more. It requires both mental and physical labor for the chemically reactive to decide what consumer goods to buy, and it is ultimately always a risk, even if they test the product with their senses before buying it or stick with brands that have worked in the past. There is no infrastructural apparatus that they can rely on to help them make these choices or protect their bodies.

While some readers might think this issue of toxins in clothes is niche, and even rooted in paranoia, something that the public can afford to ignore, there has been a recent spate of occupational environmental justice cases related to clothing that urges us to pay attention. This cluster of cases highlights the connections between chemicals in clothes, health issues, and contestation. Within the last 15 years, flight attendants from Alaska, American, and Delta airlines have all sued their employers after new uniforms gave them skin symptoms like rashes, open sores, and hives, as well as vomiting, migraines, shortness of breath, and hair loss (Elk 2019). While the lawsuit against the manufacturer of Delta uniforms, Land's End, has yet to be resolved, flight attendants lost their case against Alaska's manufacturer, Twin Hill (Nudson 2019). The National Institute for Occupational Safety and Health also ruled that there wasn't

enough evidence to establish a link between flight attendants' illness and their uniforms (Roeder 2018). However, jurors did side with American Airlines' flight attendants in their lawsuit (also against Twin Hill), awarding them compensation, with the caveat that the company wasn't negligent in its design of the garments nor in failing to recall them once flight attendants began to complain of ill health effects (Zilber 2023). This underscores both the safety issues within modern clothes manufacturing and the limited acknowledgment that this is a real problem capable of causing adverse health effects or that employers are culpable for exposing their workers to hazardous chemicals.

Food Work

Managing multiple chemical sensitivity also entails a great deal of food work including eating organic, testing for food sensitivities, limiting foods eaten, and retrofitting cooking spaces to avoid gas exposures. Eating organic can be difficult to accomplish when living in rural areas like the ones to which my respondents retreated. To solve this, Joy uses a national food delivery service to ensure the quality of her food:

> I use Azure Standard. It is a company out of, I think they're out of Oregon, that they ship stuff to locations…And they don't use pesticides in their trucks, they don't use, they don't eradicate anything. They have a very clean process. And they use clean foods, not necessarily all organic. But these are companies that they've researched and said, okay, they're doing it right, like Stahlbush. It's not organic, but they use organic practices on their farms. It's just not certified organic… but because they're rotating their fields and rotating their crops and replenishing the land, their food is really good. And they're not using pesticides, but they're not certified. Because that's the thing, becoming certified has gotten crazy. It's expensive.

Joy explains the issue with getting food that is safe for her in a rural area and with organics and pesticide exposures more broadly. While many consumers see a hard line between organic and conventional food, and that organics are totally free from pesticide exposures, Joy points out how this isn't always the case. Organic foods can become contaminated by pesticides as delivery trucks themselves are often sprayed. This was one of many times that people pointed out to me the hidden locations of pesticides and the ways pesticides filter into our lives despite processes like organic certifications that are meant to ensure a boundary between consumers and pesticides. Additionally, organic certification is expensive so small farms may not get certified even if they use organic practices. Foods might therefore be safe even without organic labels. Instead of relying on the organic label, she trusts the parent company Azure Standard to vet companies

according to their own guidelines. Similar to Danielle's experience with organic cottons, this is another case where consumer labeling processes are insufficient for those with multiple chemical sensitivity, and they must find alternative solutions.

Along with navigating the treatment and procurement of foods, many people explained to me how they had to pare back their diet, eating only foods they believed to be safe. Food sensitivities often coexist with chemical sensitivities. Several of my respondents were down to only around six foods that they could eat and some people were on strict rotation diets. Myles detailed his diet:

> I eat the same thing every day. And it's basically just vegetables, legumes and meat and part of that is in terms of what I need, and part of that is in terms of what my roommate reacts to. So, because of her reactions I can't have dairy or grains in the house, or any- a bunch of other things actually, I couldn't list them all. But so, it's just simpler to get only organic because I've even reacted to foods that were normally safe foods, but not organic. So, there must have been trace pesticides. So organic beans, lentils, sweet potato, fruit or vegetables, fish, beef, chicken, that sort of thing. That's basically all I have.

These kinds of diets are not unusual within the world of multiple chemical sensitivity, and mark one more instance of increased labor and decreased pleasure, joy, and opportunity.

While touring Barry's home, he spent some time showing me his kitchen area where he had encased his stove and hood with a clear material going up to the ceiling, so that none of the gas fumes would permeate his home. At the time I didn't think much of it, Barry had many modifications to his home, and this was just one of them. These modifications were extensive, involved all systems of the property, and took him years as well as paid help to complete. Barry has an excellent reputation for his knowledge around creating healthy homes and has done free consulting work for other environmentally ill people. In the moment I was busy trying to keep up with his rapid-fire delivery of technical information and the sheer number of complex changes he had made to the major system of his homes including heating, cooling, and electricity without seeming like a total idiot.

Soon after I came back from the field scientific studies emerged in the media demonstrating the connections between gas stoves, chemical exposures, and health problems like asthma. Data shows that gas burning stoves release the greenhouse gas methane, nitrogen oxide, and benzene. One study found that annual methane emissions from all gas stoves in U.S. homes have a climate impact comparable to the annual carbon dioxide emissions of half a million cars (Lebel et al 2022). Additional research demonstrates the health impacts emissions have on

human health, finding that 12% of childhood asthma is linked to gas stove usage and that stoves release the human carcinogen benzene at worrisome levels (Gruenwald et al 2022; Kashtan et al 2023). Although new science on the harms of chemical exposures is constantly being released, these particular findings triggered an unusual flurry of political activity. Regulations were proposed and debated in Congress. I started showing a video about the hazards of gas stoves made by a local environmental justice organization during my lectures on environmental health. My former partner, who buys organic produce but otherwise does not engage in precautionary consumption routines, purchased an air purifier for our home during my fieldwork and began insisting that we run the fan on our range hood on high every time we used our gas stove or oven. Despite all this activity that brought the social problematization of gas stove emissions into both the political and my personal realm, I still wasn't registering how all this connected to the visit I had with Barry. Over a year later though, gas stoves came up again in an interview with Sarah. She said, "Suddenly they'll [government agencies] come out with things like, 'Oh, gee, we suddenly realize the gas stoves are a problem.' It's like chemically sensitive people have been saying that for decades." This was an aha moment for me. I saw how a chemical exposure that chemically sensitive people had been insisting was important to pay attention to and was impacting their health, finally made its way into the public realm.

Sarah's quote demonstrates how the embodied knowledge of the chemically sensitive can be dismissed for long periods of time until a scientific study not only confirms their experiences but also is widely circulated and attracts political attention. However, even this scientific validation does not cause denialism to abate. As Myles said on this topic, "It depresses me so much because you want to believe that oh, we have to prove multiple chemical sensitivity is real and once we do people will stop using these fragrances around us and all that and like the gas stove thing is about kids with asthma and people are saying, you'll pry my gas stove out of my cold dead hands and stuff like that." Public concern and proposed regulations for gas stoves center around children with asthma and yet have still become politicized and subject to contestation and denialism, something we see in other cases of environmental health risks. If we could count on scientific knowledge and understanding to transform the world into a safer (less risky) and more compassionate place, then there would be more avenues of hope for those with multiple chemical sensitivity. New knowledge about chemical harms continues to be produced, but this knowledge becomes highly symbolic and charged with political meaning. We see this

most obviously with climate change, but even in the more contained and addressable case of gas stoves- a consumer health exposure with a totally sufficient alternative that already exists, electric stoves. Instead, Myles reflects on how depressing it is to have your concerns legitimated when no alternative is then offered.

Unlike the case of gas stove, some chemical exposures that the chemically reactive are deeply concerned about are backed with scientific evidence of harm but this knowledge has failed to not become public knowledge or to be politicized. That is, certain chemical exposures have failed to receive social problematization. This is particularly evident with laundry related exposures. Every person I spoke with discussed the perils of laundry detergent, including the out venting of dryer exhaust. Anne Steinemann has published numerous articles detailing the volatile organic compounds released in dryer expellant and its contribution to air pollution (i.e., Steinemann et al 2013; Steinemann 2015; Goodman et al 2019). And, similarly to the fumes produced by gas stoves, if you pay attention to the sensory world around you, you will notice when you encounter dryer expellant in the world. This is not a sensory experience completely invisible to the rest of the public, but it is one that hasn't been remarked upon, problematized, or otherwise meaningfully incorporated into our sensory experience of the world around us.

Travel and Transportation

Finding a safe car can be almost as challenging as finding a safe house. Myles explained what happened to him when his ex-wife took his old car back and he was left to search for another one.

> I had a mad scramble to find a car. I couldn't get anything from a dealership because they were all scented, like anything at a dealership, they would detail so I couldn't tell if it worked for me or not. And I tried calling places and saying, if you get a used car that comes in such and such model, can you please not detail it and let me check it out. And I got to check out one or two that way, but it wasn't really a good way to do it. So, I went on Facebook marketplace. And everybody I'd give the same spiel to and so often they'd be like, "Yeah, we don't use air fresheners or whatever." And they nearly all did. Which was frustrating sometimes, I got so paranoid about having to search every inch of whatever for those they had in their car. And oftentimes I'd find an air freshener. And then right after they told me they never use them. So, I eventually found, while I was doing that search, I found two people who are actually chemically sensitive to some degree. And one of them - their car works for me. So, I got that car.

Here, the car itself is not the problem but rather the widespread use of air fresheners within cars (something anyone who has taken an Uber has experienced firsthand). If consumers worry so much about chemical exposures (Szasz 2007; Altman et al 2008; Scott et al 2016; MacKendrick

2018) then why is this such a prevalent cultural practice? Using air fresheners embeds scents and chemicals into cars and buildings making their later use by people with multiple chemical sensitivity impractical and impossible. This is a micro glance at environmental futurity and the lifespans of chemical agents in the world. Though many people remain unaffected, for a slice of the population these hazards carry forward into time, delineating places and purchases as off the table if they wish to protect their health.

Other transportation methods like public buses and airplanes further restrict mobility. One woman I spoke with is campaigning in Canada to make buses fragrance free so that people with multiple chemical sensitivity can use public transportation. Many people testify about the impossibility of getting on an airplane with this condition. For the few of my respondents who did still travel by plane, they had to find ways to shield themselves against chemicals as best they could. This included masking, bringing a portable air purifier, not using the bathroom on the plane, and preparing themselves in advance with positive self-talk. Hotels and short-term rentals like AirBnb are also a barrier to travel due to their widespread use of fragrance products and toxic chemical cleaning agents. Liam told me,

> I used to travel a good bit and stay in hotels and everything. But now, everyone seems to be gone mad on fabric softener. So, every room you go into just smelled so awful to me. So that's restricted my movements as well apart from the COVID thing. I went to Japan about three years ago, and I had experiences here. I've gone to places and in Ireland as well and in France, they seem to just drench everything with fabric softener. So that smell is so awful for me, you know? Like I said, I can feel my lips burning and it's just a terrible taste. And so, as you can imagine that makes your life stressful because you don't know. It's hard enough traveling without having these terrible expectations about where you're going to try and rest and sleep

Liam's experience is interesting because he does not restrict this problem to the United States. Often, chemical hazards are framed as significantly lessened in the European Union, where they have made more use of the precautionary principle and have greater regulations than in the United States. Liam points to a countervailing truth, that fragrant products are popular globally and that there is not a safe space where the regional politics have effectively curtailed the impacts of widespread chemical and fragrance use or adequately accommodated those with multiple chemical sensitivity. To cope with this many respondents, even those with safe homes, sleep in their cars when traveling domestically so as to avoid chemical exposures from hotels or the homes of their loved ones. These restrictions on travel impact leisure, work, and the maintenance of relationships with friends and family who live in other places. They create a

mental, emotional, and physical load that must be managed to attempt to safely navigate unfamiliar places.

The Workplace

As we saw in the housing section, the built environment poses risks for those with multiple chemical sensitivity. The workplace is another built environment where we spend large swaths of our waking lives. Exposures here are harder to manage than the fleeting exposures from shopping or other forms of public indoor life. Like the home, paints and carpeting can be exposure sources, as can printers, copy machines, computers, and other common features of office life. Unlike the home where people may be able to achieve physical modifications, workers have little control over these features of the workplace or about decisions around industrial cleaning and pest management. In fact, some decisions trace back to the architects or contractors who initially designed and built the workplace. Improperly designed buildings can suffer from poor ventilation and air flow leading to sick building syndrome (Murphy 2006). This exacerbates multiple chemical sensitivity and may induce the condition in people who didn't have it to begin with. Additionally, the workplace is a social environment, requiring emotional navigation with others to maintain chemical safety. It is also a space significantly embedded with power differentials. Barry was faced with a particularly extreme case of chemical hazards in the workplace. He told me:

> They moved us in while they were still painting and finishing the building. And they were also crazy in that they were shocked at how bad the air conditioning bills were. It's in Arizona. And this is not a well-insulated building. So, they turned off the air handler's system all weekend long. When we came into work and more and Monday morning, it'd be like 94 in the office. Whole new carpeting, you know, the carpet covered toxic dividers all this crap. Crap. It's illegal in Europe, but it's okay for Americans.

Turning off the air conditioning on weekends was a cost cutting measure implemented by his company that put people's health at risk by trapping volatile organic compounds within the building alongside workers. While we think of professional offices as privileged workplaces unmarked by environmental hazards, examples like this show us that even for people without multiple chemical sensitivity, this isn't true. Everyone at Barry's office was subjected to toxic trespass and added to their chemical body burden by breathing in the chemical fumes off gassing from the carpets and freshly applied paints. Barry's comment also points to the culpability of the

state in allowing the production of such environments as he heatedly mentions that some of these office products are illegal in Europe. His anger suggests a sense of injustice at the failure of the state to protect worker and citizen health. Although Barry does not explicitly invoke the precautionary principle here, the idea that Europe has better workplace and consumer protections is a common one amongst people with multiple chemical sensitivity and the broader population of the United States.

Barry's quote, and the experiences of those with multiple chemical sensitivity within public spaces like the workplace and within their interactions with others, also demonstrates how existing sociological work on widespread chemical exposures, like inverted quarantine, precautionary consumption, environmental justice, and even toxic trespass doesn't fully capture these kinds of exposure experiences. We don't yet see how chemical exposures limit public life and enter into our relationships with other people. Although many of my respondents have retreated from public life almost entirely, not even shopping in person, much less holding a job or doing volunteer work, this "inverted quarantine" has been forced onto them by the inaccessibility of the public sphere. This realization was sparked by my own futile attempts to avoid fragrance and chemicals at my yoga studio. That is because people conceptualize themselves primarily as consumers rather than citizens, workers, or by other identity categories like gender (Trentmann 2007; Stillerman 2015), and by studying the person as consumer, broader social contexts fail to be implicated. While existing work has revealed powerfully the role that chemical avoidance plays in reproducing gender inequality within the institution of the family, it also subtly reveals how people position themselves in relation to society, tending to see themselves in relation to consumption and the family but not to broader contexts like work or public life. I don't see this as a reflection of the limitations of sociologists who are clearly making structural connections (i.e., Norah MacKendrick to gender, Phil Brown and Andrew Szasz to activism and politicization) but rather the way in which the general public lacks the sociological imagination to see or problematize chemical exposures anywhere except the private realm, the dominant sphere of consumer life.

The non-chemically reactive find it appropriate to maintain chemical boundaries within the private realm, but these boundaries dissolve once one steps out into the wider world (MacKendrick and Stevens 2016). Altman et al find that even once confronted with the futility of consumer prevention strategies through robust evidence of their own body burdens, respondents

assert symbolic boundaries, controlling their perceptions of chemical risks (2008). In one ludicrous example from this paper, a woman told the researchers that she is safe from the chemicals in hairspray because she doesn't use it on herself, her hairstylist does. People with multiple chemical sensitivity do not have the luxury of maintaining these contingent boundaries. Their bodies are the boundaries, but the body is not a boundary, it is caught up in the transmaterial flows between body and ecosystem, what Stacy Alaimo calls "transcorporeality" (2010). It is impossible for the body to shield us from the contaminants we have dumped into ecosystems, even as we do the work of cognitive displacement. Many of my respondents felt the impacts of chemicals on their bodies even without a known or perceived exposure.

Toxic trespass acknowledges these chemical transgressions (Redfield 1984; Malkan 2003). Environmental health and justice movements use biomonitoring studies to demonstrate involuntary toxic trespass is occurring by demonstrating the biophysical presence of unexpected chemicals in bodies (Shamasunder and Morello-Frosch 2016). However, while toxic trespass demonstrates chemical presences and implicates science and policy in these transgressions (Brown et al 2020), it doesn't explicate how our interactions or relationships with other people breach chemical boundaries. Detailing exposure pathways is a crucial piece of social and scientific discovery of toxic trespass. These pathways link between exposure sources to how people become exposed to environmental contaminants (Maxwell 2009). In the case of multiple chemical sensitivity, the chemically reactive redefine exposure pathways. Through their embodied experiences with chemicals they make a social discovery about relational exposure pathways. This is detailed in chapter 2.

It isn't only offices that are harmful, two of my respondents discussed the harms associated with working in schools which entailed exposure to pesticides, perfumes, and industrial grade cleaning products. George told me about how after he got sick he left his job on the stock market to become a substitute teacher. "Then I had to bail out of the job after 22 years. So here I am. What am I going to do? So, substitute teacher 100 bucks a day, cash. I went to a couple of schools. I got so sick and some of those schools I couldn't walk out of that place. It was horrible. So, I had to find out. I would call them up. I just asked them directly, 'Do you use pesticides?"" After calling around, George was able to find one school in his city that didn't use pesticides and that is where he was able to work. Beatrice was also subjected to chemical exposures in school during her time as a counselor. She told me:

> When I was still working, I remember not recalling what was making me very sick in the school. And then I found out later, the day before, the place had been sprayed with pesticide. And that was just a crazy kind of situation. Because here, you've got pregnant teenagers and babies crawling on a carpet. And the principal of the school had somebody come in and put spray inside the school. The next day my skin was itching. And I was reacting, and I didn't know what was going on. And at that point, I didn't know that they just sprayed for cockroaches.

This quote points to a few things: the chemical hazards within schools, the way her body physically reacted to a substance she didn't know was there, and the connections between her embodied experience with chemicals and the risks these chemicals pose to healthy people. Beatrice was concerned not only for herself but also for the "pregnant teenagers and babies". This concern is shaded by gender. This tracks with the way advocacy organizations and the state have placed responsibility primarily on women and mothers to prevent chemical exposures (Bryson et al 2001; Altman et al 2008; Kukla 2010; MacKendrick 2018). Her quote also echoes the exposures in Barry's workplace. Although people with multiple chemical sensitivity are the ones who "see" these exposures as existing in these spaces through their embodied reactions to them, other peoples' bodies aren't immune to their health impacts, even though we have not socially problematized these types of public exposures as sources of chemical risk. They do contribute to our chemical body burdens and are a form of "toxic trespass" (Malkan 2003; Brown et al 2020). Along with these exposures, there are interactional exposures at work. Coworkers who wear perfume and other fragranced products are hazardous to the chemically reactive. Coworkers can be resistant or outright hostile to requests to not wear perfume or cologne. This can become a huge source of interpersonal stress at work, especially in workplaces without fragrance free policies, where a framework of individual choice prevails. Trying to figure out how to approach bosses and colleagues about these concerns is a form of emotional labor undertaken by those with multiple chemical sensitivity. This emotional labor comes to the forefront of the work of multiple chemical sensitivity when we look at how people navigate getting accommodations.

Getting Accommodations

As we saw in the above quote about George's experience as a substitute teacher, getting accommodations for multiple chemical sensitivity is a process that hasn't been institutionally implemented. Instead, George had to understand his own needs (not being in a place where pesticides are applied) and track down a workplace that would be able to meet those needs. This

is a displacement of labor from institutions onto individuals. Accommodations don't only occur within the workplace. Keith spoke at length about how he got an accommodation from his neighbor:

> The biggest issue I had with my neighbor …was when he started priming the exterior of his house with Kilz brand primer. Kilz is really toxic because it contains an added fungicide. I was working on my laptop in my house, unaware that he was even going to paint, when I felt really acutely sick from something. I looked out the window and saw him starting to paint. The next day I went over and saw that he had a 5-gallon bucket of Kilz that he was planning to continue using. It could well have made me homeless if he did that, given how sick I got from him painting a small area. So, feeling rather desperate I explained that the Kilz was making me sick, and said I would buy him a bottle of low-VOC primer at my expense instead. He grumbled a little but agreed. So, I immediately ordered the safer primer from our local ACE Hardware and was able to pick it up two days later and deliver it to my neighbor. He used it and I never felt a thing from it, fortunately. That was a huge relief and [a] bullet dodged.

In this case, Keith did a lot of work to get the accommodation he needed for his health. As he explained, "I'm well aware that people are more likely to help you when needed if they like you. So, I think I benefitted in this case from making an effort from the time I moved in to get to know my neighbor and find common ground with him. And I had told him about my chemical sensitivities, so he was already aware of that. It helped that he was a good guy whom I genuinely liked. And I think because we already had a good neighborly relationship, he was willing to help me out when I needed it." The emotional labor Keith did to have a good relationship with his neighbor made it possible for him to trust that his neighbor would take his concerns seriously. Paying for the low-VOC primer himself also helped resolve this issue but is not an option for everyone with multiple chemical sensitivity, many of whom make do with small disability payments.

Social Life and Public Space: Practical Strategy and Emotional Navigation

The work of chemical avoidance for the chemically reactive occurs at another level than personal protection strategies like precautionary consumption and inverted quarantine. This is because this work infiltrates both private and public life. Gibson speaks to this in her work on environmental sensitivities and what she calls "community access", detailing the ways those who are chemically or electrically reactive can't participate in community spaces like churches, grocery stores, libraries, community meetings, parks, schools, the homes of friends and family, and doctor's

offices (2010). She pays particular attention to restricted education access, drawing from disability scholars who argue that paid work has been given too much primacy within the literature on disability and exclusion and that we should focus on realms of life less centered on economic production. I try to honor this tradition here through my focus on domestic work and emotion work. Gibson quotes Abberly who writes, "Disabled people have inhabited a cultural, political, and intellectual world from whose making they have been excluded, and in which they have been relevant only as problems" (2002:134). In this chapter I hope to draw attention to the facets of public and private life through which widespread chemical use produces exclusion. Just as important as loss of paid work, is the loss of social life and the loss of secure domestic spaces. In this framing I am also indebted to the environmental justice movement for redefining the environment as where we live, work, and play. This framework helps us see how environmental illness moves beyond the natural world and constitutes the complete surroundings of our body. We see this body-environment interaction particularly well in Alaimo's work on trans-corporeality, the continuous, interspersing fabric of the body and natural things (2010).

For the non-chemically reactive, who practice avoidance through altered consumption, contingent boundaries of avoidance and worry are established (MacKendrick and Stevens 2016). Contingent boundaries don't work for those with multiple chemical sensitivity. Their knowledge of environmental contamination is not only cognitive but embodied so they cannot construct a "mental geography" (Zerubavel 1993) of varied distinctions like consumers can (MacKendrick and Stevens 2016). However, like healthy consumers, they also experience their personal control over chemical exposures as uneven, particularly when participating in public life. This uneven control then shows up in their bodies. Like other disabled and sick people, they will sometimes push themselves past what they know is safe in order to manage stigma and participate in social life and relationships. This is a double-edged sword as these behaviors can be weaponized against them to say that they are not really sick by others who scrutinize them for any inconsistencies or signs of hypocrisy within their behavior. Matilde explained this to me in detail:

> Normally I don't go in [to stores], but I'm trying to face less ridicule. So now I've gone into their place. Well, now they say 'Well, you said you couldn't go into places'. Well, I'm like, 'Okay, I really don't normally' but I just don't know how to act. I just don't even know anymore what to do because I was trying to face less ridicule in this, by just going in and sucking it up and that actually made things worse. I don't even know what to do anymore…So I started doing the Annie Hopper brain retraining program. And I thought, 'Okay, I'll try it'. So, I walked into a store and

> they knew I couldn't go in, they made the hugest deal, like I was lying, and how did I go into the store? And I thought that- just the judgments and the loudness. And I knew people in that area, [so] I didn't want to go back in the store. So even to try and get better. And even if I do get better, how do I do that? When now people know that I couldn't go into buildings. And as soon as you start it's like, 'You're lying'…because of keeping me sick I need to at least try, you know. So, it's really, really hard.

By pushing herself to do things, people in her life have the ammunition to delegitimize her condition, telling her she has been lying, and making it potentially harder for her to get accommodations she might need. For her, one major accommodation is not having to go inside buildings. This is something she asks other people to do for her, and that many local store workers know about her. But sometimes she needs to go inside the building herself because no one is available to go into the store for her or she needs to make a product selection herself. At the time, she was also trying a popular alternative treatment mode for multiple chemical sensitivity known as dynamic neural retraining system (DNRS) and sometimes called brain retraining. This treatment modality is controversial in the world of multiple chemical sensitivity. Advocates see MCS as related to trauma in the limbic system and believe neuroplasticity can heal the limbic system so that the body becomes less reactive (Miller 2001, Hopper 2014). Doing brain retraining requires the practitioner to deliberately expose themselves to things they normally consider unsafe. However, it isn't clear to outside witnesses that this is part of a treatment modality and does not negate the underlying reality of the condition for the sufferer. Matilde asked me rhetorically how is she supposed to ever get better if she can't try to do things for herself sometimes? When she is seen doing things that are off limits to her, people interpret it as her "lying" about her limitations and illness. She also explained to me that similarly, when she acts with a positive affect, people use that to say that she isn't really sick. But when she is broken down, crying, and upset, people don't want to engage with her. This points to the existence of strict feeling rules around sickness and disability. Navigating these requires ongoing emotion management. This interactional process reinforces the denialism at the heart of dealing with multiple chemical sensitivity. The denialism, or contestation, of multiple chemical sensitivity is at the emotional core of this illness experience. Although I have detailed the complex, unending, and arduous labor those with multiple chemical sensitivity undertake, not being believed was remarked by many as being the hardest part of having this illness.

Emotion work on the part of the chemically sensitive is also necessary to maintain relationships and gain legitimacy and support. Studying interactive processes generally

illuminates how inequalities are created and reproduced (Schwalbe et al 2000). One important way this is done is through emotion management and emotional subjectivity. Work on femininity argues that it is a subcultural adaptation through which women learn to manage the emotions of men, suggesting that the management of dominants' emotions by subordinates is an important aspect of reproducing inequality (ibid). Therefore, who undertakes the bulk of emotional management, of their own and others' feelings, denotes power within the relationship. There are many interactional dimensions of living with chemically reactivity that necessitate emotion management. These include withstanding scrutiny from others about what is happening in your own body, having your embodied experiences be dismissed as psychological by the people you are closest to, and needing to explain to other people that choices they think of as deeply private have impacts on your body and wellbeing.

By comparing this case again to the more well studied personal protection strategies, we can trace different emotional contours between consumer chemical avoidance and the work of avoidance in multiple chemical sensitivity. People practicing avoidance with multiple chemical sensitivity often talk about chemical encounters as instantiations of violence in the world- referring to them as a "hit" or an "assault". For non-chemically reactive consumers, avoidance of chemicals is relatively passionless and practical. Altman et al discuss how their respondents are, for the most, not particularly alarmed at the evidence of chemicals within their bodies. "They typically reported (and we observed) a measured, pragmatic response to the information. Most participants found their results curious or puzzling, but rarely alarming" (2008:427). For the non-chemically reactive evidence of toxic trespass does not trigger embodied reactions, either symptomatic or emotional.

Part of the appeal of relocating to environmentally ill communities is the promise of a social life and relationships with people who understand the limitations of the body and the world as you do. Living in environmentally ill communities still poses challenges but can be a source of support and validation and has remarkably different emotional contours. As many people pointed out, other people with multiple chemical sensitivity won't be offended if you ask them to change their clothes or not use a product that is bothering you. They don't take requests for accommodations personally because they also need them.

"It's All in Your Head": Rewriting the Narrative

The experience of multiple chemical sensitivity involves multiple competing ideas about the body, reality, our senses, and the potential for scientific knowledge to reveal reality to us. What do sensory experiences like smells mean and indicate? What is it imaginable for the body to know and experience? Is it possible for science and medicine to completely miss the reactivity of the body to everyday chemicals? Many non-reactive people think not[6]. As a result, those with multiple chemical sensitivity are frequently disbelieved in their suffering, told their condition is purely psychological, labeled as crazy, and tested by family members and loved ones through deliberate exposures. Part of the work of multiple chemical sensitivity then is pushing back on the narrative that this condition is all in their heads. As Gabrielle told me,

> We were labeled as crazy women. But this label doesn't help us at all. It just reinforced the prejudice. Because when we get to emergencies [the emergency room], and we say that we have this, the clinicians, they read the report and they all jump on, 'I'm going to prescribe you- Do you have a mental health file? Do you have a psychiatrist?' And you say 'Oh god can I just have a nurse who doesn't wear a uniform washed with Gain? That's all I need.'

As we see here, Gabrielle must push back against the dominant narrative that chemical sensitivity is all in her head. This is one contour of the emotional experience of multiple chemical sensitivity, the fight to be believed. People must believe what they are saying, or at least be willing to act like they do through changes to their own personal behavior, in order to be safe for those with multiple chemical sensitivity to be around.

Like other contested illnesses, multiple chemical sensitivity hinges on these competing definitions of reality around the body. Being able to define reality grants power, as Sweet demonstrates in her article on the sociology of gaslighting (2019). Gaslighting is one way power operates in interpersonal relationships and it often does so along lines of gender. My work examines how power operates in interpersonal relationships along vectors of health and according to dominant ideologies of how health, the body, sensory experiences, and chemicals operate in the world. By saying something is happening in the body that medicine cannot or has not yet explained, people with multiple chemical sensitivity challenge the ontological stability of

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[6] Although they do believe in the power of chemicals to harm us and our health in other ways that are present in daily life (see MacKendrick 2018)

others in their lives. The person in the body is disbelieved as others tell them something else (or nothing) is really happening to them. Intimate relationships are central to both gaslighting as a power struggle and to contested illness as a power struggle. The scrutiny that those with chemical sensitivity face exists in other cases of disability as well as chronic and contested illnesses. People must "prove" that they are sick because they must prove they are deserving; of empathy, of care, of social support and state support, and of taking time off work.

Changing the story of what multiple chemical sensitivity is requires significant effort and strategy within relationships and more casual interactions. Joy has found a powerful way to do this telling me:

> I've just adopted the notion that I'm allergic to the 21st century. And when people say, Well, what's wrong? [I say] I'm struggling with some health issues…I'm allergic to the 21st century. Well, people will smile or laugh, typically. Because all of us, in one way or another, I believe, are allergic to the 21st century. Now, it could be that people are just tired of the rat race, or they're tired of working in a cubicle, or having the phone ring all day, which is all part of the 21st century. But for me, using that term opens a window of opportunity for understanding. And they'll say, "Oh yeah, I know what you mean. I hate being on my computer all day". And I said, "Yes, I can hardly be on it all day. I can usually stand it for about an hour." "Really? What do you mean?" It gives that window of opportunity because you have opened a door of understanding.

Joy uses humor to find common ground. She has found a clever way to explain her illness that invites people in and gives them the ability to create resonance with her, instead of situating her experiences as opposed to their own. She grew up involved in Christian ministry work, so I am not surprised that of my respondents she seemed to have some of the most sophisticated tactics for bringing people into her experience. Many people also describe their illness as an "allergy", despite believing this to be medically incorrect. They go with an explanation that other people can relate to and understand through their own bodies and experiences of the world.

Conclusion

In this chapter I document how chemical avoidance, the only known strategy for managing multiple chemical sensitivity, displaces labor onto the individual sufferer. I bring the reader into the built and social world of the chemically reactive in order to show why this avoidance work is so staggeringly difficult. This avoidance work is not merely done through changed consumption

practices, as in personal protection strategies[7], but involves an intensive remaking of physical space (the home, the car), decontamination strategies, testing products with the body, ongoing navigation of relationships to secure accommodations, and the attendant emotion work this navigation requires. In trying to avoid the toxic trespass of chemicals, the chemically sensitive confront social structure in the form of the existing organization of work, social norms that govern relationships and embodiment practices, ideologies of control over the body and nature, medical and state institutions that mete out resources and set the boundaries around what it is culturally possible to believe about the body's experiences. Ideologically, this includes dominant beliefs like that power doesn't exist in social interactions or relationships, that the natural world is controllable, and that the body is fully knowable through modern medicine.

[7]While consumers seem satisfied that they can manage the ongoing risk of chemical contamination produced by risk society through the marketplace, those with multiple chemical sensitivity unveil the magical thinking behind this approach.

CHAPTER IV : WHEN AVOIDING CHEMICALS MEANS AVOIDING OTHERS: REDEFINING TOXIC EXPOSURES AS SOCIAL PROBLEMS

> "You have the power to reduce or eliminate the disability and make the sufferer's life bearable and even productive, or you can also increase the disability, which ultimately can lead to distressing conditions such as isolation and poverty."
>
> -L'Association pour la santé environnementale du Québec / Environmental Health Association of Québec

Multiple chemical sensitivity is not only an environmental illness but is also what Kroll-Smith and Floyd call a relational illness, which they define as "the degree to which debilitating symptoms are believed to be caused in part by the personal habits and routines of people who live or work in the social circles occupied by sick people" (1997: xii). As the Environmental Health Association of Quebec explains, "This is probably one condition, where the daily management and the good state of health of the person with multiple chemical sensitivity, are strongly dependent on the choices and actions of people around them and also those that they encounter in their daily lives" (ASEQ-EHAQ 2024). These quotes highlight the importance of both strangers and loved ones in the health of those with multiple chemical sensitivities.
This way of seeing illness makes use of our sociological imaginations, revealing that our choices, experiences, and social locations are interconnected. Important to the experience of relational illness is asking other, unafflicted people to make changes to their behavior. This is due to the impact other's actions and bodies may have on the sick or at-risk person's health. In this formulation of illness, proximate others become vectors of risk. This raises important normative questions of social responsibility. What do we owe to one another's health? Where are the lines between personal autonomy and our moral obligations to others?

These questions can become politically charged as we saw during the COVID pandemic, a recent and noteworthy example of a relational illness. Although there was robust scientific evidence to support the respiratory spread of COVID and the efficacy of vaccines, masking, social distance, and getting vaccinated all took on political contours. Another health risk that has

been made relational is peanut allergies. Peanuts are now banned in many schools and airlines have proposed banning them on airplanes as well. DeSoucey and Waggoner's article on peanuts and planes analyzed comments on the matter on the Department of Transportation's website and found that commenters ideas around "fear, trust, rights, moral obligations, and liberty in the act of sharing space with others" came into conflict with each other in this context (2022:50). Their work calls for us to develop an ethic of empathy they call "responsible sociality" when we are in communal or social settings. Multiple chemical sensitivity reveals further how this ethic is often absent in social life and the social, emotional, and physical toll this takes on people with chemical sensitivities.

People with multiple chemical sensitivity redefine what is hazardous in the world, pointing out how everyday spaces and other people's bodies can cause them physical harm. In this chapter I break this down empirically into polluted spaces, contaminated bodies, and the feedback loop between the two. By redefining what is hazardous to their health, the chemically reactive make chemical exposures a social and relational issue. They then attempt to recruit other people into helping them manage these exposures. I call this redefinition "relational exposures", whereupon chemicals become seen as a form of contagion and other people become vectors of risk. I argue that because chemical exposures are relational, the chemically reactive cannot protect themselves through individual strategies alone. Their experiences fracture the myth of Western individualism; that we can go it alone. The chemically reactive need other people to acknowledge our chemical interconnectedness in order to safeguard their physical, emotional, and mental health as well as to maintain their relationships. When other people don't take up this mantle of social responsibility, this becomes the most challenging aspect of chemical avoidance and living with this illness. The choices and actions of others become associated with disbelief, denial, and even betrayal. Several of my respondents noted the pain they felt when their friends choose "their laundry products over them". In this chapter I ask the following questions: How does relational illness work in the case of multiple chemical sensitivity? What are the implications of transforming the meaning of chemicals in daily life into relational exposures? What are the interactional strategies for managing this kind of chemical contamination? In answering these questions I tease apart how these chemicals enter people's lives and how this alters their experiences of the body, space, and relationships.

This line of thinking unveils an under considered dimension of environmental injustice, one that is relational. Thinking about environmental justice in this way can make it easier for us to see illness and disability's relationship to environmental injustice. We can witness the ways in which power is embedded in our relationships with other people. Power is a crucial component to theorizing environmental injustice. By asking questions like: "How is power wielded in interactions and relationships? How does the environment mediate these experiences? How does the body mediate these experiences? What social forces keep these connections from being seen and recognized?", we can expose further instances of environmental injustice, and work towards building a more equitable world. In this chapter I draw from concepts within the sociological literature on chemicals in society (inverted quarantine, toxic trespass, precautionary consumption) as well as literature on relationships and environmental justice. I end by looking at both Covid and secondhand smoke as complementary case studies in relational exposures, to show how these abstractions bear on other parts of our lives. While multiple chemical sensitivity may seem exotic and beyond many of our daily concerns, these parallel cases make clear how relational exposures are entrenched in our lives, our public policies, and how we organize (or fail to organize) institutions and interactions around social responsibilities towards others.

Redefinitions

The chemically reactive redefine what is hazardous about chemical exposures and pollution, suggesting they are not only a matter of individual choice (as employers of precautionary consumption suggest) or of corporate and government malfeasance (as in environmental justice cases) but rather that chemicals spread between bodies and spaces making contamination an interactional issue that requires a response from others. I call this redefinition "relational exposures". Decision making that was thought to be deeply personal is revealed to have implications for others, through their bodies, health, emotions, and ability to sustain relationships and occupy certain spaces. As Joy shared with me, "This is not something that just bothers us a little. This can actually have incredibly detrimental effects on our bodies, our minds, our emotions, and it takes so much. One thirty second hit can take weeks to recover, depending upon what it was." Other people's choices around chemicals, mostly experienced through their product usage, deeply impact those with multiple chemical sensitivity and result in contestations. These

experiences transform the meaning around chemicals in everyday life into a social concept. Other people's bodies, clothes, homes, and yards become areas of contestation. This can be challenging for both those with multiple chemical sensitivity and those without the condition to navigate. Other people are seen as having responsibilities in social interactions that they often do not even know about. When these responsibilities are raised, they are often met with denial, disbelief, and push back. As Kelly explains, "Most people, they don't get it. It's like, 'Your illness is affecting me. It's taking things away from me' right?" Although some people do find support and accommodation from family, friends, or health care providers, chemicals in social life remain an ever-present issue in interactions with new health care providers, neighbors, strangers and often certain family members. Even those willing to accommodate them are often restricted in how far they can go. As Peter said in reference to his closest friends, "Everything is to a limit". Chemical avoidance is the most employed strategy of mitigating and coping with multiple chemical sensitivity, requiring sufferers to build an inverted quarantine around themselves. However, multiple chemical sensitivity shows how other people and their relationships with chemicals break these quarantines. Both the physical spaces that surround those with multiple chemical sensitivity and the bodies of other people matter for understanding and navigating chemicals as relational.

Polluted Spaces

Through multiple chemical sensitivity, spaces normally thought to be safe from toxicity like yards, homes, office buildings, and doctor's offices become suffused with pollution. While sick building syndrome, a related condition to multiple chemical sensitivity, has implicated office buildings as causing chemical harms (Murphy 2006) and yards have become indicative of chemical dangers in environmental justice cases like Love Canal (Gibbs 2010), these spaces have not been widely problematized by the Environmental Protection Agency or taken up by consumer action groups like the Environmental Working Group. In fact, the social interactions that my respondents detail show us that the general public does not see these spaces as risky or as a source of health problems. If they did then people with multiple chemical sensitivity wouldn't be constantly negotiating exposures in their relationships and public lives. For example, Matilde has been viewed with scrutiny and suspicion for opening personal care products in the store and

smelling them to see if she can tolerate the product. She has had to explain her condition to store workers and security guards so they don't think she is shoplifting. People with multiple chemical sensitivity are vulnerable in public and private spaces and therefore must find ways to maintain an inverted quarantine through chemical avoidance in both types of space. Neighbors in particular can be a problem for practicing chemical avoidance. Their choices about home and yard care might involve applying pesticides and paints, dispelling scented laundry products through dryer vents, or burning trash. A necessary condition for responsible sociality is the ability to trust "proximate others", such as neighbors. The experiences of those with multiple chemical sensitivity shows how private spaces like yards also become places to practice (or reject) this ethic of care. Public and private space both matter to those with multiple chemical sensitivity, but what is public and what is private space when chemicals transgress these boundaries? This dynamic between neighbors elucidates how yards and homes can become sites of chemical contestation. As Myles explains to me,

> It's really scary with multiple chemical sensitivity to confront neighbors because there's just so many stories of people who get resentful and then intentionally expose you to stuff. So, it's one of those things where we'd rather not bring it up. Yeah, there's been cases, I think I've heard of people, like dumping pesticides on your lawn and stuff like that, just because they think you're crazy. And they think that you're asking too personal things of them.

Myles had told me that his neighbor was burning yard waste in his ditch and that this was a problem for him. Although he finds the area he relocated to (a coastal region of the United States) to be climatically favorable for his condition, the local "culture of fire smoke" presents a health problem for him. I asked if he had ever talked to his neighbor about the burns, which is when he shared the fear he has over these kinds of interactions with neighbors. This is not an uncommon feeling amongst people with multiple chemical sensitivity and is in part why people are drawn to living in Juniper, or other areas of the Southwest. However, I saw this didn't totally eliminate these issues. Fear, as a result of vulnerability to other's use of chemicals, is one of the many emotional contours of multiple chemical sensitivity. Here too, Myles explains that certain asks are "too personal". In this case, what others do in their yards- a factor clearly related to the culture of private property in the United States. This is despite the fact that these decisions spread to others, in this case in the form of smoke, which Myles can get sick from and must attempt to manage. He and his roommate communicate when there is any kind of contamination in the area, like smoke and close all the windows. In the past, she would have also run an air

purifier but he cannot tolerate those, so this is no longer an option. Multiple chemical sensitivity is unique to the individual and everyone has slightly different reactions and triggers, adding complexity to accommodations and shared space.

Pesticides are also a commonly cited issue with neighbors. Pesticides are a noted health problem for agricultural workers (Harrison 2011) and are culturally acknowledged and problematized through the two-tiered market of organic and conventional agriculture (Cairns, Johnston, and MacKendrick 2013; Obach 2015) but pesticides exist in other spaces as well. While pesticides on food from agricultural practices remain an issue, and one that drives many with multiple chemical sensitivity to buy organic, the chemically reactive also report that the use of insecticides and rodenticides within restaurants, grocery stores and schools impacts their health. Likewise, there can be issues when neighbors use herbicides in landscaping. As Keith said about neighbors without multiple chemical sensitivity "You just never know, you get the people that love the herbicide". Although he hasn't had a problem with his current neighbors, there is more security and safety in having neighbors who also have multiple chemical sensitivity and are unlikely to use something like herbicide. Keith and I discussed his experiences with prior neighbors in a different rural area:

> The biggest issue I had with my neighbor …was when he started priming the exterior of his house with Kilz brand primer. Kilz is really toxic because it contains an added fungicide. I was working on my laptop in my house, unaware that he was even going to paint, when I felt really acutely sick from something. I looked out the window and saw him starting to paint. The next day I went over and saw that he had a 5-gallon bucket of Kilz that he was planning to continue using. It could well have made me homeless if he did that, given how sick I got from him painting a small area. So, feeling rather desperate I explained that the Kilz was making me sick, and said I would buy him a bottle of low-VOC (volatile organic compound) primer at my expense instead. He grumbled a little but agreed. So, I immediately ordered the safer primer from our local ACE Hardware, and was able to pick it up two days later and deliver it to my neighbor. He used it and I never felt a thing from it, fortunately. That was a huge relief and bullet dodged.

This marks an example of resolving a chemical contestation and shows what is possible when other people are willing to exercise responsible sociality (DeSoucey and Waggoner 2022) towards others. In this case, Keith was able to stay in his home and to avoid any health effects from his neighbor's painting. He further explained,

> I'm well aware that people are more likely to help you when needed if they like you. So, I think I benefitted in this case from making an effort from the time I moved in to get to know my neighbor and find common ground with him. And I had told him about my chemical sensitivities, so he was already aware of that. It helped that he was a good guy whom I genuinely liked. And I think because we already had a good neighborly relationship, he was willing to help me out when I needed it.

The emotional labor Keith did to have a good relationship with his neighbor made it possible for him to trust that his neighbor would take his concerns seriously. Paying for the low-VOC primer himself also helped resolve this issue but was an expense not everyone with this disabling condition may be able to afford.

Similar chemical challenges are also present with non-direct neighbors. Many respondents explained to me the issues they have walking through their neighborhoods and encountering pesticides, cars with their doors open and air fresheners inside, people wearing scented products, and laundry exhaust coming from dryer vents. This is especially frustrating as many people with multiple chemical sensitivity are homebound. They struggle being in public spaces like workplaces, libraries, and stores and they often can't tolerate the private spaces their friends and family live in. Walking is an easy way to leave the house and provides exercise which some people feel helps manage their condition, but outside environments are not always safe either. As Peter told me, "I stay away from anything outside". Isaac explains, "Living in Big City in a dense neighborhood was hard, you go walking, and you get hit by scented dryer sheets, which is probably universally the worst for all of us. And you'd have to hold your nose and kind of put your hand over your face and run back inside and stop breathing." Isaac references how the exposures from laundry products, particularly dryer sheets, spread through the air and become environmental, and therefore an issue for his health. Residential dryer expellant is a contributor to air pollution, with over 25 volatile organic compounds identified in emissions from fragrant detergents and dryer sheets most of which are unidentified on product labels (Steinemann et al 2013). This knowledge is therefore not visible to consumers, even those who want to avoid chemicals, nor is it easy to grasp how this product could be impacting others or the environment writ large, even though it is. Not only is technical information missing from products, but unlike secondhand smoke, laundry expellant has not been culturally problematized into a relational exposure, so people do not have a framework for seeing how their choice of detergent could possibly impact other people. However, Isaac recognized and felt these choices right away in his body and he had to take immediate action to prevent himself from breathing in expellant, physically covering his mouth and retreating back into his home.

Interior spaces, homes and domestic maintenance routines also become an issue when living with other people, whether they are family, roommates, or other multiple chemical

sensitivity sufferers. Melissa moved in with her parents due to her health and she explained to me a significant conflict they had, which occurred around their house.

> Melissa: For example, they wanted to stain the house this summer. Like, that is going to mess me up for a long time. And trying to find a product that wasn't like three times as expensive that I could also tolerate that would also meet what they were looking for was a challenge. And we had a lot of fights about it.
>
> Isabella: Okay. Did you find something?
>
> Melissa: Yeah, I'm not sure how well it worked but we did eventually find something
>
> Isabella: Like how well it worked on the outside of - on the house?
>
> Melissa: I think some of that had to do with a person applying it, he didn't really follow the directions, it was going to require some extra effort on his part to do it correctly and he just did it his way. So, it didn't turn out quite as well as I think it could have.
>
> Isabella: That's frustrating. And did you feel like you were impacted by the product? Or did you leave for a while? How did you deal with that?
>
> Melissa: Yeah. I went camping for a week. And when I came back to the house, I had to have the house closed up for a little while after that, it did eventually dissipate

When homes become unsafe, people become unhoused, living out of their cars or vans, couch surfing with friends or moving in with family. Keith alluded to this risk in the paint story with his neighbor. Alice also raised the specter of homelessness with me as she told me how her landlord wanted to put in a fence that she felt would be harmful to her health. She said this action is contestable through the Americans with Disabilities Act and housing laws promising the right to quiet enjoyment of property but would require legally challenging her landlord. Housing is the number one social and political issue that respondents raised, beyond even chemical regulations or bans. Housing and the search for a safe space is a driver in most moves out to the Southwest. For people living out of vehicles, the climate, and large swaths of public lands under the Bureau of Land Management make surviving and avoiding chemicals seem possible, whether or not that is actually the case.

Additionally, some of my respondents see massage therapists, acupuncturists, dentists and doctors and they have to navigate whether the benefits of medical or therapeutic services outweigh costs from the exposures they will have in those spaces, even if providers are willing to use unscented detergents on sheets and clothing and refrain from cleaning before their appointments. Kelly, who like many of my respondents has mold sensitivities as well, eventually decided the mold exposures she was getting weren't worth it to continue receiving massage work

even though she felt it was effective at detoxing from chemicals. Melissa and I had a conversation about how she manages the chemical side of this.

> Melissa: I go to a community acupuncture clinic, and she requests that everyone be fragrance free, because it bothers her too. But her clinic is right next to a hair salon. And they have a shared ventilation system. And I leave that place smelling like a hair salon. So, if it doesn't affect her that much then I know we're not really experiencing the same thing there.
>
> Isabella: That must be so frustrating because acupuncture is a healing modality that you're doing to bring relief to your body and then, but you're having to take a hit from the hair salon. So, then it's like balancing off. I guess you'd have to just balance, like if the good from the acupuncture outweighs the bad.
>
> Melissa: My strategy is- so with COVID, you know, the doctor's offices now are just filled with disinfectants. It's so gross. So, I have one set of clothes that are like my stinky clothes that I wear to acupuncture and other doctor's appointments. And then I just come home, and I immediately wash those clothes and then take a shower. And then that way, I don't have to detox the clothes every time I have an appointment.

Relational exposures from chemicals plague these public spaces. One unfortunate side effect of the COVID pandemic was how it exacerbated the chemical exposures people are up against in public spaces. New cleaning protocols were implemented, and customers were encouraged to use disinfectant wipes on carts and hand sanitizer on themselves when entering stores. This strategy for curbing COVID is not believed to be effective at mitigating the spread of this illness and has been flagged for potential occupational health issues (Wilson et al. 2023). While the bodies of the non-chemically reactive are not actually impervious to chemicals, they are able to experience these spaces as unpolluted because they don't share the same embodied response to these exposures.

Contaminated Bodies

Multiple chemical sensitivity is not just an issue of physical spaces but also of the body. Our relationships exist between our bodies, not just our abstracted selves (see Littlejohn 2021 on birth control politics for a compelling demonstration of this). This is part one of why relationships are so central to MCS. The other part is the disbelief, denialism, and contestation that arises within relationships and complicates chemical management. In this case, other people's bodies are potentially dangerous for those with multiple chemical sensitivity to be close to. If we think of our bodies as constituted by our physical forms as well as our clothes, hair, shoes, and the products we apply onto our bodies and clothes and hair and shoes, then we can see how chemicals get onto ourselves and become subjects of conflict, contestation, and

accommodation. This creates challenges with both close ties and with strangers. In this way, people with multiple chemical sensitivity redefine other people as contaminated, which is not what we've observed in other cases of chemical exposures and health.

> Myles: Yeah, it's so obnoxious at a certain point…I've gotten to the point where these smells, you know, because I don't have laundry smells or anything in my house, I am not habituated to them. And so, yeah, you'll be walking behind, a group of women or something. And then you'll smell it, but also taste it a little bit. I guess, it just feels like they're just constantly polluting the air. And it's like, this is so unnecessary. And it makes my life so much worse. Like, please.

Myles refers to the chemicals he perceives on people he is walking near, suggesting these could be the result of laundry products but possibly other things as well like perfume, lotions, or sunscreens. Not only can he smell these but he can also taste them, suggesting a more discerning sensory experience of chemicals than most people (like these hypothetical women) are having. He also transforms something that is commonly thought of as a personal and private choice into a relational exposure. Laundry detergent and other cleaning and personal care products are problematized by concerned and informed mothers and organizations like the Environmental Working Group as posing consumer risks, but they aren't widely seen as doing relational harm, as being implicated in our interactions with other people. For instance, the EWG actually has a list of safe fragrances for people to use that meet their highest standard of EWG verified (Environmental Working Group). This line of thinking takes only the individual body using the fragrance into account. It does not consider how fragrance exposures may impact social others, not only those with chemical sensitivities but also asthmatics, autistic people, and people with headache disorders, all of whom fragrances represent a health risk (Steinemann 2018; Steinemann 2019).

The implications of other people as contaminated mean that people's social lives erode because others are no longer safe to be around. This is a partial reason why multiple chemical sensitivity often tests, limits, and ends relationships, though disbelief, denialism, and the frequent relegation of people with multiple chemical sensitivity as "crazy" is another piece of this story. While relationships are impacted in other cases of disability and chronic illness (Shriver and Waskul 2006), multiple chemical sensitivity is particularly challenging because it is a relational illness that requires proximate others to change aspects of their own lifestyles and relationships with chemicals. Proximate others have to undergo accommodation processes not only in their spaces, as previously discussed, but also to their bodies.

Hannah, a friend of someone with chemical sensitivities, described this to me:

> I learned that the hard way a couple of times, I'd go over, and I had used deodorant, which had, you know, because I thought, Okay, I have nothing that has any fragrance to it. And I'd just be there. And I never went into her house, we met outside on her front patio, her front porch, so to speak. And all of a sudden, I could tell, she would reach for the breathing thing. And she started shaking. And I thought, oh my god, it's the deodorant. And so, I'd forgotten to use the fragrance free deodorant. And so, a couple of times when I would go there, and I wasn't quite sure what I had done that morning, I would just test where the wind was coming from. And then I would make sure I was downwind while we were talking, so the wind would not blow it toward her if there was anything on me at all, you know, any type of fragrance, because she was just so allergic to them. And but I learned that over the years.

Hannah was someone in a more casual relationship with a chemically reactive person. She didn't live with her friend, in fact she didn't even go inside her house. Because of this, she was able to make only temporary changes to her own routines and product usages. She just changed out the products she used before she visited her friend, although as we see sometimes she did not remember to do this. I discovered there were tensions around how much you need to do to be safe for someone with chemical sensitivities to be around. Where will you be co-existing, inside or outside? How much do you regularly use fragranced and chemical products? How severe are their sensitivities? Chemical sensitivities are highly individual and vary in severity. What affects one person (like paint or essential oils) might not bother another person.

As I learned in the field, to fully rid myself and my belongings of chemicals would basically require a withdrawal from the "healthy world" as one respondent called it. Most people with multiple chemical sensitivity do not expect that of those without the condition. Instead, they create their own routines and practices to manage these chemical transgressions, like decontaminating surfaces after people visit and keeping separate indoor and outdoor clothing sets. Some people offer visitors safe clothes and products to use. During my time in the field interviewing people, we almost always sat outside and I would be told to sit in a chair downwind of the person with multiple chemical sensitivity just as Hannah did when she visited her friend. The work of this kind of chemical management is intensive and merits its own separate consideration (see chapter 1). It is the bulk of the illness work (Corbin and Strauss 1985) of multiple chemical sensitivity, adds vastly to domestic labor, and entails strategic emotional labor to access accommodations and maintain relationships. There is an ever-present tension between recruiting other people into chemical avoidance practices, like getting them to switch to unscented products, and recognizing that people without multiple chemical sensitivity will

always remain somewhat contaminated and trying to nevertheless maintain relationships across the lines of relational exposures.

Chemical Contagions: The Movement Between Bodies and Spaces

Persistent chemical exposures make navigating public spaces difficult. Letting someone else into a chemically safe space can also be risky, as they may contaminate the space with something they have on their body or clothes. Peter explained to me how contaminated bodies can pollute spaces:

> Everything is to a limit. You know, my two closest friends, Richard and Louise, they were married… And I can see both of them a little bit. But not a lot. Richard has a thing. He loves Old Spice. His grandfather was an Old Spice guy. He's an Old Spice guy. He'll do me a favor and he won't bathe when he visits, but you know, just the residue. Sometimes I can tolerate him, for a few hours, other times not. Sometimes we'll go out to a restaurant that's not too bad because when food smells are in the air, it actually helps. Louise has got something going on with her hair. I don't know if it's a shampoo or color. Well, I don't think she colors her hair. I think it's shampoo or I don't know. But shampoos are really bad for me. So, I'll just go to her house because she's afraid to contaminate my furniture and it's like that kind of stuff. Somebody comes in, sits on my couch. It's kind of a hair raising thing...

Peter is worried about his ability to tolerate the chemicals on his friends' bodies and of this contamination spreading within his home. Whenever someone does come into his home, he has a multi-step decontamination procedure he employs to rid his furniture of any chemical transfers. If he doesn't do this he will eventually feel the impacts in his body from the chemicals that have been brought into his space. For him, multiple chemical sensitivity primarily presents as breathing problems and brain fog. In an interview with Myles, he detailed how he prevents the spread of chemicals that his body may have acquired while out in the world:

> For drugstores, I'm okay in a drugstore long enough to go and pick up my medications. But because my roommate insists that if I ever go inside, like if I leave the house and go inside somewhere else, I have to bring my outdoor clothes and then I come in and I have to change at the very least if not shower too. And so sometimes to simplify that I'll just do outside pickup of my medications.

Melissa described using the same strategy to navigate appointments where she is exposed to disinfectants and other chemicals. Their quotes show claims being made about how chemicals can be picked up on clothes and bodies through simply being in the world, inside other public or private places. This articulates a relationship between the body, space and chemicals wherein the body is vulnerable to chemicals existing in public and private spaces but also can become a conduit that moves chemicals from one place to another.

This way of thinking about chemicals conceives of a feedback loop between bodies and spaces. The body can bring personal care products or the fragrances and chemicals picked up in the world (like the car exhaust Barry told me was on my breath) into public space or into someone else's home. Conversely, being in public space can cause chemicals to enter the body, not just through completely unintentional and unobserved exposures like car exhaust but also in the ways norms of public space are often organized around chemical and fragrance heavy products. We've all encountered some version of this, like in gas station restrooms where the only hand soap available is that scented pink formula or in yoga classes that burn incense or require the use of Lysol wipes to clean shared props. Although we may know that these chemical exposures are a health risk to us, those of us without multiple chemical sensitivity don't see the ways that these exposures can get into our social interactions and cause health problems for other people. Prior work demonstrates that non-chemically reactive people are likely to draw a symbolic boundary around these exposures, keeping themselves from socially problematizing them, even if they regularly practice precautionary consumption (Altman et al 2008; MacKendrick and Stevens 2016). Those with multiple chemical sensitivity ask us to consider the chemical exchange taking place between bodies and public and private spaces. While the powerful concept of "toxic trespass" (Redfield 1984; Malkan 2003; Brown et al 2020) uses human chemical body burdens to trouble the chemicals coming into our bodies through our environments and consumer products it doesn't articulate a relationship *between* bodies themselves or frame bodies as having the potential to contaminate physical spaces. However, this is a well stated problem for those with multiple chemical sensitivity. As Whitney told me:

> Nope, nobody comes into my home unless they're toxin free. And living a toxic free life. You know, that's- my children all live that way. And also, they do detoxes before they come. Because one person in your home for a short time can totally contaminate your home. And you can react for months afterwards.

This idea was echoed in many of my interviews and in the time I spent in the field, where I was often invited to glance inside someone's home to see the accommodations they had made for chemical exposures but was very rarely invited in. Whitney's children were willing to change their own products for her, as she said, "my children all live that way", but they still had to take extra precautions before visiting her. She told me when her children come to visit:

> I ask them not to stop anywhere else before they come here because transference can happen from say if you stopped into a coffee shop or whatever. Which actually, the second example actually

> happened. My daughter was out and she was coming here. She stopped into a coffee shop and they happened to be mopping the floor. Toxic scented crap. And she came in here and it stopped my breathing. So yeah, not good.

Other people's choices and actions get a lot more complicated when this idea of transference is brought into how they navigate social life and the built environment. As Stacy Alaimo explains, sufferers of multiple chemical sensitivity experience the "transcorporeality" of the world; the constant interpolation between bodies and spaces (2010). At the same time, Whitney's children have shown a willingness to change their behavior for their mom, to forgo certain conveniences and take on additional labor for her. This brings us to my next section, on how relationships work for people with chemical sensitivities. If exposures are relational, it stands to reason that certain risks and responsibilities become implicated in relationships with others.

Relationships: Stories of Betrayal and Support

Throughout my field work, I heard many stories about how relationships are tested by this illness. The fact that this illness is contested brings in additional complexities to navigating it within relationships. Do loved ones, doctors, acquaintances, and service providers choose to believe the sufferer's account of their body? Or do they choose to accept conventional and dominant ideologies of what it is possible for the body to experience? The stories I heard reflected themes of both support and betrayal. The dominant narratives about relationships within the social world of multiple chemical sensitivity feature divorce, abandonment, and financial destitution. However, I also saw many examples of relationships that persevered or were formed within the midst of this illness experience.

Myles' story was an ideal type narrative of what happens to romantic relationships stressed by chemical sensitivities. He was in the middle of a divorce, driven by the toll his illness needs took on his relationship. Deep ruptures like these can occur in relationships. However, there are also betrayals experienced in interpersonal interactions, like when the chemically reactive are exposed to dangers by the people around them or when they are disbelieved. Myles and I spoke at length about whether the people in his life seemed to believe him and whether they supported him. He told me:

> [My wife] seemed to believe me…Although her friends and her mom definitely didn't believe me. Her mom was a nurse practitioner. And she came to visit one time and was pretty thoughtless about exposing me to fragrances and stuff. Including expecting me to drive them through wine

> country right after she put on this lavender scented lotion. And I was driving her another time. And I just heard the sound of lotion getting applied to skin. I was like, just, you know, let's get home as fast as possible. So yeah, she didn't take me seriously. My ex-wife would tell me like, "oh, yeah, I was talking to my mom again. She just keeps telling me about various ideas of what she thinks you have". And yeah, her friends said, like, "Oh, if there was something that bad wouldn't we know about it?" ... Something along those lines. Like, who's ever heard of this? Like, nobody has this, this can't be real. So, the people in her life in general, didn't believe me, with the exception of her brother, her brother had worked in a chemistry lab. And people get TILTED. And so, when she told him about it, he was like, "Oh, what was his exposure? Like, what did it?" so that was the one person in her life who believed me. And so, I don't know what she believes now. But the way she's just pretty viciously in court, trying to argue that I'm perfectly well makes me think that "Well, she's, she's done with me". "I don't want to deal with this guy." And she's arguing. She's having her lawyers argue pretty hard, that I'm perfectly healthy. But I can't know what she privately believes.

While Myles' ex-wife was clearly motivated by the context of her divorce and not wanting to have to pay him spousal support, it was clear that throughout their relationship, most of the people in her life did not believe him or take his concerns seriously. Many people expressed their hurt and frustration at the ways their family, friends, and even service providers fail to support them in their illness or to believe that it is real. Not only do those with multiple chemical sensitivity experience betrayal from their bodies but they often feel betrayed by the people in their lives who choose their products over them. As Gabrielle told me "I was angry [at] my body, I said, "What are you doing to me, you know, I feel you betray me". This points to the structural and cultural entrenchment that chemicals have in our lives, and the subsequent strain this can cause to relationships. While Gabrielle felt like her body betrayed her, many people feel betrayed by their spouses, families, and friends. To betray someone is to expose them to danger, in this case both physical and emotional harm. People feel betrayed by their bodies, their doctors, their friends. They cannot trust the apparatus of the world that they had been taught they could rely upon. When other people do not take up the mantle of social responsibility towards them, this is the part that is the hardest. It becomes associated with disbelief, denial, and a betrayal of social bonds.

While these types of experiences do happen to many living with chemical reactivity, I was also struck by the counternarratives, the ways people work to overcome the barriers posed by multiple chemical sensitivity and be in relation to those living with the condition as Whitney's children have done for her. How are people (both the chemically reactive and the non-chemically reactive) able to sustain relationships despite exposure risks? What are the limitations to intimacy that chemicals in social life create for those with multiple chemical sensitivity? Over

a Zoom call Isaac described to me the support his mother has provided him and the way she has recruited others in the family into accommodating him:

> My mom would do dinners, and we'd have people over like family thing. And once in a while, you know, sometimes it'd be someone with fragrance on, could've been laundry detergent, could have been some body lotion or something. And this would be Friday night, and it would ruin my weekend. And my mom would call me the next day, concerned "Are you okay? "And it wouldn't be until like, Sunday night, or Monday, when I'd feel myself again. And I'd just be sitting home, you know, feeling sorry for myself, like nursing this chemical hangover. And it just got to a point where you're like, "Is it worth even going out?" So, there's that. You know the social aspects are huge. And it's like, but my family was so amazing. I mean, I love them. I love all of them. They would call people and remind them don't wear this and don't wear that. And they knew who the more suspect people were, and I'd sit on the other side of the room. I still do that today.

Isaac's immediate family has tried hard to enable him to still participate in their family life. Clearly this isn't always perfect as he still gets sick after being at gatherings. However, his mom offers him emotional support, keeps reminding people about the risks and responsibilities present in their interactions with Isaac, and has steadfastly believed him and tried to influence other family members to believe in what he is experiencing. Because of this he has been able to continue to be in relation with his family and although he lives in the Southwest now he does sometimes go home to see them. While their actions can still sometimes impact his health, because they are willing to assume responsibility for his health and to try to manage their own chemical contagions, he is still able to have rich emotional bonds with people. People are able to sustain relationships when the healthy people in their lives are willing to take on physical and emotional labor as Isaac's mom has done for him. When they are willing to believe, or at least act as though they believe, the experience of the world that the chemically reactive person is having.

This idea was underscored in my interview with William and Samantha. I spoke to them together at their home in Desert City and was struck by William's steadfast devotion to his wife who has both chemical and electrical sensitivities. This has caused huge changes in their finances, their lifestyles, and their relationships with friends and family. Throughout it all he has stayed by her side. He told me, "Everybody back in those days- probably still do- they think it's 'that person's crazy.' And that's probably the most important part emotionally for someone stricken with MCS is someone to believe. And I've never doubted Samantha for one second ever saying, well, it's your imagination, [you're] psychosomatic, you're crazy." The importance of

belief was stressed to me by all my respondents. It was a non-negotiable for them when it came to maintaining relationships.

Despite others' best efforts this illness imposes limitations on intimacy. If other people don't or can't make permanent changes to their lives and routines, then many relationships are forced to take place largely outside. I spoke to people in Juniper whose families would fly out to visit them and would only be able to spend time together outside. One of my respondents met up with his long distance girlfriend at a hotel and had to spend almost their whole time together making the hotel room safer for them to spend time within. Being in these relationships demands flexibility, as intricate sets of concerns manifest with them. It is also important to act in a way that retains the chemically sensitive person's dignity. Beyond the isolation and loneliness, this illness evokes feelings of shame. It was described to me as "humiliating", "demeaning", and as a "betrayal" of the body. Scheff writes about the tensions between Western individuals and our social realities as members of relational and emotional worlds. He says:

> Individualism is the dominant theme of all relationships in Western societies. This focus ignores the web of personal and social relationships that sustain all human beings. The myth of the self-sustaining individual, in turn, reflects and generates the suppression and hiding of shame and pride. Since pride and shame, or at least their anticipation, are the predominant emotions in social interaction, suppression supports the status quo, the myth of the self-contained individual. But the obverse is that as we become aware of the massive amounts of emotion and disguising of emotion that occur in social interaction, we can make visible what is otherwise invisible, the state of any given relationship or set of relationships. (Scheff 2014:132-133)

Individualism is a dominant theme within health as well. We are expected to take full personal responsibility for our own health and well-being. This dominant ideology comes into conflict with relational illnesses. Shame occurs when you can't take full responsibility for your own health anymore, when your body can't participate in the world anymore, and when it can't do so in a way that isn't legible to other people because your illness is contested. While people do manage this illness as individuals to the best of their abilities it bumps up against these social myths that we can act as though we are not physically, emotionally, and socially entangled with one another.

The Environmental Health Association of Québec writes on their website, "You have the power to reduce or eliminate the disability and make the sufferer's life bearable and even productive, or you can also increase the disability, which ultimately can lead to distressing conditions such as isolation and poverty." The power is ultimately in proximate other's hands,

not the hands of the sufferer themselves. This framing brings up questions of justice, responsibility, and environmental inequality. When healthy people ignore their social responsibilities to the chemically sensitives, it leads to degraded living conditions and social isolation. Although a contested illness, multiple chemical sensitivities is a response to a proven environmental problem, that of chemical pollution. We can look at the issues that surround it as issues of environmental justice. Environmental injustice is about much more than the distribution of environmental hazards and risk, or even the relationships between subjugated people and structures of capitalism and settler-colonialism (Gilio-Whitaker 2019). It also concerns damaged relationships to place and more-than-human nature, the loss of sacred sites, the severing of ecological knowledge passed down through intergenerational relationships, cultural reproduction, and emotional and mental harm (Willette, Norgaard and Reed 2016). For instance, in the Karuk nation the decline of salmon and other important foods has led to families spending less time together, resulting in the transmission of less cultural knowledge (ibid). These are all crucial ways in which intimate relationships with others are essential to the production and enactment of injustice. This is a dimension of environmental justice that has been most carefully and closely considered by Indigenous scholars as well as by settler scholars doing allied work on Indigeneity and settler colonialism. However, because this hasn't been a priority in the field writ large there is much that we do not know about how environmental injustices interrupt and transform relationships or how environmental issues enter into the most private spheres of our lives: our bodies, our friendships, and our families.

We do know that health is marred by degraded environmental conditions. We know that environmental impacts on health are often contested by the state and corporate entities. We know that illnesses that are environmental in origin and illnesses that primarily affect women are underfunded, under researched, and often suffer from social de-legitimation. Looking at this case gives us insight into what happens to individuals and their relationships when they suffer from these problems. When responsibilities for health change, relationships change. When people are asked to take on different forms of environmental praxis, it can be challenging to motivate them. When people do want to stay in a relationship with those who have chemical sensitivities the emotional dimensions of this care become crucial. Healthy people are presumed to have more power. They have the power to engage in the world in conventional ways that replicate our

chemical dependency. They have the power to accommodate or not accommodate the person who is chemically at risk.

Conclusion

There is an intricacy to navigating this experience with other people that demands respect, labor, communication, trust, and a willingness to change individual practices and accept possible new realities about the world. By claiming new ways in which chemicals are implicated in physical spaces and on other people's bodies, those with multiple chemical sensitivity transform chemicals into a relational health issue. Prior work on chemicals, health, and environmental toxins rarely finds chemicals as relational objects within social interactions with others. Though chemicals are approached frequently as an environmental problem, those with multiple chemical sensitivity claim them as a social problem in which other people's personal actions bring chemicals into their lives, rather than just the activities of industrial polluters or existing omnipresent pollution (though this presents health challenges for them as well). Therefore, those with multiple chemical sensitivity reject the cultural mandate that health is a matter of total personal responsibility (Gibson 1997). They break the social norms of personal responsibility, insisting that we have obligations to each other. Whereas some illnesses, like breast cancer, undergo causal contestation that attempts to reframe them as environmental in origin rather than related to genetics or lifestyle (McCormick, Brown, and Zavestoski 2003; Klawiter 2004; Brown 2007), multiple chemical sensitivity is not only claiming to be an environmental illness but a relational illness (Kroll-Smith and Floyd 1997). This illness experience underscores the ways in which we are implicated in each other's health and wellbeing.

Multiple chemical sensitivity is a life transforming experience that prohibits many interactions with material culture and thus with other people. Though people with multiple chemical sensitivity are burdened with many traditionally environmental facets of this condition, like needing to buy organic food or coping with air pollution, the social pieces of this create deep emotional experiences around accommodations, sustaining relationships, and existing in public and private space. Through claiming that chemicals can spread interactionally, and contamination can move between bodies and spaces, those with multiple chemical sensitivity assert that chemicals are more deeply entrenched in our lives than the public realizes. They also

assert that they need other people to practice responsible sociality around chemicals in order to make the world safer for them to live in. There are other comparable cases that also revolve around conflicts between personal choice and health. These include the COVID pandemic, allergies and dietary restrictions, secondhand smoke, and sobriety and drinking in social life. Further work should explore how these other cases of relationality and health are navigated within social life and within relationships. What are the necessary conditions to be in responsible sociality with each other around these experiences and what do they have in common with one another?

CHAPTER V: DETECTING CHEMICALS: EMBODIMENT, OLFACTION, AND COLLECTIVE MEANINGS IN A SCENTED WORLD

"We can risk being wrong about the threat posed by unusual odors, but we cannot afford to remain silent"

-Melanie Kiechle (2017)

When I arrived in Juniper, the first person I met with was Nancy. She is the unofficial community liaison and was who I had reached out to about coming there and speaking with people. During our initial meeting sitting on folding chairs out in her backyard, she provided me with information about the community, the reasons some people may be hesitant to speak with me, and how I could be safe for the chemically sensitive to be around. This included how I should navigate public space. As I wrote in my field notes,

> Nancy told me that I should try to not go in stores - specifically she said if there was something I realized I forgot - a nail file was her example- I should ask if she had one before I went to a store. I asked about what to do when I needed to grocery shop. She said that I should put my hair in a braid, twist it up and cover it with a kerchief and a hat. She also asked if I had gloves I could wear in the store and told me that many people have separate "town" and home clothes. The thing is that all my clothes are "town" clothes initially. I've worn everything into stores before. I bought a new top and linen pants in San Diego but I read in some of [Pamela] Gibson's work that clothes made in Asia (as these were) are often treated with pesticides that cannot be washed out. So, these clothes may actually be my worst option. I am not sure if Nancy was advising me as a person in contact with people with MCS or as she would someone who has MCS…In reality, I have not approached going into stores precisely as Nancy recommended. I don't have a kerchief and feel extremely weird wearing latex gloves into a store. I have put my hair up and in a hat, made sure to shower before visiting people (including rinsing my hair), and divided up my clothes by what I have washed in vinegar or baking soda and what I haven't. Another thing I have done is opt for pick up/take out in most cases.

At the time I wrote this, I didn't understand exactly why she was telling me to take these precautions. However, during my time out in the field I became increasingly aware of how places smelled, especially scents I attributed to chemicals, in ways I had never noticed before. The Walmart in town had a thick, plasticky odor that I worried would stick to my clothes and my hair and impact my respondents like Nancy warned me. I knew enough by then about the science

of chemicals to know this smell was likely created by hundreds of products off-gassing volatile organic compounds that were then trapped within the concrete, windowless walls of Walmart. Although the smell was familiar to me- it smelled just like Target- I'd never thought about what it was or what it might mean before. It began to seem like something potentially bad was entering my body. But why hadn't I ever noticed or thought about this scent before? It was an unfelt part of the world to me. I did not create an embodied connection between the physical sensation and my cognitive awareness of scents, nor to my learned knowledge of chemicals.

A similar experience was remarked upon by Keith in our interview. He told me that before he had gotten sick, he had visited a hardware store as part of his job duties and afterwards one of his coworkers said, "Don't you think that you just feel kind of, like contaminated or something after being in there?" And he said to her "No, I never- I don't think so. I never even thought about it, you know? But now I think about it." It wasn't until Keith got sick that he started drawing connections between this experience and his own body and health. Both having multiple chemical sensitivity and being brought into the world of multiple chemical sensitivity changes interpretive frames around scents and therefore material engagement with the world and the body. I refer to this process as "embodied resocialization". In this chapter I examine this process in greater detail.

While I was in the field, I had another discussion about managing my own contamination, this time with Barry. My body again became implicated as a source of exposure for him. He told me,

> Even you- just traveling in -your being in a car on the road, with car fumes and stuff. You would be breathing out car exhaust. It's very noticeable to someone with multiple chemical sensitivity for a couple days, two or three days. I mean, it takes that long for your body to get rid of all that. But you didn't know…when you live in the soup you don't notice.

Here, Barry is telling me I am ignorant of the extent of chemical exposures that surround me and are within me. At the same time, he is letting me off the hook for this by saying I wouldn't notice because I live "in the soup". This evokes a vivid image of swimming in a bowl of chemicals and suggests that the world is so thoroughly flooded with chemicals that we can no longer use our senses to notice when they are present. At one point I picked up some consent forms at a print shop. As soon as I arrived, I noticed a strong smell reminiscent of new carpeting wafting out the open doorway. Although I had my hair tied back (taking what Nancy had told me to heart), I immediately became concerned I might pick up the smell on my hair or clothes. I hovered

outside the door waiting for a worker to be free to help me before running briefly inside in order to avoid this chemical transfer process that I had been cautioned about.

Barry is also saying that these chemicals, like those in car exhaust, are being absorbed into my body and then expelled through my breath, in a way that is perceptible and potentially even harmful to someone with multiple chemical sensitivity. If I stopped doing certain things, like driving, my body would quickly get rid of these chemicals, and I would no longer be problematic in this space. However, to fully rid myself of these chemicals would basically require a withdrawal from the "healthy world" as Keith called it. Most people with multiple chemical sensitivity do not expect that of those without the condition. So how can people without this condition manage their own chemical contamination? How do they come to know how to do this? And how do the chemically sensitive make sense of their attempts? How do people on either side of this chemical gulf continue to navigate the world in relation to one another?

Smell makes the invisible visible. The chemically sensitive have an invisible illness that they must manage with unrecognized and unvalued labor. The exposures they problematize are themselves unseen and can only be felt through olfaction (the capacity of smelling) or physical symptoms. The chemicals those with sensitivities react to permeate everyday life. They come from car exhaust, laundry products, dryer expellant, personal care products, medicines, household cleaners, and pesticides, among many other things. These chemicals often emit odors, especially if they are fragranced products like air fresheners, perfumes, and laundry detergents. Sensory experiences of the world are therefore critical to detecting these environmental dangers for people living with this illness (Hsu 2020). While smell is the primary sense used in these detection processes, visual cues like makeup, hairstyles, and fashion choices also signal particular kinds of consumption practices and chemical usage. Although these harmful chemicals cannot always be smelled, olfaction is an important tool that can indicate the ongoing dangers that surround and enter the bodies of the chemically reactive. Olfaction is therefore crucial to the chemical avoidance practiced by those with multiple chemical sensitivity. It is a necessary, though insufficient, tool for managing this illness experience. Olfaction is also a tool that may be taught to others. The attention that we pay and the meaning-making that we do around the smells in our lives is subject to interpretation and change.

In this case chemical avoidance is not just about scientific knowledge, labeling, or consumer research. Rather it is practiced through tacit knowledge, a form of expertise that is

gained by lived experience rather than formal training (Kiechle 2017). Tacit knowledge can help us think through questions like: What can the body know? How does the body "know" things? How does tacit knowledge conflict with other ways of knowing (i.e., the scientific method)? How does it conflict with other ways of transmitting knowledge about health, chemicals, and our bodies (like labeling, the work of consumer advocacy groups, and chemical body burden studies)? I examine how this tacit knowledge is attained amongst those with chemical sensitivities, what collective meanings they make about chemical odors, and how they transmit practices to their peers through the concept of "embodied resocialization". Tacit knowledge allows us to make sense of sensory experiences that link our bodies to environmental health.

Environmental Sociology and the Body

Interestingly, while environmental sociology has a strong focus on health, it has engaged in only limited ways with theorizing the body. This may be due to tendencies within the subfield to focus on macro-level theories, leaving fewer pathways into studying embodiment and socio-nature relations. The work of Jade Sasser and Michael Mendez provide models for how to understand the way environmental degradation is an embodied experience. In Sasser's work on the discourses around so-called "overpopulation" she argues that women are pressured into "embodied environmental responsibility". This perspective - advanced by white, wealthy actors in rich nations- sees women who use contraceptives as fulfilling a social responsibility to slow population growth due to the pressures it creates on the environment (Sasser 2016). She writes that, "Discourses positioning the fertility of poor women of color (WOC) as a driver of, and solution for, climate change provide a useful tool for analyzing the way in which these bodies are always already marked as problematic and environmentally polluting" (2016:58-59). Framings of global climate change are organized around race, class, and geography and in this case, solving the problem is attached to the bodies of women, especially poor women of color (see also Sasser 2014; Sasser 2018).

Mendez's concept of "climate embodiment" emerged from his work with environmental justice activists in California who see the human body as a "site of intersection between social, political, and environmental dynamics" (2020:34). Currently, the chief objective of California's climate policy is to reduce global greenhouse gas emissions. However, local environmental

justice advocates argue climate action should also address the problems with local air quality. These problems are not solely about greenhouse gases but the other harmful substances that are co-released alongside them and harm human health. This perspective views the harms of climate change as not just global and ecological, but local and embodied (Mendez 2020). This perspective on embodiment is shared amongst those with chemical sensitivities when it comes to chemical pollution. As one person wrote on the subreddit r/ChemicalSensitivities, "Logically, if #$_& sticks to walls and items for months from exposure just once, how do you believe your body can actually effectively get rid of it easily?".

Marxist environmental sociologists have also explicitly engaged with the body through corporeal rift theory. This theory extends Marx and Engles' work on the metabolic rift, their explanation of how capitalism severs human and ecological-waste cycles and leads to environmental crisis, to the human body. Under capitalism, human bodies are seen as "free gifts" to capital in an analogous way to nature and both are expropriated. For humans, our bodies become free gifts to capital through paid, enslaved, and socially reproductive labor which ultimately undermines our bodily capacities (Foster and Clark 2018; Loustaunau et al. 2022; Betancourt 2024). While the corporeal rift often refers to actual deaths, it holds theoretical promise as applied to human reproduction[8], cultural reproduction (see Betancourt 2024), the quality of human health (see Foster 2016 on Marx as a food theorist), and even bodies in pain.

How does the human body, itself a part of nature, exist in relation to waste, pollution, and chemical accumulation? Pollution from chemicals, heavy metals, microplastics, and nanoparticles bioaccumulates in ecosystems, animals, and human bodies. The Anthropocene, often visualized through diagrams of the sedimentation of the earth's geological record, is also deposited within our own bodies. Historian Kate Brown theorizes that the human body acts as the last sink for waste as the pollution of industrial production runs off and becomes sedimented in our bodies and in our health histories (2016). She began her research on Ozersk, a closed town that was home to Russia's first plutonium plant, hoping to learn of state secrets. The people who came to see her (mostly elderly women) had other ideas. They were more interested in telling her

[8] Marxists feminists (i.e., Tithi Bhattacharya, Lise Vogel, Nancy Fraser, and Susan Ferguson) have done significant work on theorizing socially reproductive labor and its relationship to both patriarchy and capitalism but to my knowledge have not taken up corporeal rift yet, though these concepts would make sense to consider in tandem.

about their secret bodily experiences- genetic legacies, reproductive histories, and physical maladies. These were the physical manifestations of radioactive materials. She writes that, "A failure to see bodies and to use them as archival maps of exposure helps explain the emphasis on cures rather than the environmental causes of a growing number of debilitating and deadly diseases" (Brown 2016:45). This "failure to see" is explained further in Christopher Sellers work on "body blindness" within the environmental movement (1999). He explains how the strategies of the early US environmental movement that were used to win court cases blurred the links between contaminated environments and damaged human bodies. He writes,

> The environmental movement has fostered agencies and laws whose commitments, be they to 'environmental health' or to 'ecology', were defined in terms of 'biological' body-environment interactions that have remained much more constrictive than those environmentalists imagined or feared. There is a substantial difference between those environmental pathologies clearly demonstrated by the tools of contemporary toxicology and epidemiology, and the terrifying bodily experiences of those stricken with Multiple Chemical Sensitivities or exposed to environmental threats that remained not only invisible but unprovable. Just as the justice of the post-World War II liberal state entailed ideologies of color and gender blindness, so its version of environmental justice turned a deaf ear toward those more 'subjective' environmental terrors. It confined its regulatory sweep to a naturalistic human ecology that only animal studies and their human experimental equivalents were allowed to define (Sellers 1999:58)

This tangled web of the environmental movement's strategies, the legal system, the tools of toxicology and epidemiology, the narrowing of regulatory reach, and the ideologies of the liberal state, leaves no room for the "terrifying bodily experiences" of the people who have been exposed to unprovable environmental harm. These more "subjective environmental terrors" are often only validated by the embodiment and tacit knowledge of those who claim them. In the case of chemical sensitivities, it is not just their physical symptoms but olfactory experiences of the scented world that signal body-environment interactions are taking place.

Sensory Histories & Fresh Air

Smell used to be a significant piece of understanding and navigating the connections between the environment and the health of the body. Odors have been socially imbued with meanings across time, with important and ranging impacts for population health, urban planning, and environmental and medical justice. Melanie Kiechle's book, *Smell Detectives: An Olfactory History of Nineteenth-Century Urban America,* explores how a social and medical consensus was created on what smells signified during the antebellum period (2017). Olfactory experience was equated with environmental knowledge, something that remained unchanged until after the

Civil War when germ theory took over and smells were no longer seen as causing illness. During the antebellum period, sensory experiences with smells were an important component in producing both commonsense and expert knowledge on health and pollution. Foul odors and "vitiated air" were seen as the cause of illness pre-germ theory, after which they became seen as symptoms of unhealthy environments. This wasn't a completely untrue supposition. "Vitiated air," a term used particularly for air with high concentrations of carbon dioxide, identified a hazard that both smelled pungent and caused physical harm and even death.

Smells shaped urban environments in the antebellum period by encouraging urban residents to spend time in nature and to advocate for parks within the city as they sought out olfactory oases. Urban planners also incorporated concerns about olfaction and fresh air into their design choices while physician inspectors examined the air inside patients' homes, proposing health recommendations that included going on walks to get fresh air and opening windows to aid in ventilation. These were actually competing approaches to improving health and environments by the major social actors in this case. While some fought for public parks, in particular the creation of Central Park, so city dwellers could exercise in the fresh air, others homed in on ventilation within the home, believing that improving residences was of utmost importance to health promotion. In both these approaches, fresh air was thus seen as a necessary condition for good health and its promotion was important in the planning of cities, the lobbying against public nuisances like slaughterhouses, and the creation of urban parks.

Today, the chemically sensitive are reengaging with these perspectives on smell, health, and fresh air. Multiple chemical sensitivity is a part of the ongoing history of "fresh air". One of my respondents is active in the "WHO says we need fresh air?!" campaign based out of Canada. This is an ongoing art project that documents and advocates for the lives of those living with environmental illness through videos, texts, and photography. Their goal is to build communities that can support and sustain people living with complex environmental conditions. This understanding of fresh air involves both the widespread environmental pollution that degrades air quality along with the air quality of indoor built environments. This creates extreme challenges. Where is this kind of pure air located? As Samantha told me:

> For me, Isabella, it became everything. Everything. I couldn't tolerate [it] when I sat on the couch. This is when I was in the depths of this. I'd sit on the couch, and I could almost taste the dust. Everything…in the house was bothering me. It's like I just wanted to go up on a mountain in a tent

> and live by myself. I just wanted fresh air. That's all I could tolerate was fresh air. But how do you do that in this society?

What is fresh air? How do we create air that is fresh for ourselves within daily life and how do political bodies regulate the air we breathe? These concerns are integral to modern practices of both chemical avoidance and illness prevention that are practiced on a large scale across society. The Clean Air Act attests to this fact. The recent politicization of concerns around gas stoves, indoor air pollution, and childhood asthma is another such example, as are the forgotten promises of improved ventilation made during the Covid pandemic. Gaard details eco-critical concerns around air pollution and smog in both the United States and China. She argues we have denied our dependency with air despite the crisis of air quality we face in the Industrial Capitalist era. She asks us to connect our breath more deeply to our embodiment by "re-storying" our experiences with the air we breathe (2022). Those with chemical sensitivities are "re-storying" their experiences with breath, with air quality, and with the chemicals that imbue the air in our everyday lives.

The conceptions of fresh air made by those with multiple chemical sensitivity relate not only to outdoor air quality but also indoor air quality. This set of concerns deeply relates to fragrance in social life which is seen as contaminating indoor air quality. Whitney, who lives in Canada, explained,

> A lot of people say, 'We have a right to wear fragrance'. No, you don't have a right… you can choose to do it but breathing safe air is a right, a life right. MCS in Canada is a recognized disability. And because of that…we have the right to be accommodated…And if they're coming into even a large space, and they have fragrance on. There is no wall around them to contain that fragrance. That whole area is contaminated. There's no such thing as [a] mild or light fragrance. They just don't smell as strong, but they have the same chemicals. So, they're going to make somebody sick.

Reflected in this quote are tensions within social life about the supposed freedom of choice, conditioned into us by the political regime of neoliberalism. Even accommodations themselves are a neoliberal (hyper individualized) response to disability in social life. Multiple chemical sensitivity is a perfect storm; the tenets of modernity reach their highest potential under neoliberalism as a political project, which atomizes us even further from each other than capitalism alone. While this condition may be the consummate modern illness, conceptions of how sensory experiences produce healthy environments and healthy citizens are much older. These sensory experiences are just no longer being widely used by the public to interpret

environmental health. This puts those with chemical sensitivities in a tricky position to explain to others in legible terms what they are going through.

The Smell of Modernity

If we fast forward from the antebellum era to the Post-World War II era, we can see how our existing social and moral order produces certain realities about cleanliness, domestic labor, olfaction, and health. These socially constructed realities tell us that domestic and aesthetic labor are crucial to women's gender performance (Kwan and Trautner 2009; Schneider 2011;Mears 2014), that cleanliness aligns with moral and racial purity (Zimring 2015), that fragrances are not in conflict with public health, and that perfuming ourselves and our homes is a crucial part of self-regulation and moral goodness (Low 2006). Added to this is how the logics of individualism create antisocial behaviors around relational health. Over their lifetimes people have already developed tacit knowledges about which odors are foul and why, how to address these odors, and what such smells convey about a person. Ironically, this often leads average consumers to a suite of practices that the chemically sensitive ardently wish to avoid. Reliant as many of these practices are on harmful chemical usage, they operate in direct conflict with the realities that the chemically sensitive assert. For example, what it means to be clean. We have collectively decided that to be clean or have a clean home means to smell a certain way and we frequently achieve this using scent heavy products like Febreze or fabric softeners. However, as one of my respondents noted, "Clean doesn't have a smell". Clean may not have a smell but modernity does, it is the smell of the "scented world", the smell of "scent immersion" where most of our consumer products and many of our public spaces are replete with encapsulated scent technologies to deliver fragrances that last.

Fundamental to modernity are the ideas of control and separation. Under modernity we are seen as having a discrete relationship from each other and from nature. This ideology has its origins in the Scientific Revolution and Enlightenment thought which gave rise to a mechanistic, rather than organic view of nature, and encouraged human dominion over the natural world (Leiss 1972; Merchant 1980). Richard Norgaard summarizes this view nicely writing, "I trace the present environmental and social disaster to the Enlightenment idea that we can be free from nature and free from each other, which is absurd. We must live in relation with each other and

with nature. We must do so in much more informed, intricate, and delicate ways than markets, shrunken governments, and new technologies have organized us to do" (2024). Certainly, those with chemical sensitivities are asking for more “informed, intricate, and delicate ways” to live in relation to one another as I discussed in chapter 2. This would require that we consider each other's unique needs, interrogate our embodied practices, understand our health as relational, and overall work to overcome our alienation from one another. Better regulations and increased relational responsibility go hand in hand when it comes to addressing the scent immersion of modernity.

Embodiment and Olfaction

Senses and emotions are intimate, embodied experiences that nevertheless can be understood sociologically. Like illness itself, senses and emotions take place within and through the body. Embodiment is the experience of *being*- not merely having- a body. Crossley argues this is most keenly felt not through experiences of our bodies but through our bodies’ experiences of the world around us (2007). The body is a social object, shaped by norms and institutions and subject to particular forms of meaning making and inequality. While everyone has a body, embodiment is not a universalizing experience, but rather it is as much a site of difference as it is commonality. Our bodies occupy different locations in social hierarchies and the social world (Pitts-Taylor 2016:45). Furthermore, our embodied selves emerge through interactions with others. We enact embodiment in ways that are performative, relational, discursive, and sometimes achieved through boundary-work (Boero and Pascoe 2012). In other words, our embodied selves are social selves. In Littlejohn’s work on birth control, she analyzes how pregnancy prevention, an embodied strategy, is gendered compulsory labor. Her work demonstrates the competing meanings made around the experiences that bodies have before, during, and after sex and how this contributes to social inequality by demanding more of women despite the equality of the actual sex act. While this work is not about the senses, sensory experiences of the world are another clear place of embodiment where we craft different meanings in our daily lives.

In everyday life smells signify both aesthetics and danger. Though rich places of meaning-making for individuals around all sorts of social problems and hierarchies, smells- and

the sense writ large- remain largely excluded from sociological theorizing. Georg Simmel advocated for a sociology of senses in 1907 that still remains underdeveloped over a hundred years later. In his work on the sociology of sense impression Simmel asserts that the senses of sight and hearing tend towards objectivity and can be more easily shared, while taste and smell are more subjective and reveal individualistic tendencies (Carnevali 2018). Smell is currently an undervalued sense in the Western world, especially compared to vision. Linguists note the absence of words that we have in English for particular smells and even for air itself (Gaard), instead being forced to rely on descriptions, adjectives, and nouns (Kant 2006; Martina 2023). In Hsu's book, *The Smell of Risk: Environmental Disparities and Olfactory Aesthetics*, he details how Western aesthetics have dismissed smell as an important sense and argues that olfactory aesthetics are in fact critical signifiers of environmental disparities. He traces the similarities between the narratives of the chemically sensitive and those of fictional detectives, showing how they both use smell in the process of "environmental detection" (2020). Building on this work, Dupuis looks at the relationship between the altered smell of water in areas of the Amazon and environmental destruction caused by mercury, sewage, other waste, and oil spills. She writes that, "The changing smell of water in the Amazon promotes what I call 'slow smelling,' where harmful smells go unnoticed and become an accepted part of the odors of a place" (2022:1). She relates this to Nixon's idea of "slow violence" (2013) where violence that occurs gradually is not seen as violence at all. Likewise, people living near the Amazon have adapted to slowly changing smellscapes and don't see them as manifestations of violent environmental harm. We may ask ourselves, what are the altered smellscapes of modernity and how have we accepted them? What smells are we failing to notice or remark upon even if we exist in spaces of environmental privilege? Technologies of odorization and deodorization have shifted and intensified. We are now exposed to vastly more chemically scented products than ever before, many of which contain chemicals known to be carcinogenic or harmful to our endocrine systems (citations).

Smells frequently crop up in the data and narratives of environmental justice and contamination cases without being explicitly developed into theory. For example, in one of Lois Gibbs' books on Love Canal, "Odors, chemical," is listed in her index on pages: 8, 21, 32, 36-37, 45, 60-62, 80-81, 84, 91, 132, 150, 155, and 198 (Gibbs 2010). And in 2014 the residents in Charleston, West Virginia traced a pervasive licorice smell to a chemical spill of 4-

Methylcyclohexane Methanol (MCHM) that had contaminated the local Elk River. Yet, we do not often see work that interrogates how people come to know a smell is harmful, achieve a collective meaning around a smell, or how these smells then become a part of the process of contestation in environmental justice cases. How do state and scientific agencies respond to data on sensory experiences beyond illness symptoms? How are smells used to trace pollution to the source -as was the case in both Charleston and Love Canal- and how are they dismissed or normalized? And what about smells from perfume and air fresheners? At first glance, these smells appear quite different. They are consumer commodities that we choose to bring into our lives. And yet, they also have known health effects and in their dispersal are also forced onto others without their consent. They are also smells that we all have the capacity to experience and notice within our daily lives as they permeate untold spaces of modern life from doctor's offices to Airbnbs to gas station bathrooms.

Olfaction as a Tool of Chemical Avoidance

Olfaction is an important tool for practicing chemical avoidance and therefore for embodied resocialization. I went into the field expecting people to rely heavily on labeling to avoid chemical exposures, as MacKendrick's respondents do in their practices of chemical avoidance (2018) and as mothers do around organic foodwork (Cairns, Johnston and MacKendrick 2013). Examining labels is something that consumer advocacy groups such as the Environmental Working Group teach people how to do. What I found was that the chemically sensitive rely heavily on their own senses, especially smell. To my knowledge, there is no organization teaching people how to better rely upon their embodied, tacit knowledge of the world to produce better health for themselves and their families. In my interview with Matilde, I asked her how she found products that she could tolerate:

> Matilde: In the beginning, I just kept switching one shampoo to the next to the next…And then I'd finally find a product. Okay good, this works. The next thing you know it's been discontinued. So, the stress of something being discontinued, I cannot even tell you, because then you got to start the whole process again. And I remember I was in this one store, and it was in a bad area in [Canada]. And I go in, I'm sniffing all the products. So, the security guard comes along. And I had enough smarts to ask for the manager. Because I know I'm not stealing you can…check my bag. I don't care, check everything. Because now I'm taking everything and opening it up trying to see what I can handle… I was hanging out for like an hour. So of course, it looks like- well, maybe a thief would move a little bit quicker but so I asked the manager maybe they can help me. Thank goodness I did that. And then after a while they knew that I was that one coming in.

> Isabella: When you're figuring out what products you can use, a lot of it sounds like it's just using your own senses basically. It's not like oh, I know there's a certain thing on this ingredient list that I can't tolerate or that I can tolerate. How do you figure that out?
>
> Matilde: Well, well yeah, fragrance if it says the word fragrance and other than that, I can't remember and when I'm in a store, I can't think straight. So, I start smelling. Then I'm at a certain point [where] that doesn't even help because you're in the store and you're reacting to everything. It's so hard, so now it's really, it's just trial and error so it's a lot of wasted money.

Matilde uses labeling in so far as she will automatically dismiss products that list fragrance as an ingredient but beyond that she does not have a list of chemicals that she avoids. Instead, she uses her own body, especially her sense of smell. In doing this though she was viewed with suspicion by security who assume that by violating this social norm she must be up to something nefarious like shoplifting.

While Matilde knows she has to avoid fragrance, we also see that fragrance-free is not a sufficient condition for those with chemical sensitivities. She was still having to sniff the products to see if she would react to them. These kinds of exposures and this technique of olfaction isn't just limited to personal care products. Whitney and I had a conversation where she detailed how this works in the case of clothing. She told me

> Whitney: But it's not as hard as one would think once you have the knowledge [of] what you're looking for…. And also, with experience. Like right now I can buy cotton items from Land's End. And I'm fine. [They're] not certified organic, but I do great.
>
> Isabella Clark: I mean, I guess it's possible that they just don't pay for the organic certification, but they are using a healthy process.
>
> Whitney: Yeah, well, wherever they're getting their items from they are definitely doing it the right way because I can't smell anything, and I get no reaction from their new things. You know, and mind you I do put it through decontamination. As soon as I get it. I don't wear it before I wash it. I haven't run across anything that bothers me at all.

The work Whitney does is quite different from the labor consumers practicing chemical avoidance are found to do around labeling. My respondents talked a lot about chemicals and fragrance generally, but they didn't mention particular chemicals often or refer to watchdog groups like the Environmental Working Group that were founded to help consumers navigate these landscapes of risk. Instead, they use their own bodies as a tool. Olfaction and physical sensations help them to make sense of their exposures and practice chemical avoidance.

Collective Meanings

What collective meanings do the chemically sensitive make about the chemical scents embedded in our world? The chemically reactive discuss the scents of modernity as violent, anti-social, and poisonous to people and the planet. Overall, they view them as a sign of conformity to the broader social mandates encouraged by corporations and advertisements. An amalgam of synthetic chemicals and actual fragrances, these scents are saturated with powerful cultural associations, attached to personal memories, and embedded in the cultural and physical construction of our modern world. This makes problematizing them an uphill battle. How do you get other people to see using dryer sheets as a violent consumer behavior that drives ecological degradation and poisons other people?

In the case of the chemical sensitive there are few overt indicators of pollution to connect with their sensory experiences. This is unlike in environmental justice cases where novel and intense odors have uncovered polluting sources. Instead, the scents the chemically sensitive problematize are part of a rich tapestry of culture that conveys significant social meanings around difference and inequality and props up our social and moral order (Low 2006). They are therefore working against deeply entrenched cultural meanings and practices. Instead of being able to point the finger to a single source of clear malfeasance, that other people could also see and recognize, they are often indicting the behaviors of proximate others, not just corporations. As the Reddit user CelestialMoonbeam commented, "The fragrance industry is completely out of hand, they are basically poisoning people for profit and brainwashing the masses into thinking their chemicals are 'clean' and 'smell nice.' I think one day we'll look back at all of these chemical fragrances and see it the same way as smoking, or when they used to put lead and other toxins in makeup and hats." People have become convinced these fragrances and chemical products are something they need and desire. Part of this is about what it means to be and smell "clean". As the people I spoke with frequently said, "Clean doesn't have a smell".

Violence

The smells that disgust other people like body odor and fecal matter were remarked on by my respondents as not disturbing or taxing to them because they weren't hurting them. Smells that non-chemically reactive people interpret to be pleasant signifiers of wealth, cleanliness, and

gender performance like perfume, soaps, and cleaning products were disparaged and even seen as forms of violence. The language of being "hit" or "assaulted" by chemicals and fragrance is common within the world of multiple chemical sensitivity. Isaac describes these exposures as "hits" telling me, "You go walking, and you get hit by scented dryer sheets, which is probably universally the worst for all of us". Nancy said, "We have assaults daily, every time we go out, even sitting in our own houses. When vehicle exhaust or animal wastes from the farm or insecticide or a neighbor, anything like that, comes into our living space. It is an assault usually. The UPS guy who came this morning with lots and lots of fragrance on. And I had to go out and get the boxes. That was an assault. Can't tell him that." There is a violence to the social reality of the chemically sensitive that goes unseen by others like the UPS delivery guy. These exposures produce physical pain and discomfort in them.

Sometimes other people even deliberately exposed chemically reactive people to chemicals they had told them were harmful in order to "test" them. These kinds of deliberate exposures are a way to assert control over reality by "proving" that the chemically sensitive person is faking their illness if they don't have a reaction. This is of course seen as deeply harmful by the chemically reactive person. It is not only a form of violence but also one of betrayal.

Anti-Social

While scents may be chosen based on individual preference, they are collectively experienced. The individual choice immediately acquires a social form through our sense of smell. Immanuel Kant noted how of the senses, smell is "less sociable" than taste due to its simultaneous nature as both more social and more intimate. He wrote,

> Smell is taste at a distance, so to speak, and others are forced to share the pleasure of it, whether they want it or not. And thus, smell is contrary to freedom and less sociable than taste, where among many dishes or bottles a guest can choose one according to his liking, without being forced to share the pleasure of it…For taking something through smell…is even more intimate than taking something in through the absorptive vessels of the mouth and throat. (2006:50-51)

The chemically sensitive know this. They discuss the tensions around individual choices and fragrances, pointing out how fragrances are inherently shared experiences. Whitney told me,

> If they're coming into even a large space, and they have fragrance on. There is no wall around them to contain that fragrance. That whole area is contaminated. There's no such thing as a mild or

> light fragrance. They just don't smell as strong, but they have the same chemicals. So, they're going to make somebody sick anyway, no matter what. So, a scent free space is one that doesn't allow any fragrance. A space that has reduced fragrance is no, there's no such thing. There's absolutely no such thing.

Wearing fragrance is an antisocial behavior because it hinders the participation of those with chemical and fragrance sensitivities. This subjects them to social isolation. As CelestialMoonbeam posted on Reddit, "I feel we need some kind of campaign to get a total societal overhaul so that people wearing fragrance are seen to be as antisocial as smoking. And scented candles should just be banned entirely, there is no reason for them at all and they are so toxic." This is quite a challenge as other people see perfuming themselves as a prosocial behavior done in order to smell nice before interacting with others. This behavior then indicates the necessary self-regulation to manage bodily odors. Their perspective directly conflicts with the meaning-making other people are doing around fragrances in social life. Smell and morality often go hand in hand as to smell bad is to break taboos about self-presentation and regulation and impinge upon the social and moral order (Low 2006; Synnott 1993).

Canaries in the Coalmine: Chemicals are Poisonous to People and the Planet

For decades, the chemically reactive have called themselves "canaries in the coal mine" after the birds that detected carbon monoxide in mines. If the birds became sick or died, the miners knew to leave or put on respirators. Canaries are the most iconic sentinel species, but other animals and organisms have also been used throughout history to provide advance warnings of danger, especially those related to environmental hazards (Committee on Animals as Monitors of Environmental Hazards 1991). The chemically reactive see themselves as signs of disarray in our ecological arrangements. Whitney told me:

> The whole system of the body is impacted by chemicals, and they really need to understand that because that's going to be the end of us…Every organ system- I think we have 11 of them. Every one of them is impacted by chemicals, daily chemicals, so nobody's escaping it. They may not have MCS, we're just the early warning system. But the long-term effects like cancer, dementia lupus, all of these autoimmune diseases, we didn't have as many autoimmune diseases until this chemical revolution after World War Two, right?

Whitney sees people with MCS as sounding the alarm on the health issues that chemical saturation poses to human health. She points out how everyone is exposed to chemicals in their daily life so "nobody's escaping it". Like the climate activists Mendez worked with (2020), she

connects her embodied experiences to the interlocked problems of environmental degradation and human health.

While browsing the subreddit r/ChemicalSensitivities I came across a post asking other people with the condition, “Why do people say we’re crazy instead of accepting this is real?”. SerendipityofLove replied:

> I have a few friends who have similar ‘scent’sitivities, not as severe, so some do understand but, as a whole, it’s a scented world out there. Unfortunately, there comes a point where we need to just accept the fact that the world doesn’t stop for us. All we can do is try to acclimate and make adjustments i.e., buying a purifier, sealing my door/windows, spraying hydrosols I can tolerate that distract my nose from other odors. When it’s really bad I just have to sit in my apartment with a mask on. I also have a cloth mask that I drape over my nose while I’m sleeping when cooking odors seep in and the purifier doesn’t totally eliminate them. (All posts edited lightly for grammar and spelling).

What does SerendipityofLove mean by a scented world? Where do these scents come from? Are the chemically sensitive speaking about the scents from flowers, from industrial pollution, from a lack of hygiene practices or from too vigorous of hygiene practices? In my work I found that the scented world was created through industrial pollution, the practices of individual embodiment, and the culture of what another Redditer called “scent immersion”, that is the practices of putting fragranced devices within homes, workplaces, bathrooms, retail stores etc. SerendipityofLove’s post suggests that only people who experience scents in a similar way (through their own sensitivities) can understand this condition. In the absence of this shared embodiment, other people assume the problem must be in the mind, that the chemically sensitive person must be “crazy”. The way that SerendipityofLove deals with this is by first accepting the external conditions of the world and of other people’s behavior and then changing as much in her own environment as she is able to. The user uraniumnectarine replied:

> I do all this stuff too. but the kinds of scents we're hurting from were changed a few years ago, in every brand, to ridiculously higher amounts of fragrance inside encapsulation designed to stick and keep emitting. They go through walls and are in almost every product--things that were never fragranced until now. If a product invades other homes when they have their windows closed and air cleaners on, it shouldn't be on the market. Period. I try to be as chill about it as I can, but this is a worldwide health concern, and needs to be organized against at the top. These things interfere with pollination and have fully contaminated water systems. The environment is already so fragile, and I think this is at risk of being a big tipping point. I think being chill within the context of a day is an important goal, but it's dangerous to be passive politically. This stuff is killing us.

Though uraniumnectarine states that they employ the same strategies as SerendipityofLove does to manage chemical contamination on a daily basis they are emphatic about their limitations. They connect the harm these synthetic fragrances not only to harm within their own body but

also to widespread environmental degradation. The scents in consumer products are often marketed with names like, “spring meadow”, “clean breeze”, “April fresh”, and “ocean mist” (“Detergents for Freshness/Scent”, n.d.). While these names are clearly meant to evoke nature, nothing could be more unnatural to those with chemical sensitivities. The chemically sensitive long for the fresh air evoked in names like “clean breeze”. Ironically, dryer emissions loaded with such fragrances are one of the largest barriers standing in their way. The chemically sensitive draw direct connections between the impacts these scents have on their own bodies and the harm they are doing to the planet. Our sensory experiences allow us to recognize dangers in the environment. This application of tacit knowledge has a long history and used to be accepted as both common and scientific sense. This changed post-Civil War with the advent of germ theory (Kiechle 2017). If World War II brought the chemical revolution into our lives, the Civil War is what altered prior health paradigms that allowed us to draw on tacit knowledge to recognize these exposures using our own bodies and senses and to mark them as sources of harm.

Embodied Resocialization

My own experiences in the field show that people’s interpretive frames around scents can change. Testimonies from my respondents show that the behaviors of proximate others towards chemicals and scents can change as well. Whitney has successfully resocialized her children into being willing participants in her health. However, even this has limitations such as when her kids experience a “transference” event. We see at the end of this quote how they still do not or cannot notice these exposures the way she does.

> Isabella: You said that your children do detoxes before they come over. So, what does that process look like for them?
>
> Whitney: Well, they have to use non-toxic, unfragranced products. In addition to that, I get them to put a little bit of baking soda in their shampoo, and apply it to their hair, and then [a] rinse and the rinse was apple cider vinegar, a cup of apple cider vinegar to half a cup of water and let that sit on your hair for a little while. And then you can rinse it off. And it may smell, like it smells strong to you. But once it dries, there's no smell left at all. So that removes, you know that the baking soda is an alkaline and the vinegar is an acid, so most fragrances will be removed with that from your hair because your hair is quite porous. So yeah, so that's what I get them to do. And then their clothing. They have to be using a toxin scent free laundry system. So, all three of them do that. So, that's their lifestyle, or their choice. That's not something they have to do just for coming with me. And then also, I ask them not to stop anywhere else before they come here because transference can happen from say if you stopped into a coffee shop or whatever. Which actually, the second example actually happened. My daughter was out, and she was coming here. She stopped into a

> coffee shop, and they happened to be mopping the floor. Toxic scented crap. And she came in here and it stopped my breathing. So yeah, not good.

The chemically sensitive have practices in place for fragrance removal as well as avoidance. Total avoidance is impossible when everyone else is moving through the scented world. Physical sensations as well as olfaction are an indicator the chemically sensitive that they have encountered a chemical exposure. This means embodied resocialization is not only about noticing smells but can sometimes involve drawing connections to your own body's response to the world. This is illustrated in this quote by Hannah, a friend of someone with multiple chemical sensitivity. Hannah lives in a nursing home now, but she used to regularly visit with her friend in Desert City whom she met through her church. We spoke over the phone one day shortly after I had returned from my second trip to the field where I had interviewed her friend. She recalled:

> I'm sitting out in my backyard. And all of a sudden, I'm horribly, horribly dizzy and I thought 'Oh, my God what the heck is wrong'. I was smelling the creosote when the wind was from that direction. I went in and I thought, 'Don't tell me that I'm allergic to this stuff'. I have certain allergies, but I was dizzy. I was lightheaded. And so, I went in the house. And I mean, I got over it very slowly. But it was scary. And I thought, 'holy cow'. And so, then I started doing research because she [her friend with MCS] did research about creosote.

Creosote is a wood preservative often used to fortify railroad ties and as a pesticide. In Hannah's case her exposure to creosote came from railroad ties that a neighbor had recently unloaded into their yard. Though still commonly used, creosote contains many known carcinogens and has been linked to cancers in railroad workers (Carlsten, Hunt, and Kaufman 2005). It is also an exposure that Hannah's MCS friend P. was especially sensitive to. Although Hannah did not develop multiple chemical sensitivity, I mark this experience as an embodied resocialization for her, one in which she was able to revise her prior understanding of smell, physical sensation, and environmental detection and therefore resocialize her body and its relationship to the world of chemicals. Hannah's experience blurs the lines around who is vulnerable to exposures and who "has" chemical sensitivities. In this instance, Hannah herself was sensitive to a chemical exposure that made her physically sick. Despite this profound and admittedly terrifying experience, I found that while people who wanted to be in responsible contact with the chemically sensitive experienced resocialization, it was hard to make it stick. For example, Hannah told me how she only switched her products before going to see her friend, she did not permanently change her consumption practices. This points to how strongly our existing embodied socializations are ingrained in us. How can we make relational exposures into stickier

cultural concepts? Other people fail to see chemical sensitivities as a legitimate illness, but embodied resocialization is one way in which they can catch glimpses into this world. I don't think embodied resocialization is something people with chemical sensitivities are deliberately working to accomplish but I do think that their claims about chemicals, the body, and olfaction in particular leave lasting impressions upon the people who interact with them.

Tensions around Embodiment

How do the chemically reactive make sense of the tensions between their embodied experiences and those of the non-reactive? To understand non-reactive people's reliance on scents, in particular perfume, some people turned to a physical model of addiction to explain the hostility and resistance they are faced with when asking others to go fragrance free. As uraniumnectarine wrote on Reddit: "They're addictive and were made to be addictive and cause nose blindness, again purposefully, so one needs more and more and more". As a sociologist, I don't find that explanation compelling, but I do understand why someone with multiple chemical sensitivity, in whom scents do produce such a visceral reaction, would look for explanations within the body to make sense of the widespread cultural phenomena of fragranced products. This comment also blames companies for creating such a scent immersed world. Some people, like the Redditer rebelphoenix, believe that "They can't smell it, so they don't think it exists". Is it true that people can't smell "it" or are many of our chemical encounters so unremarkable to us as to go unnoticed like with my experience of big box stores? This harkens back to what Dupuis explores in her work on "slow smelling". It may be the noticing that is missing, not the olfaction itself. If that is the case, then how could other people be made to notice? This is the task of embodied resocialization, to get other people to notice and then hopefully to get them to change their own practices.

Nancy has a long history of activism work around chemical sensitivities and she offered me a perceptive analysis of the tensions around scents and embodiment in our culture:

> Nancy: Concerning things that went wrong…that we ought to have done differently. In the late 80s, early 90s were places we got trapped. I think one of them was that one of the most injurious products that people run into, that keeps a lot of them home is chemical fragrances, perfumes, laundry products, any scented chemical products. And there was a national movement to discourage people from buying fragrant products. Well, that sounds innocent enough. Sounds like …that we would explain ourselves and someone would say 'Oh, I get it. Okay. Yeah, we get it'.

> That didn't happen at all. What happened is that we worked on anti-fragrance issues. And most of the emphasis was on fragrance as worn by people. Big mistake, real big mistake.
>
> Isabella: How so?
>
> Nancy: Because it immediately raises the issue of individual choice. Like, I choose to wear this and you can choose to leave that kind of stuff. And the individual choice issue is kind of a cover for some other things that are going on. Like, if you are a woman in our culture, you grew up with a younger brother, who said 'You stink. Yeah, you're ugly. You're fat. You stink. You stink'. What's a young girl gonna do? You start looking for ways to not stink. Because you can extrapolate from [the fact that] your little brother thinks you stink to any rejection you face anytime in your life could have to do with it. You smell wrong. You have body odor. You have some kind of cosmetic imperfection.

Nancy's quote offers an ideal type narrative of how people get socialized into using scented products initially. She connects this strongly to gender, suggesting that for girls and women the pressure not to smell is especially strong. Scented and fragranced products are a huge source of concern for the chemically sensitive and certainly the ones that are most embedded in their interactions with others. At the same time, they are also the most intimate of our chemical entanglements. We use them most frequently on our own bodies and in our homes and they play a crucial part in aesthetic labor and the performance of the self. As Nancy suggests when she mentions rejection, women especially may use aesthetic practices to work out deep emotional responses to their treatment by others, particularly men. Even for people who don't use perfume, fragrances are contained within most deodorants, soaps and detergents, and skin care and hair care products. Along with being an important aspect of gender performance, they also signify our place in the social and moral order (Low 2006) and denote race and class boundaries (Cerulo 2018). While race, class, and morality didn't come up explicitly in my interviews when it came to scents, Peter also spoke about gender:

> Peter: And then one January a guy I kind of had to work closely with came in. His wife got him a new cologne and all the girls loved it, but it just kind of took my breath away. I would just have a problem breathing and he refused to not wear it. [I] went through the medical and the nurse was chasing him around and as I was exposed to it I just kept getting worse and worse and worse. So finally-
>
> Isabella: I was just going to say, so you asked him "Can you not wear this cologne? It's making it hard for me to breathe" and he just said "No"?
>
> Peter: Yeah, basically. He said, 'But the girls like it'. It is tough because you can't breathe so you're trying to talk to somebody. And it's, you know, you come off like a weirdo to start off with. So, you leave, he shrugs he thinks it's no big deal

Peter's story also refers to how gender performance socializes people into using smells as it makes them attractive to others. His comment at the end about feeling "like a weirdo", relates to how shame, stigma, and the moral order are produced through our embodied behaviors and practices. It is socially expected that people be able to tolerate fragrances, because it is a social taboo to smell of body odor and fragrances are a significant management tool for this. To not be able to tolerate fragranced odors violates an expected norm.

Denial, Complicity, and the Question of Sanity

Aside from addiction and socialization narratives, another way that the chemically reactive make sense of other people's use of fragranced and chemical products is through the framework of denial and complicity. People are complicit in these behaviors due to socially organized denial around what chemicals and fragrances are capable of doing to our bodies. Gabrielle told me, "When a person doesn't want to believe, because he knows that if he believes, he has -or she has- to change her manners, her products." This process of change is something even people with chemical sensitivities have to go through by acquainting themselves with new products, understanding where fragrances and chemicals are, and noticing when they are reacting. An important component of embodied resocialization then is belief. We've seen how being labeled as crazy is a key way of dismissing the concerns of the chemically sensitive. This is central to the difficulty of making this resocialization stick.

Kari Norgaard addresses how denial is socially organized in her work on climate change. Norms of attention and conversation are powerful aspects of how we socially arrive at denial and choose to turn away from certain issues (Norgaard 2011). Even for people with chemical sensitivities, who are practicing different norms of attention and conversation, these linkages can be hard to arrive at. Whitney pointed out the gaps that can exist in people's practices between fragrances and chemicals more broadly. She is a member of an environmental illness clinic in Canada and meets with a support group virtually. She told me, "I'm in a Zoom group that I meet with. And they all talk about avoiding fragrance, but they use toxic chemicals. When I try to explain to them that it's like, you can hear crickets in the room, whether they don't want to hear it, or it really scares them. Because they are doing very toxic things." Even within the social world of environmental illness, there exists tensions around how the body should move through

the world, how people interpret chemicals and scents, and how much risk management they are willing to practice.

People have different interpretations of both the external sensory world and the response the body has to this world. One result of this is the ongoing contestation and outright denial of others' illness experiences. Those with multiple chemical sensitivity have to fight against dominant interpretations of reality and push for a revision of the world. How they revise the dominant understanding of the world is through their own tacit knowledge and embodied resocialization of themselves and others.

Conclusion

Multiple chemical sensitivity is an indictment of modernity; an illness that we are all complicit in. To believe in it means to believe that we share some responsibility in its perpetuation. To end it would mean that we would have to change our own lives. This aligns with findings on other environmental problems such as climate change, microplastics, textile waste, and consumption that demonstrate the ways we as individuals have a responsibility to engage with these problems, including by changing our own lives (Norgaard 2011; Kennedy 2022; Altman 2015). Embodied resocialization attempts to change the practices of modernity at the level of other individuals, to recast relationships between bodies and environments in ways that support more relational responsibility towards those with chemical sensitivity. However, these resocializations are fragile. The peers of the chemically sensitive may be willing to change their practices as a form of support but they do not appear to create the same collective meanings that those with MCS make around chemical smells. These meanings are that chemical and fragrance exposures are fundamentally poisonous to human bodies and the planet, a form of social violence, an anti-social activity, and a symbol of conformity to dominant ideologies pushed by corporations that are antithetical to human health. These smells have entered into our lives without much private or public conversation or attention paid to them and therefore without pushback. In this historical period, sensory experiences of the world are not seen as valid ways of making knowledge about our bodies and our health. This puts the tacit knowledge of the chemically sensitive under scrutiny. Sympathetic peers can be taught to redirect their attention to their senses and to make different behavior choices around chemicals, however this is usually an ongoing negotiation. In

the absence of continuous physical symptoms of one's own it is hard to fully grasp the experiences the environmentally ill have of the world. What remains invisible even once others have been taught how to smell what the chemically reactive smell or how to avoid what they ask them to?

CHAPTER VI: GEOGRAPHY AS REMEDY: PLACE, HEALTH, AND RELOCATION

> "American culture is desperate for "safe" havens, inventing categories to define that safety and to project the ameliorative fantasy that we can attain mastery of our environments"
>
> -Julie Grossman 2005, from a cultural analysis of Todd Hayne's film *[Safe]*

Multiple chemical sensitivity is a unique environmental justice case because the chemically sensitive are encountering an allegedly fair distribution of ecological hazards. They are coming into contact with chemicals that exist in the public air, water, food supply, public and private spaces, and consumer products. They haven't been unjustly or acutely poisoned as a result of working in an exploitative, chemically dominant industry (Cable, Shriver, and Mix 2008), living in a poor or racialized community near waste pollution (Pellow 2004), being abandoned and sacrificed by the state (Pulido 2016; 2017) and they aren't suffering from particularly high chemical body burdens that correspond to intersectional inequalities (Edwards et al 2023; Mansfield 2012). In fact, many of my respondents, and those most likely to be diagnosed with multiple chemical sensitivity, encountered ecological hazards from positions of environmental privilege. They worked in industries that were largely based on office work and considered non-hazardous, like publishing, marketing, engineering, and computer science. They lived in affluent suburban or urban areas. The usual suspects of place-based hazards like toxic waste facilities, animal agriculture, or heavy trucking routes were missing from their lives. They should have enjoyed a life unmarked by any noticeable environmental health issues. Instead, they live in a protracted environmental crisis. Claiming that environmental health problems have marred, transformed, and unmade the basic relationships of their lives and their ontological stability complicates what we know about environmental health problems, what these problems look like, who they affect, and how they enter into people's lives. It shatters our existing perceptions of security and stability, both in our bodies and in our social relationships to proximate others and to the institutions we rely upon. Multiple chemical sensitivity bursts this bubble of stable

modernity, underlines all our vulnerabilities, and demonstrates how quickly we can be pushed out of the mainstream "healthy" world and dominant culture. This case shows how social inequality is not just about pre-existing categories of identity, but rather the processes through which immiseration, discrediting, and stigma occur.

If the chemicals encountered by those with multiple chemical sensitivity are not geographically bounded or examples of acute pollution, can multiple chemical sensitivity still be an environmental injustice? Yes. Many environmental justice issues exist that are not geographically bounded. Limiting our scholarship to geographic concerns prevents us from seeing the additional ways environmental inequality, and environmentally dispersed harm, are socially produced and enacted. However, there is a significant geographical dimension to multiple chemical sensitivity. This is the issue of health and place as it concerns relocation. While relocation does come up in questions and concerns about residential mobility (Taylor 2014), it has typically been studied as a response to acute pollution. Here, relocation is a core health strategy in managing chronic environmental illness. Central to the struggle of multiple chemical sensitivity is the search for a safe place (Coyle 2004). This search exists at micro and macro scales for the chemically reactive. At the micro level this involves creating an intimate sphere free of chemical contamination. We see this in the ways I was denied access to most people's homes while I was in the field and in the narratives of the chemically sensitive who report the detailed and demanding work of creating safe interiors in homes, cars, vans, and even tents. Along with this creation of micro-environmental spaces of safety, we see this in how people seek out better places to live. This involves two intertwined dimensions, permanent relocation to a new environment, often the American Southwest, and the adaptation of nomadic lifestyles to track down a place that the body can tolerate. In the words of Steve Kroll-Smith, "people [are] forced to find new habitats for their bodies" (Zwillinger 1999:83).

Retreat to the Desert

Like in other cases of environmental injustice, multiple chemical sensitivity is a story of health, geography, and redefining the hazards of particular places. Those who are environmentally ill reinscribe normally safe social landscapes, like offices, homes, and grocery stores with chemical risks marking them as polluted (see Chapter 2). This reconceptualization follows the familiar

beats of environmental justice organizing which redefined the environment and the focus of the environmental movement to include the places we live, work, and play. However, most environmental justice work links certain places to particular communities, demonstrating how geographically based social marginalization connects to unequally distributed environmental hazards[9]. This isn't the case with multiple chemical sensitivity, in which sufferers experience physical symptoms in response to chemical exposures that have been politically unremarked upon (Coyle 2004). There is no particular place or space that people need to live within or near in order to come into these toxic contacts because chemical trespass is always occurring within our bodies under the conditions of modern risk society (Malkan 2003; Brown, de la Rosa and Cordner 2020). Rather, it is widespread industrial and consumer practices seeping out as environmental exposures that make people ill. While multiple chemical sensitivity does not originate in customary geographical arrangements it frequently leads to a geographic response. The chemically reactive often seek out safer places to live, locally and nationally. Within the United States, the Southwest is a key site of relocation for the environmentally ill.

The Appeal of the Southwest

Long histories exist of the perceived relationships between health and the environment. Documented primarily by medical historians and geographers, the genesis of such studies is considered to be Hippocrates' treatise *On Air, Waters, and Places* which argued that elements of the local environment impacted human health and wellbeing (Valenčius 2000). We will skip ahead from 400 BC to the 1800s, to examine the particular role that the Southwestern United States has played in the geographic imaginations of settlers. The search for health, known as the "health rush", is believed to be the second greatest driver of settlement to the American West, after land seizures (Baur 1952; Baur 1959). How was the American Southwest socially constructed as an area particularly conducive to health? Historical case studies on tuberculosis find that the robust activities of politicians and the professional networks of doctors who had

[9] Some scholars assume this means the environmental justice movement simply desires that environmental hazards be equally spread amongst society. This vision of "environmental equity" is a distortion of environmental justice which fights against the production of toxic exposures writ large and the systems that demand their production (the settler state, racial capitalism, and militarization) ("Environmental Justice / Environmental Racism")

established sanatoriums in places like New Mexico, Colorado, and Southern California, shaped the Southwest as an area for health seekers (Jensen 2009). In these early accounts of relocation and health tourism in the Southwest, health seekers were driven by local and national political economic factors. These included the desire for white settlers to physically colonize the West and the economic motivations of individual towns, like Silver City and Albuquerque, NM and Los Angeles, CA to develop industries that would attract residents and tourists (Baur 1952; Jensen 2009). These motivations merged with the widely held common sense of nineteenth century Americans who understood health as tied to environments. These commonsense understandings are believed to be influenced by the travel advice literature of the time as well as the recent translation of Hippocrates into English (Valenčius 2000). Medical wisdom and popular opinion of the time viewed a change in climate as positive for pulmonary ailments, especially tuberculosis. What is particularly interesting about tuberculosis is that its health tourism continued to flourish into the early 1900s (Jensen 2009), despite the fact that Robert Koch discovered the tubercle bacillus in 1882 (Abrams 2010). This means that doctors of the time knew that tuberculosis was spread as a germ. However, this did not stop them from continuing to think that the environment would play a significant factor in recovery. Once the public internalized these facts of tuberculosis transmission, fears of contamination proliferated in the same places that had once courted tuberculosis patients. Train cars were regulated and fumigated, and contemporary accounts suggest some patients were displaced from their boarding houses once their landlords learned they had tuberculosis (Abrams 2010).

Tuberculosis and health seeking behavior had crucial political ramifications for settler colonialism, particularly in New Mexico (Lewis 2012). Within the context of New Mexico's struggle for statehood, local politicians desired white bodies that would legitimize this statehood and portraying Indigenous and Hispanic populations as immune from tuberculosis helped attract white residents. New Mexico had been a United States' territory since 1850 but Congress balked at giving it statehood. A constant theme in the repeated denials was the current population's racial makeup, as mostly Indigenous and Hispanic non-English speakers lived there. This population was viewed as decidedly not "American" and seen as dangerous and uncivilized and was why a statehood bill in 1988 failed to pass. Attempts were thus made by local and federal authorities as well as businessmen to "Americanize" (whiten) New Mexico. Political focus was also redirected to the climate and its purported health-giving properties. The existing populations

were captured in these sentiments, as advocates of statehood argued that the native populations were immune to tuberculosis due to the favorable climate. The advertising literature of the time began backing up these claims by reporting about how healthy the native population of New Mexico was. How *did* tuberculosis patients impact the health of New Mexico's native Hispanic and Indigenous populations? Did the health seekers spread tuberculosis to local residents? This is a shadow side to the health seeker movement that has received far less historical attention (Lewis 2012). The lack of data collected at the time, and the relative isolation of Indigenous and Hispanic populations makes these questions difficult to answer in full. We do know that deaths from tuberculosis soared in New Mexico particularly amongst the "indigent" tuberculosis patient population. As such, people with tuberculosis and without means were warned away from New Mexico. The failure of the state to address these issues led to the creation of New Mexico's public health association in 1917. Shortly after New Mexico was struck by the 1918 influenza epidemic, something which their salubrious climate could not protect them from. This cast the huge gaps in public health into even greater relief and proved the impetus for establishing a state health department, Public Health Laboratory, and eventually state sanatoriums. With these agencies and public health research established in the area, it became clear that Hispanic and Indigenous residents did not enjoy immunity from tuberculosis as they made up a large percentage of patients. With these changes also came increased understanding that it was the prescription of rest, diet, and fresh air that aided many tuberculosis patients and not the climate itself. This etiological understanding of the disease however, combined with racialized claims about health meant to lure white people to the region, led to the spread of tuberculosis to native New Mexicans, who would likely not have encountered the disease were it not for the political push to have New Mexico gain statehood (ibid). Tuberculosis migrations lasted until about the 1940s, when effective treatment became available (Ott 1996)

Not all health seeking behavior and relocation revolved around tuberculosis. Bauer's work on the health rush and Los Angeles explores how LA created an identity for itself as a place of wellness by building more generalist health resorts, not just sanatoriums (1952). This identity was built around Southern California's environmental conditions; the year round sunshine and mild climate was perceived as conducive to overall health and wellbeing. Has health tourism to the Southwest died off or has it taken new forms? The experiences of people with multiple chemical sensitivity, and potentially other contested illnesses like chronic Lyme,

suggests that the Southwest remains an important symbolic and material space for achieving health.

The history of the Southwest is intimately tied to health seeking behavior and the history of respiratory illness is deeply connected to travel and relocation. What are the factors in common with multiple chemical sensitivity? Multiple chemical sensitivity is also an illness in which both travel and relocation have been constructed as essential to healing or abating symptoms, in both local and regional contexts. It is also an illness in which the Southwest has taken on particular salience as a salubrious place. How has this happened in the absence of acute settlement attempts, local politics aimed at health tourism, or a proliferation of established health facilities like sanatoriums and health resorts? Without these political economic factors at play how has the Southwest remained important for ideas about health and wellbeing? While at first glance it seems as though people relocate just to escape pervasive chemicals, this poses a conundrum: How could there be particular landscapes with distinctly less chemicals than others? And if there are, wouldn't these just be the affluent white communities which can be found scattered across the United States? Why is the Southwest seen as a particularly good place to live[10]? I argue there persists common sense understandings of the relationships between climate, the body, and health. There are also more subtle organizational and network factors at play. As multiple chemical sensitivity is fundamentally about a search for a safe space, this search takes on geographical contours. It is the particular environmental conditions of the Southwest that make it a good fit for those with environmental illness, along with the social networks within the region, the relatively high amount of environmentally ill housing, and the geographic arrangements of the state around public lands.

Health and location came up frequently in my interviews. In this excerpt I had just asked Martin if he had ever considered returning to his home country and if he thought he would receive better care there. I tried to remove identifying details throughout my work, but I don't think it will give much away to say that they have a notoriously better health care system than we do in the United States.

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[10] The Southwest seems particularly at odds with chemical purity once we consider its history with nuclearism - both uranium mining and bomb testing. Some parts of the landscape are highly irradiated and have been treated as "wastelands" (Voyles 2015)

> Martin: It's complicated. It's complicated. I mean, the healthcare system is much better than here. MCS is more accepted there than here. The [home country] government actually funded an MCS Research Center for eight years once, and they put up some very interesting stuff. I mean, it was small, it was like, a million dollars a year … or something like that. And there are support groups and things like that. But it's a small country…and it's rather densely populated. There's no desert, there's no place you can move and have 40 acres and be away from your neighbors. So, what a lot of people also do over there [is] heat the houses with firewood, and firewood smoke, that's like a battle even a mile away if you're right downwind…This is much better than that. I feel much better in a desert than I do in a wet environment…That's why a lot of us moved to the desert because we don't do well with pollen. We don't do well with mold. We don't do well with lots of things.

Here we can see the relationship between the environmentally ill body and common ecological elements. These understandings can be traced back to early scholarship in medical geography whose central question was how elements in an environment- like climate, vegetation, miasmas, weather, moisture, disease-carrying organisms, pollution, etc.- affect the health of the local population (Valenčius 2000). While people with multiple chemical sensitivity don't engage with overall population health to determine where a good place is for them to live, they certainly think about the elements in an environment beyond pollution. For the chemically reactive, the most frequent additional elements of concern are smoke, terpenes in wood, pollen, mold, and electromagnetic frequencies. Weather itself also matters. Heating and cooling homes can create challenges because they can help create mold within homes even in dry climates. They also can be an issue for people who are electromagnetically sensitive. These concerns intersect with the issue of housing, as many people are forced to camp or live out of their cars and must live in areas where they can seek out cooler places in the summer and warmer places in the winter. The Southwest is perfect for these requirements without necessitating lengthy travel. Does moving to an environment with better elemental factors positively impact the health of the chemically reactive? What challenges remain? How do people living in Juniper view the potential for health restoration? I asked Keith about the relationship between his health and relocating to the Southwest, specifically coming to Juniper.

> Isabella: So, moving to Juniper do you feel like your health has been affected being here? Has it improved? Is it kind of the same as it was when you were traveling [camping around the Southwest]?
>
> Keith: I think it's the same. Yeah, cause…ever since I came to [the Southwest], I basically lived in really clean, low pollution areas. So, you know, I'm not getting exposed to a ton of exhaust or factory fumes or anything like that. You know, so I was, we were living a really clean life when we were camping.

Here, Keith homes in on the elemental factor of pollution. He mentions exhaust as well as fumes from industrial production and how their absence meant he was able to live a “really clean life”. This cleanliness implies a lack of chemical intrusions. For him, the Southwest is mostly about a respite from the chemicals. However, for his former partner, who convinced him to camp with her for years, this relocation was also driven by mold exposures. Although she relocated to the Southwest, she was unable to tolerate the mold in her supposedly safe housing, and she had to find a new place within the Southwest to live. This led them to a period of their lives spent nomadically (more on those experiences in a bit).

How do people decide where to relocate? I talked to Mark about how his wife determined where they should relocate. She is environmentally ill, while he is not, and he was one of the few family members I was able to interview during my field work. I value his perspective as he is someone who takes this illness experience seriously, has to participate in much of the illness labor himself, but does not have the same relationship between his body and place.

> Mark: You know, we tried finding places in California, but then she decided no place in California would probably work for her.
>
> Isabella: Okay, why was that?
>
> Mark: I think she just felt it was all going to be too polluted. And the (wildfire) smoke is a big problem. This actually out here, the smoke this year, it hasn't been a problem. Because they didn't do the controlled burns. The previous three summers…So the air is generally pretty good here… And that's what most of the people that are here, I think are [here] for air quality. I think that's one of the big attractions. Of course, [when] the pig farm fires up. Do you know about the pig farm?
>
> Isabella: Where is the pig farm? No one's talked to me about that yet.
>
> Mark: Yeah. It's probably six miles or so west on...
>
> Isabella: The road that I'm on?
>
> Mark: Yeah, and it's a big operation. I mean, it's an industrial pork factory. And it's changed ownership a number of times. I think what it is, is once a week or so they have to clean out the- they run some cleaning operation, right. And a lot of stuff gets pushed out…and if the wind is blowing in your direction there. It's awful. And it'll last you anywhere from 20 minutes to three hours. It's like you have to be inside, right? I once made the mistake of having laundry out. And it's like you have to throw it out. You can't get that stench [out]. I tried washing it a couple of times, and it's like, no, it just has to go.

For Mark’s wife pollution and smoke were the chief factors in deciding where to go. Pausing on the pig farm for a moment let's consider Mark's comments on the wildfire smoke. Although he is telling me it has not been a problem this year, he implies that it is a problem in other years, years that they do controlled burns in the area. The wildfire smoke is what drove them from California

but now it is migrating into the Southwest as ecologies rapidly change under new climate regimes. One of the appeals of the Southwest is its rurality. However, the existence of the pig farm, which most people did not mention in our interviews, indicates how imperfect even rural areas are for escaping pollution related to industrial production.

After pollution, mold was the most salient environmental element in relocating. Many of my respondents had coexisting mold sensitivities that limited their housing options at both the micro and regional scale. These can also limit participation in public life in a similar way to chemicals. Kelly, for example, can't attend church or go to the local hospital due to mold, and mold has played a role in her ability to seek out wellness treatments like massage because many of these facilities have mold. Melissa told me how mold sensitivity exacerbated her chemical sensitivity. “I feel like moving to [the Pacific Northwest] and having mold exposure is what took my chemical sensitivities from kind of like an annoyance and bumped it up to like, very life limiting.” Here we see the role of geography and elemental environmental factors in exacerbating illness. Melissa ended up leaving the Pacific Northwest for the Southwest after realizing there was nowhere there that her body could tolerate. She is currently trying to relocate again, to a different Southwestern state where “you're more likely to find pockets of what they call good air”. She also remarked that there’s a place south of where she lives now “that feels so much better to me then where I'm living, and then where I'm living feels better than in town”. Melissa is participating in micro-relocations, trying to match her body to the part of the region where it feels best and where there will be the lowest levels of aggravating elements in the environment.

Terpenes in wood can be a similar aggravation that leads people to seek out unforested parts of the Southwest to live. For a time, people moving from the West Coast also found relief from wildfire smoke as we saw in Mark’s comments. This smoke is another environmental element that can impact the health and symptoms of those with environmental illness. As climate change worsens, wildfire smoke has become a major consideration even for people living in places like Juniper that are considered some of the best in the country for mitigating symptoms of chemical reactivity. One respondent walked me through his escape plan for wildfires and two of my respondents had together done work in local politics to try to prepare emergency responders for the needs of those with chemical sensitivities during wildfire evacuations and crises. The relationships that the chemically reactive have to their environments, and the ways

they consider elemental factors in relocating, demonstrates the entanglements of chemical and natural concerns. Their narratives blur the lines between what is cultural and synthetic and what is natural and environmental. This is a major premise of environmental sociology itself, that ecosystems and social systems are inextricably bound. While environmental sociology pays less attention to the body's role in this process Stacy Alaimo's work deeply situates the body within this ongoing relationship. She writes, "the human body is never a rigidly enclosed, protected entity, but is vulnerable to the substances and flows of its environments, which may include industrial environments and their social/economic forces" (2010: page 28). In her chapter specific to chemical sensitivities, she writes that "[MCS] may well be the quintessential example of what I'm calling trans-corporeality, as those who are chemically reactive experience their selves as coextensive with the material world" (2010:116). This coextensive relationship with the world is a piece of why people with this illness work so hard to seek out places their bodies can tolerably co-exist with the material world around them. This is not just about chemicals but also about smoke, mold, electricity, allergens, and other environmental substances.

Dozens more stories of relocation can be found in the environmentally ill artist Rhonda Zwillinger's photography book, *The Dispossessed: Living with Multiple Chemical Sensitivities.* Zwillinger compassionately documents the lives of people who relocated to the Southwest hoping to escape from chemicals and improve their health, a journey she took herself. Of her own story she writes, "Moving to Tucson with the hope of finding a clean, 'safe' environment in which to heal, I found instead a pesticided, petrochemical polluted ex-paradise. Within a few months, I bought five acres of land in an isolated spot in Northern Arizona and had a 450 square foot 'safe' house built to my specifications" (1999:7). Here, she draws our attention further to how the Southwest is an uneven landscape of respite. Although I met people in online support groups who did live in Tucson and other Southwestern cities, I also met people like Zwillinger who were forced to leave these cities for more rural areas. We see this unevenness not only in the divides between the perceived safety of urban versus rural environs but also in the Southwest's history of nuclearism.

Much of the Southwest, especially New Mexico and Nevada, is intensely chemically contaminated from uranium mining, nuclear testing, and weapons testing. These militarization processes are forms of what has been termed "internal nuclear colonialism" (Kuletz 1998), "wastelanding" (Voyles 2015) and the "treadmill of destruction" (Hooks and Smith 2004). They

cannot be analytically subsumed by mere capitalist accumulation and production or by cultural incentives for chemical production. These theories of militarization and environmental destruction direct us to pay attention to the way in which nuclear environmental harm is a facet of settler colonialism that disproportionately harms Indigenous people. These harms manifest in the body as radiation and chemical poisoning and also in the destruction of sacred landscapes and relationships with more-than-human communities. In her work on the closed Russian city of Ozersk, home to Russia's first plutonium plant, Brown writes of the nuclear legacies engraved into residents' bodies (2016). She calls the human body the "last sink" and the "ultimate radioactive storage site". Here too, I would like to conceptualize the relationship between waste - which requires waste sinks- and the body as the last sink. We are all of us repositories for waste. The Anthropocene era is often visualized through stratigraphic sections of the fossil record that illustrate different geographic epochs. However, evidence of the Anthropocene exists within our bodies as well in the forms of microplastics and chemical residues, and in the aftermath of those residues as they alter fundamental processes in our bodies and the bodies of generations to come. Those with multiple chemical sensitivity claim an embodied knowledge of this process, this reality.

There is an irony in the Southwest's construction in the geographical imagination (Harvey 2005) as simultaneously a site of relocation for health, healing and wellbeing, and a place intimately layered with ecological and physical violence. These layers rarely came up in my interviews. Even nuclear waste - a significant form of pollution- was only addressed by one of my respondents. This could be due to the specific places that I went to in my fieldwork, but it could also indicate the unthinkability of certain forms of pollution and the ways in which some people may enjoy a protective ignorance about certain chemical histories.

Relocation as a Chemical Avoidance Tool

Relocation is the ultimate avoidance tool for those who can afford it or those who have exhausted all their other options. Relocation is entangled with narratives of both economic privilege and profound desperation. Some people who relocate are those who can afford to carve out a private "safe space" in the form of environmentally ill housing. For others relocation is born of extreme desperation. These people do not relocate to live in custom environmental

housing but rather travel around in their vehicles, camping on Bureau of Land Management territory or in small communities of other environmentally ill people. This complicates our understanding of environmental privilege; on the one hand relocating to Juniper (or somewhere similar) and building chemically and electromagnetically safe housing takes some amount of financial backing, and it is recognized by many as the best-case outcome for the severely chemically sensitive. On the other hand, relocation to the Southwest can be a last resort. Keith told me this about relocating and coming to Juniper:

> We need more housing because there's so many people who- affordable housing, too. There's so many people who just can't live in regular houses and apartments, either for chemical and or electrical sensitivity reasons. And they just have nowhere to go, and I know multiple people living in vans or cars, who are just really sick, and they don't have the money to even consider buying a place like this. I mean, Martin always says, 'We're the lucky ones' that yeah, it sucks to be us. But in a way, we're really fortunate that we have a tolerable home on 20 acres. I mean, there's many people that would give anything for this kind of setup and I've been there and I'm really grateful to have it, but I also want others to be able to have that too.

While Keith and Martin consider themselves "the lucky ones", relocation is a fraught choice. Myles told me,

> Yeah, and the fact that for some of us to feel well we often have to go way out in the middle of [the Southwest] or whatever, and just how lonely the prospect of that sort of thing is and that a lot of the times we're navigating between, like, what's best for health and what's a livable life? And, you know, trying to be like 'Well, I mean, I guess the city is okay'. And I'd rather live in a city and not feel my best and maybe even progress my disease a bit, then waste away and wait for death, while just sitting at the edge of some empty road in [the Southwest]. And now, it's not even like [the Southwest] is safe anymore, thanks to climate change and the wildfires. So, there's no good place for us at this point.

He traces the differences between physical health and emotional wellbeing. Myles believes relocation would worsen his quality of life even if it helped him cope with his chemical sensitivities. He also points out that due to broader ecological changes there is "no good place" at this point in time. I would trouble the idea that there ever existed a "good place" to escape pervasive chemical pollution. Similarly, we can see how quickly the idea of climate havens are vanishing as supposedly safe places like Western North Carolina and Vermont are struck by floods of Biblical proportions. These are momentary ideas that respite can be found, that we can carve out inverted quarantines, that we can make ourselves and our loved ones safe as the ecological degradation of the world accelerates around us.

Even respondents who had chosen to move to Juniper mourned their old lives, especially having public activities they could participate in and being in politically more liberal areas. Nancy told me,

> Most people with this disease can't, can't just pick up and move right? If family responsibilities or a spouse with a job or kids in school or they know that their particular way of being a human being would not fit into [Juniper] for whatever reason. It's somewhat conservative here. There are a lot of people who are stuck in the city, for one reason or another, like they have a good doctor there. Or their entire social life is there, and they would rather die in the city than live someplace where they would feel like an alien. And that is absolutely fair. I mean, it's not fair to them. But it's fair to draw that conclusion.

In this excerpt Nancy points out the reasons why relocation is not always an option, including issues of identity, which she describes as one's "particular way of being a human being". This is something that came up in other interviews as well. I heard of several instances of harassment from people living in Juniper directed at gay couples and people of color who were part of the MCS community. There is a tension around how "safe" Juniper is. It might be more chemically, electrically, and ecologically safe but it may not be socially safe for all people to relocate there. Nancy also noted the precarity of Juniper as a site of relocation.

> If the family over there across the street, who are not environmentally ill people, if they weren't growing organic corn, if they decided well, let's just spray the crap out of this whole place. We'd have to move. That scares me. So, I figure with any luck I'll - this place will still be intact for a long time. And if not, then I guess I got to think about where to land on my feet someplace else, but I don't know if I can, but that the housing situation is such that we are the luckiest of all to live here and have a house or a trailer or sleep in our car.

The safety of Juniper is tenuous, contingent on the actions of proximate others as well as on larger social and ecological forces. We can already see how climate change, in the form of wildfire smoke, is beginning to transform the region and introduce new concerns and barriers to residents who have relocated for their health.

Nomadism

Relocation is not necessary about permanence, which often involves the lasting creation of safe space and the ability to be in community with other sufferers like it is for many who move out to Juniper. Especially for those living in poverty, nomadic lifestyles are often imposed by multiple chemical sensitivity. However, sometimes this imposition comes from the inability to tolerate any environments. As Ms. and Mr. P tell Zwillinger "We travel around the Southwest in our trailer throughout the spring and summer. We cannot find a place to settle that we can both

tolerate" (1999:81). Another woman profiled said, "I rented an apartment only to have access to a bathroom and slept outside in my tent. This was the beginning of my nomadic life. I traveled south to live near the beaches until springtime, then up the east coast to Maine. I still live in my tent which is currently installed in the backyard of my rented house" (Zwillinger 63). Still another woman said, "I live in Northern Mexico near the ocean and have had to move myself, my daughter and the sauna eight times in 18 months seeking a 'safe' place to live" (1999:74). These narratives parallel those of consumptives in the region from the early 19th century. While those with economic privilege could afford private sanatoriums, prior to the creation of state sanatoriums, many people flocked to the area thinking it could cure their tuberculosis but without the means to recover comfortably (Lewis 2012). This population hoped to "chase the cure on their feet" (Lewis 2012: 148) thinking that the climate alone would cure them. Unlike the chemically sensitive, they became the target of public policy efforts, and many places began refusing to rent rooms to those who were sick. While the chemically sensitive are not explicitly targeted in this way, they do get caught up in the broader politics of housing, homelessness, and the use of public lands.

This idea of a nomadic life is echoed in my interview with Matilde who described herself to me as an "environmental refugee". She told me,

> Matilde: If I just leave the environment away from all this stuff, my bladder still bothers me but not to the same extent
>
> Isabella: What does leaving the environment look like? Because obviously, these things are so prevalent everywhere, like I've learned just through doing this project that pesticides are way more places than I previously imagined that they were.
>
> Matilde: Yeah, yeah. So, I'm actually kind of like an environmental refugee. I'm having a really hard time trying to figure out where I can belong because I'm always on the run in my van, well when it runs.

I was struck by Matilde's phrasing of "leaving the environment". How can one separate oneself from that which we are inextricably bound into? It would be like leaving the body itself. But here we see that what she means is finding a different environment, a place where she can "belong".

Escaping the American Dream

When the chemically sensitive retreat, what are they retreating from other than chemicals and environmental elements? Steve Kroll-Smith frames this as an escape from the American dream writing, "A small, but growing number of people from the world's most prosperous nation are escaping from nothing less than the 'American dream.' They are seeking refuge from a material culture whose promises of the 'good life' are sources of profound physical and emotional impairment. And they are unwelcome reminders to the rest of us that human bodies and physical environments are never separable" (Zwillinger 1998). In this search for refuge from a toxic and untruthful material culture we can see the links between culture and environmental injustice. Zwillinger refers to this retreat as a "dislocation" and calls people with multiple chemical sensitivity the "dispossessed". These word choices imply a disturbance and a deprivation from a usual state of being, belonging, and ownership. However, these promises of the "good life" as Kroll-Smith puts it, are built on the continued existence of capitalism and settler-colonialism, cultural practices that use consumption as a shortcut for meaning and identity, alienation from each other and from our environments, and commodity fetishism. The American dream rests upon ongoing and historical ecological violence, violence that many people are inculcated from. People with chemical sensitivities occupy a strange social location. On the one hand, they don't seem to think too much about the history of nuclearism of the region, ecological violence that targeted Indigenous people in the region. At the same time the chemical saturation many of us are accustomed to is read as a form of violence to them. They know intimately, in a bodily way, how the proliferation of chemicals is jeopardizing life, health, and the wellbeing of all creatures on earth. The evocative phrase "canaries in the coal mine" is used by those with environmental illness to describe their historical position in the world. This phrasing powerfully connects their bodies to the bodies of other living creatures.

The Problem of Housing

At the end of my interviews, I always asked about what the government could do for people with chemical sensitivities and if there was anything else they wanted me to know. Frequently, this is where housing policies came up. Housing conditions and homelessness are environmental justice issues that are receiving more attention within urban and environmental sociology as climate

change exacerbates them both (Goodling 2020; Speer and Goldfischer 2020) In the below example Nancy emphasizes this desperate need for housing. This is reflected in activism work she and others with chemical reactivity have done in California and the Southwest to get state housing that is chemically safe.

> Isabella: Is there anything else that you really want to make sure that you say or that I know.
>
> Nancy: We need housing. We need housing. Terribly bad. Not all of it here. And it's, it's wonderful to have this neighborhood. And then it's lasted us for 30 years. That's amazing. It might not last forever. I know that somebody could move in next door with a laundry product problem and drag us off? In which case we're gonna have to sell our stuff and try to buy yurts or something. I don't know what they have. Because we could get run out of here real easily.

In the below excerpt Nancy explained to me how tenuous relocation to Juniper was. I knew from reading about the community online that they were not well protected from the encroachment of businesses or other residents and that they had no formal protections in place from the state. I wanted to hear Nancy's perspective on that as someone who is one of the longest residents in the community and someone who has done a great deal of activism work.

> Isabella: Do you see that as like if they put in certain businesses down this road? That seems dangerous to you.
>
> Nancy: It is. We don't have zoning protection. The closest we have to protection through zoning is the 40-acre parcels and they can legally be divided into two parcels. And that's why so many of us have yards that are this particular size. We don't have protection; we don't have covenants that are enforceable. I mean, we don't hurt each other. We go way out of our way to keep our colleagues as safe as we can. And of course, we blow it sometimes and make our friends sick, but we sure try not to. But if some - if people who are not us want to use conventional products, like if the family over there across the street who are not environmentally ill people if they weren't growing organic corn if they decided well, let's just spray the crap out of this whole place. We'd have to move, you know. That scares me. So, I figure with any luck I'll - this place will still be intact for a long time. And if not, then I guess I got to think about where to land on my feet someplace else, but I don't know if I can, but that the housing situation is such that we are the luckiest of all to get to live here and have a house or a trailer or sleep in our car.

I already mentioned precarity, but here we can see how that precarity is tied to both housing and the lack of regulations in the form of zoning protections. Nancy explains how the size of the lots sold in her area acts as a slight form of protection as they are big enough to give a bit of a buffer from the actions of neighbors. Without state interventions, their wellbeing is critically tied to the actions of proximate others and their willingness to accommodate them.

Conclusion

What can this case tell us about relocation, safety, and environmental health? To paraphrase Taylor (2024), what does it tell us about living in the aftermath (or in this case, continuation) of environmental illness? In a way, where geography might be a partial solution, it also creates a more traditional environmental justice struggle in some ways. Once people cluster, for an environmental reason, for a community reason, etc., then they exist as a unit and must struggle through similar problems as other environmental justice communities in the more traditional sense. This means they must deal with zoning laws, being an effective political actor as a community, and dealing with any acute sources of pollution that do exist near their residences.

This relocation to escape a pervasive environmental problem is a harbinger of what is coming now with climate change migration and relocation. People with environmental privilege are beginning to factor climate change into their decisions about where to live and build their lives (Simon 2024). The people who are left behind are often those with particular vulnerabilities- the impoverished, the disabled, and the elderly. Geography is taking on new environmental justice contours as climate change makes and remakes our natural and social worlds. It is eerie to see a parallel case that already happened and is already happening, when it comes to seeking escape, finding a safe space, and carving out a piece of the world in which you can be inculcated from the greater ecological rifts that are carving through our lives. Climate change takes on salience not only for the way people engage in parallel problem-solving endeavors but for how it is expected to transform the Southwest. The American Southwest is getting hotter, dryer, and more prone to wildfires. What will happen to people with environmental illness already living in this area? What will happen to people with multiple chemical sensitivity elsewhere who no longer have the Southwest as a place of potential retreat and healing? The Southwest functions as a way to give people with this illness experience hope. They hope there might be a place that they can go where the conditions of their lives can change.

This search for a safe space from environmental illness parallels the search for climate havens. Certain cities and towns like Buffalo, NY and Cincinnati, OH are now even billing themselves as a “climate change refuge” and “climate haven” respectively. (Be in Buffalo 2024, City of Cincinnati 2024). At the same time, climate change is advancing so rapidly as to quickly dissolve these myths. Asheville, NC, a town some residents report moving to in recent years

specifically because it was seen as "safe" (Simon 2024), has been devastated by Hurricane Helene. Some of the smaller mountain towns in Western North Carolina have been completely destroyed by flooding. This is an area 300 miles from the Atlantic coast. I lived in Asheville in my early twenties, and it is a place I have always carried with me in my heart. Vermont too has been subject to climate change induced flooding. This is expected to get worse as temperatures rise and rain patterns change (Picard et al 2023). This framing of particular places as "climate havens" matters because it illustrates how alive and well the fantasy of a safe place is even (or maybe especially) in the face of devastation wrought by a changed climate. As Grossman writes, "American culture is desperate for "safe" havens, inventing categories to define that safety and to project the ameliorative fantasy that we can attain mastery of our environments" (2005:n.p.). One such invented category is climate haven. This category reasserts ontological stability in the face of climate change, suggesting some spaces will remain protected, and even ideal as the City of Buffalo's website argues. They write, "In the not-so-distant future, Buffalo may have the most desirable climate in the United States…The effects of climate change may cause frequent drought, unlivable heat in some areas of the country, and a higher quantity and severity of natural disasters, each of which Buffalo is better protected from" (2024). But there are no places that will be spared from climate change, whether because they experience disasters or their ecologies change, or because the social impacts of climate change inscribed themselves onto these places. For example, where will climate refugees go? How will these relocations reshape places? The conditions that we live under now threaten human and more-than-human life. The ramifications of these ecological unmakings are coinciding with the unraveling of democratic governments, greater violence over resources, and increasing death and sickness from disasters, pandemics, and food insecurity.

CHAPTER VII: CONCLUSION

Chemical pollution is one of our major environmental challenges. Despite this, there is much that remains unknown in how we should address chemical pollution, as consumers, as citizens, as institutions, and- as my work makes clear- as social and sociable actors. What sets of chemicals are we supposed to be concerned about? How do we know where they are? Is it acceptable for the environmentally privileged to fear the contamination that lurks in consumer products when so many people are being poisoned in more acute and egregious ways? What are the thresholds for how many novel chemical inputs can enter our bodies and ecosystems before doing irreparable harm? As people in the United States and Canada living under neoliberal governments, we are taught and conditioned to manage our chemical body burdens with market-based solutions. We are told to be concerned about the risks that chemicals may pose to our health (and our children's health) in the future, but we aren't explicitly taught to notice or fear the impacts that toxic chemicals may be doing to our bodies today. We aren't asked to invoke other people and their relationships to chemicals when we shop, clean, dress, cook, or garden. Looking at the case of chemical sensitivities breaks apart the social myths we tell ourselves about how environmental problems are separate from social problems, especially when it comes to our intimate lives. In my work I ask people to think about how the problem of toxic chemicals is one that can become embedded in our social lives.

To better understand how chemicals are socially constructed as present in our everyday lives I posed the following research questions:

1. How do people with multiple chemical sensitivity practice chemical avoidance?
    a. What tools and resources do they invoke to determine where chemical risks are present?
2. What are the outcomes of practicing this chemical avoidance?
    a. In particular, how does practicing this chemical avoidance impact their relationships with other, non-reactive people?

To answer these questions, I conducted an ethnographically informed interview project pulling particularly from strategies of enactive ethnography (Wacquant 2015). My study serves as an empirical investigation of the way a subculture creates and enacts practices around environmental health. Multiple chemical sensitivity exists in a liminal space between the acute

chemical poisoning demonstrated in environmental health cases and the haphazard consumer responses generated by risk society. Prior work examines how concerns about chemical pollution are organized through personal consumption (Szasz 2007; MacKendrick 2018) or within environmental justice critiques of industry and the state (see Bullard 1990; Cole and Foster 2001; Pellow 2004). Instead, this case demonstrates that chemical contamination can be an issue of concern within interactions and relationships. In particular this case works as an empirical test of Szasz's concept of inverted quarantine. In Szasz's work inverted quarantine is a pipeline to political anesthesia because it convinces people they *can* go it alone. As my project demonstrates, the chemically sensitive are forced to go it alone. Unfortunately, this is not a very successful strategy for them. As we saw, chemicals and fragrances permeate their living spaces and cause them distress in their interactions with other people. They need other people and broader social forces to align with their practices around chemicals if they want to participate in social life. Instead, they live in social isolation. Their chemical practices do not lead the belief that individual consumption and behavior changes alone are a sufficient defense from the toxic hazards in our world. They also do not lead to apoliticism, even though sometimes it may be hard to see how politics are enacted in their lives as they struggle to manage their health.

In this dissertation I trace how these practices of chemical avoidance displace significant amounts of labor onto the chemically sensitive (Chapter 1). Like the illness itself, this labor is invisible work. It isn't recognized as valuable to the economy, or even to the social reproduction of the individual. Major outcomes of practicing chemical avoidance in this way are redefining risks as relational problems (Chapter 2). This has profound impacts on people's relationships and can lead to social isolation if proximate others are not willing to take on new responsibilities of chemical and bodily management. I also found that rather than relying on labeling and scientific research on chemicals, the chemically sensitive learn to rely on tacit, embodied knowledge in order to avoid chemicals in daily life (Chapter 3). Another significant way in which some people with chemical sensitivities practice chemical avoidance is through relocation. The American Southwest is a particularly popular place to relocate. I find that the Southwest holds symbolic weight both for the chemically sensitive and within broader histories of health seeking behavior in the United States (Chapter 4). Most importantly, I show how these facets of the illness experience compound into profound isolation from the world in both the public and private sphere. Even the economically privileged cannot find a retreat to the safety of domestic life that

remains pleasurably sociable. Being cut off from the world in this way leads to profound feelings of alienation, shame, and betrayal. This dispossession from the world is driven by differing constructions of where and how chemicals exist in our social lives. This illness is one that is fundamentally relational in nature.

Relational Illness

Chemical sensitivity is an example of a "relational illness." Kroll-Smith and Floyd define such illnesses as ones in which "the degree to which debilitating symptoms are believed to be caused in part by the personal habits and routines of people who live or work in the social circles occupied by sick people" (1997: xii). In this case, such relationality is due not to a virus but to chemical exposures which are seen as present and transmittable in social interaction. Here I think it is helpful to think through how MCS parallels the COVID-19 pandemic. For those of us living in Western countries, COVID-19 was an inciting event that transformed our breath into a social object. Seemingly overnight we became expected to take responsibility for how our breath spread in social interactions and public space. New norms, practices, and discourses emerged as we made sense of these shared responsibility. We also saw during COVID-19 how individualized the response was, how politicized community protection strategies became, and how the most vulnerable members of society were written off. Even now, the immunocompromised are watching as the world refuses to permanently transform in any way for them. Promises of increased ventilation in buildings (which would have also benefited those with chemical sensitivities) have fallen through and vaccine mandates continue to slacken. Instead COVID-19, like other viral infections, became once more something to manage alone as individuals. This parallels how people with chemical sensitivity experience the world. They are uniquely vulnerable to a persistent health threat that everyone else accepts can be managed individually. While chemical sensitivity as an illness is invisible to most of us, we all lived through the visceral and emotional realities of COVID-19. This included the newfound responsibilities that were created and then unmade as well as the struggles of social isolation. What would it look like to address these relational illnesses, not just at personal or institutional levels but also within our relationships with others? How can we enact what DeSoucey and Waggoner call "responsible sociality" towards others around chemicals (2022)?

In the case of chemical sensitivities, there are several things that might change if we took the assertations of the environmentally ill seriously. From an institutional perspective, new lines of research and citizen science might emerge that addressed the issues of "undone science" (Hudson 2022) that surround this illness. It could be significantly easier for people to access the disability benefits they are supposed to be entitled to under this diagnosis. Organizations and workplaces could better implement fragrance-free policies with clear expectations and communications about how people can achieve fragrance-free bodies when in certain spaces. This solution co-exists with changed norms of communication around the body, product use, and expectations of others within social lives. Bodies and odors are particularly taboo issues in social life, which works as a barrier for productive conversations with others around this issue. And finally, taking this illness experience seriously also means taking social isolation itself seriously as a society. We need to work harder to be in good relation with one another and enable all members of society to lead dignified and social lives. We cannot disentangle our bodies from our material environments. We cannot be free of nature, and we cannot be free of each other. Those with multiple chemical sensitivity transform chemicals into a social health issue, rejecting the cultural mandate that health is a matter of total personal responsibility. We can't manage chemical exposures alone, we need to find ways to manage this together, beyond the family, beyond the work mother's do for their children.

Contributions to environmental sociology

Relationships and embodiment are at the heart of this case. My work addresses one particular way that structural problems get into our relationships and how the environment is a part of this. When our family and other intimate ties are our main social safety net, as they are in the United States, and those relationships falter, what happens to people? They slip not through the cracks but through the gapping chasm at the heart of our social order. This is, of course, true of innumerable cases of social inequality, precarity, and poverty. In this case though, relationships falter as a result of different interpretations of the body and reality. Significantly, these different interpretations revolve around understandings of how chemical exposures enter into our daily lives. Those with chemical sensitivities are making the case that environmental health risks are present and affected by our interactions with others. The threats and risks that they perceive arise in mundane and privileged spaces and they arise through the actions and embodiment of social

others. This brings relationships and embodiment to the fore of a significant environmental problem, that of pervasive chemical pollution and exposures. It spotlights how chemical pollution is an issue that does not exist separately from our social lives. Theoretically, work on the body is slim within environmental sociology. My work foregrounds embodiment within a case of environmental health, letting us see how interpretations of our bodies, our interpolations with our environments, and our sensory experiences are historically shaped and subject to change.

Further work

I gathered more data in the field than I knew how to manage, especially within the time constraints of writing a dissertation. In analyzing my work and thinking through its theoretical significance I was frequently left feeling like I was looking through a "kaleidoscope" (Kari Norgaard, personal communication). Slight shifts in perspective created new images of what my data meant and what it might say about how we organize ourselves and our interactions in relation to the environment. There are a few threads that I plan to return to in future work on this case. Class position is clearly important in how people are able to access diagnoses and knowledge about chemical sensitivities as well as how they are able to formulate effective and dignified responses. And yet, higher class state does not necessarily inculcate people from experiencing significant environmental health issues. Examining this could lead to productive theorizations of how class positions work under capitalism with relation to the environment, particularly as it comes to health and risk. Additionally, this case is one of a contested illness that is both gendered and environmental. As contested illnesses are usually bracketed by either gendered or environmental origins, an eco-feminist analysis could shine light on how the delegitimization of both gendered and environmental concerns co-create contested illnesses. The most challenging part of this project for me was finding a way to balance the sociological necessity of approaching all illnesses as beholden to degrees of social construction with the desire to not discredit or further stigmatize my respondents and all people suffering from unexplained illness. Methods work that extrapolates best practices for managing these sets of concerns, both of which are valid but exist in a delicate tension with each other, could be of benefit for future scholars and for people living with these kinds of illness experiences who seek to understand why researchers discursively represent them in particular ways.

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