

Spring 2021

The Real on Food-Related Medical Conditions: Narrativizing the Respective Lived Experiences of Eight Interlocutors Around Their Unique Food Needs

Christina Sinclair Jones
Bard College, cj1923@bard.edu

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Recommended Citation

Jones, Christina Sinclair, "The Real on Food-Related Medical Conditions: Narrativizing the Respective Lived Experiences of Eight Interlocutors Around Their Unique Food Needs" (2021). *Senior Projects Spring 2021*. 225.

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The Real on Food-Related Medical Conditions:
Narrativizing the Respective Lived Experiences of Eight Interlocutors Around Their Unique
Food Needs

Senior Project Submitted to
The Division of Social Studies
of Bard College

by
Christina Sinclair Jones

Annandale-on-Hudson, New York

May 2021

This senior project is dedicated to my parents. I love you both, so very much.

Acknowledgements

For my entire life, it has been my parents and me; we are a family of two plus two makes three. I love them both with all of my being. Mamma and Daddy, you each own perfect halves of my heart. Mamma, tack för allt du gör för mig, och för all ditt stöd. Jag älskar dig. Daddy, thank you for teaching me how to use my work and my music to “hang tough” as an act of love for myself and for my future. I love you.

Momsey, I feel you with me every single day. Thank you for continuing to play such a huge, active role in my day-to-day. I cannot imagine my life without your guidance and love; so very much of what I do, I do in an effort to become more like you.

Aunt Quay, thank you for being my “Godgrandma.” You mean the world. Auntie Kendal and Quay Quay, thank you for everything.

Godmommy Angie and Auntie Chrissy, thank you for being my fairy godmothers.

My beloved friends, thank you for being my rocks. In no particular order, Janel, Jackie, Iza, Julianna, Irene, Ana, Brooke, Juliana, Shaunee, Sarina, Kaila, Alex, Olivia, Kelcey, Walker, Triple L-C, Lily Mo, Laith, Shannel, CSJ, Emelie, Aurelia, Celia, Ori, Ella, Laura, and so, so, so many more!!!

Eileen, thank you for being my “Bard Mom.” You don’t even know how much I appreciate you and all of the love and support that you’ve given me over these four years.

Paul, thank you endlessly for guiding me through this Sproj-writing process.

Monique, thank you for being the best mentor that a girl could ever ask for.

Peter, thank you for it all. You have taught me enough for a lifetime in these four years - I will always use what you’ve taught me, and when I make music, I will think of you.

And last, but *certainly* not least, Yuka, thank you for it all. Thank you for instilling in me a deep love of Anthropology and deeply-generative curiosity. Thank you for advising me for four years and for helping me navigate all sorts of highs and lows. Thank you for encouraging me and challenging me to write the best ethnographic research project that I could. I am so excited to continue our work together in the near future!

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Christina Sinclair Jones

Chapter I: Introduction

My dad and I were at Target, rushing around the school supplies pop-up sections that they had set up at the very front of the store. It was the first day of my senior year of high school, and as I was already feeling the stress and dread with which I would soon be embarking on my college application process, I was determined to ameliorate my anxiety by distracting myself with labeling and organizing new notebooks and jell pens. Dad had just finished working for the day and it was early enough in the afternoon that it was still quite hot outside: a September afternoon in New Jersey. I took the train home from school and ate one of the little hummus and pita packs from Trader Joe's that had become my favorite snack of the moment. As I was eating, Dad told me that he was already set to go, and we left to try to beat the school supplies crowds. It felt exciting, and different somehow, to be shopping for notebooks and pens as a senior; this particular Staples run felt to me like the beginning of the end of one of my many childhood traditions.

We had just gotten into the store, and Dad was reading the labels of various notebooks to rule out the ones that were not college-ruled, when I began to gag and dry heave. I was petrified already, as I am quite afraid of vomiting, and I cry each and every time that I have the misfortune of vomiting, to this day. There I was, tearing up at the front of Staples. Dad immediately began to ask me if I was alright, if I wanted to sit down, if we should walk over to the bathroom, if we should get some help... and the one question out of all of these which I remember most vividly - and with a shudder, I might add - is, "Sweetie, are you breathing?"

I realized that I wasn't. I wasn't breathing. I was born with asthma, and I would have

asthmatic flare-ups as a kid. Still, I had never felt anything quite like this, this sensation of one end of my throat enveloping the other, so as to close off my throat entirely, erecting a barricade to keep anything, including air, from passing through my esophagus. I gasped for air and did not get any. There was surely air around me. Dad was breathing; the people blurring past me were breathing... This wasn't like the wheezing or the dry, relentless coughs to which I was accustomed. No, this was wrong. "Daddy, I need help," I managed. He nodded and with a look in his eye of fierce protectiveness that I have never seen in any human's eyes but my father's, he grabbed hold of my hand and quite literally dragged me out to the parking lot.

When my dad is nervous, he forgets the directions to places with which he is familiar. Thinking back on our car ride to St. Barnabas, my heart pangs and I feel an urge to text my father that I love him, for he struggled so much with getting directions on Google Maps to a hospital six minutes away that I know he was terrified. He must have asked me thirty times if I was breathing by the time we got to the front entrance of the emergency room, and he kept his right hand on my left leg for the entire car ride. I remember the warmth coming from his hand and I find myself feeling grateful, as this warmth quite literally kept me alive. It was my grounding, and it is all that I remember of this ride, other than the check-ins from Dad, and the fact that Old Short Hills Road looked confusingly foreign to me.

When we got to the check-in desk at the E.R., Dad told the nurse who was checking me in that he thought that I might be having an asthma attack, but that it seems different to him from anything else that he has ever seen me go through. Before I was even given a hospital bed, I was put in a wheelchair and the nurses at the front of the emergency room took my oxygen level. It was just below 100. Odd. So odd. No one, the doctors who eventually examined me included,

knew why I was breathing so well according to the pulse oximeter when I had been dry heaving and coughing spastically, just to keep myself alive, and simultaneously gasping for air and sort of flailing my arms around because what I was experiencing felt exactly as I imagine drowning feels.

It was frustrating. I was given fluids and spent several hours breathing through various oxygenated masks and machines as I sat up in that stiff hospital bed, my long legs sort of half-hanging over the creaky frame. Ironically, a nurse offered me a peanut butter and jelly sandwich while I was in bed, and I declined this offer only because I knew that I would be eating dinner that Dad would make once we got home. I say that this is ironic because just a few weeks later, once I had gotten the results back from the many rounds of skin and blood allergy tests that I would soon be taking, I would find out that I am severely allergic to peanuts. That peanut butter sandwich might very well have earned me another few hours in that very same hospital bed!

Dad and I left the emergency room without answers. Yes, I felt markedly better physically than I had in Staples earlier that afternoon. However, neither of us had any clue as to what had brought on what I can now properly call my first anaphylactic reaction. Not knowing what the cause of what I had gone through that day, or even what it exactly was that I went through, was really scary. I cried a lot that night. Not knowing made me feel small. It knocked me down from the high that I had been riding from finally becoming a senior. I did not know if that scary episode, whatever that scary episode even was, would happen to me again. That in itself was an overwhelming thought to have. All I knew was that I did not want to have that feeling ever again.

~ ~ ~

Why I'm engaging in this ethnographic research and where I come in

I've opened my senior project with this vignette in order to share a small piece of my own food allergy story. At seventeen years old, I had been eating anything and everything that I wanted to eat for my entire life (with the exception of getting an occasional stomach ache after having eaten too much dairy, of course). Chicken tikka masala, a dish whose most important spice is curry, had been my favorite celebratory meal for so long that my parents had begun to assume that as soon as my birthday came around, it was chicken tikka masala that I would be requesting for a special birthday dinner. This is exactly why it was so shocking - and confusing - to find out that I had developed a life-threatening food allergy to curry. The vignette that I opened with describes my very first anaphylactic reaction as I was experiencing it at the time, without ever considering food allergies as a medical condition that could apply to me. It was from this anaphylactic episode that I learned, after a great deal of doctor's visits and blood tests, that I was deathly allergic to curry. *"How could something I've grown up eating suddenly become something that could kill me?"* I asked myself. I felt defeated and sad, as if my body had betrayed me. It seemed incomprehensible that my body's reaction to curry could change so quickly and so drastically from absolutely loving it to shutting down in its presence.

Many folks develop food allergies as small children, so they grow up with an awareness of how to live and operate safely as a person with food allergies. What anyone who suffers from a food-related medical condition learns very quickly is that learning to live with a food-related medical condition entails a duality of grappling with the emotional and the logistical. This project will dedicate space to sitting with and thinking through the emotional and the logistical, respectively. Now, I find it important to state that I was never a "food allergy kid." I spent some

of my most formative years not needing to think about what I could or could not eat. The potentially-deadly traces of an allergen might be contained in something that I was ordering at a restaurant, or taking a bite of something that would send me to the E.R. at a cookout, never crossed my mind as a child. Nevertheless, food allergies found their way into my life in a huge way; I have certainly become a “food allergy adult.” Now, every time that I take a flight, I submit notes to the airline with which I’m flying listing all of my food allergies; I tell each and every stewardess that I come across while aboard the flight about my food allergies and verify that none of the foods to which I am airborne allergic are being served on the flight; and I tell the passengers sitting next to me, in front of me, and behind me that if I even smell curry, cinnamon, or the finely-ground, deliciously-artificial spices in Doritos chips, I may die. It’s dizzying, even for me. Whenever I dine at a restaurant, I end up asking the server to omit or replace so many of the ingredients in a dish on the menu that I might as well have ordered my own custom meal. I often find these rituals of self-advocacy around my own food allergies to be burdensome and annoying. I know that I cannot have so much as a shot at a safe flying experience if I do not pester each and every person around me about whether or not they will be eating curry during a flight, for if someone were to eat curry around me, I could not simply jump out of the window of the airplane to escape exposure to my allergen. I am stuck on a flight until it lands, which means that I simply must speak up and do whatever I can to ensure my own safety. In the same vein, I must be very clear and very specific when I order a meal at a restaurant, in order to do all that is in my power to avoid accidentally eating a food to which I have an allergy. If I do not take it upon myself to tell the server who is taking my order about my book-long list of food allergies, I may very well end up eating something that makes me seriously ill, for I can’t depend on anyone

else to do this work for me. Speaking up means drawing attention to myself in public; thinking ahead of every move that I make; and constantly being aware of what I am eating, as well as what the people around me are eating. I have to speak up, regardless of whether or not I want to. When I'm tired, or I'm feeling shy, I deeply resent the fact that I have to draw attention to myself by engaging in my draining food allergy safety rituals.

What makes me feel the most rotten of all is having to ask the people around me not to eat what they are eating because of my airborne food allergies. Whenever I have to do this, I feel so upset and ashamed that I could cry. *“As if it isn't bad enough that I can barely eat anything anymore, I now have to keep other people from eating their food too?!”* I think to myself in moments of critical self-talk. It feels like a cruel added layer of humiliation to have to approach people, be they complete strangers or friends of mine, and request that because of me and my own needs, they not enjoy the food that they have. Food is to be enjoyed, and I really love eating delicious things. When my mom buys me those barbeque chicken tacos from my favorite restaurant, I start smiling before I even take the tacos out of their container, and I do a happy dance. What if some person came up to me and asked me not to eat my tacos simply because they are airborne allergic to, say, corn, and my tacos are in a corn tortilla? If I did not have food allergies myself, I might be angered by this. This sort of hypothetical scenario, in which I am being inconvenienced by someone else's food allergy needs in the way that I imagine myself to be inconveniencing others with my own food allergy needs, plays on repeat in my mind. I find myself feeling fearful that I am frustrating the people around me or detracting from what I'd like to call their “food happiness.”

The feelings that so often show up for me around having food allergies, such as embarrassment, shame, and resentment, have not been given much room to fully manifest themselves in my life. No one has ever asked me how my food allergies cause me to feel emotionally, so I've pushed my feelings around my food allergies away and buried them deep within myself for years. During that fateful senior year of high school, after weeks of having arms that itched from getting rounds and rounds of skin scratch tests, and after having shown up to gym class for over two weeks donning different bandages every day because I had gotten so much blood drawn and sent off to various labs, I had to figure out how to do life again - this time with food allergies as a very big and very new addition to my own personal mix. I hated having to ask my friends to pick a different restaurant for Friday dinners; I didn't like changing their plans, or feeling un-fun. I also hated coming home late from going out with friends with a rumbling, empty stomach because I had been too shy or too nervous to tell them that it wasn't that I wasn't hungry, but that I couldn't eat any of the food that was available. Thinking back on that first year of learning how to live with food allergies brings me pain. I find myself wishing that that scared, anxious, and angry teenager had been given an opportunity to vocalize how she was feeling, instead of silently dragging painful emotions around with her everywhere she went. Remembering the web of emotions that I was silently dealing with around my food allergies back then, and knowing how living with food allergies still causes me to feel today, is exactly what has moved me to write this senior project on medically-imposed dietary restrictions (a term I use to encompass dietary restrictions due to any and all food-related medical conditions, instead of limiting the scope of this ethnographic research project to food allergies alone): I figure that surely, if I have spent years silently fighting my own internal battles over my food allergies, there

must be someone else in the world who is also having to process difficult emotions as a consequence of having a food-related medical condition, on their own. I want this project to be a safe space where any and all emotions which show up around medically-imposed dietary restrictions are welcome, and can exist, be discussed, and be shared with others. I am committed to honoring the respective narratives of my interlocutors throughout this senior project. Giving voice to, sitting with, and analyzing the emotional complexities of everyday life as a sufferer of a food-related medical condition is the project of this ethnography.

My senior project is a native ethnography, which makes me a native ethnographer. Because I myself have been living with a food-related medical condition for five years, I am able to write this particular project with a very sincere and generative empathy for my interlocutors. I can personally relate to so many of the difficult feelings and painful emotions that my interlocutors have shared with me during our interviews; I am writing about my interlocutors from a place of shared understanding and experience. Something as seemingly-mundane and everyday as getting lunch with a friend at a cafeteria on campus can feel extremely cumbersome and stressful for someone with medically-imposed dietary restrictions. While the anxieties of everyday movement through spaces that we experience as people with medically-imposed dietary restrictions might be easy to ignore for a person who does not have medical issues around food, I am keenly aware of just how heavy and difficult these anxieties can be to shoulder. In my experience, the negative emotions and the stress that so often accompany daily interactions can cause a tremendous amount of grief for the individual facing them. That is exactly why narrativizing and discussing at great length the challenges and feelings brought about by the difficulties of the everyday is at the core of the work that my senior project seeks to do: I wish to

cause people who do not suffer from food-related medical conditions to think about the sort of emotional burden that the people around them, people like my interlocutors and myself, are silently shouldering in our daily lives.

At the very end of our ethnographic interview, Hanna was very sweet in thanking me for talking with her about her autoimmune disease and the range of emotions which show up for her around it. “Thank you so much,” she said. “It feels good actually to have someone that do understand, and it feels nice to kind of explain... what I have to someone that can maybe relate and understand what I’m saying, so it feels good.” Hanna’s words really touched me. I feel as though I’m the one who ought to be saying endless “thank you”s to Hanna and my seven other interlocutors. I feel deeply honored and grateful that my interlocutors have shared their stories with me, and I cherish the trust that I will adequately narrativize their respective lived experiences which they have placed in me. I write this project with an internalized sense of responsibility: I feel responsible for capturing my interlocutors’ day-to-day feelings, as well as the challenges they face - be they emotional or logistical - around their respective food-related medical conditions, in a way that is becoming of them. My interlocutors have made themselves vulnerable by sharing some of their most deeply-rooted and painful emotions and self-talk with me. I fully intend to honor my interlocutors and to treat their respective experiences with respect in my writing.

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Unpacking my own positionality vis-à-vis Blackness

In addition to the fact that I suffer from several life-threatening food allergies myself, there is another piece of my identity which I wish to be fully intentional about disclosing and

addressing: I am a mixed-race Black woman. I am very proud to be a Black woman academic doing native ethnography. As Black people, we are so often deprived of the opportunity to tell our own stories, and Anthropology, as an academic discipline whose roots are deeply entrenched in colonialism, has a history of imposing limiting narratives upon Black and Brown people. By writing this native ethnography on medically-imposed dietary restrictions and speaking on my own lived experience with food allergies, taking reflexive turns throughout this project to narrativize my own body and the things that it feels, I am claiming the power to tell my own story as a Black subject of anthropological analysis. This is a deeply empowering project to write, as it allows me to reinvent the discipline that I hold so dear in a way that creates space for me, my Black body, and my Black voice.

Now, I simply must acknowledge the fact that as a person of mixed-race and lightskinned, I possess privileges that darker-skinned brothers and sisters do not possess. My light skin speaks directly to my proximity to whiteness, something which indisputably privileges me over Black people whose skin is darker than mine in our white supremacist society. The fact that I am lightskinned makes it easier for me to tell my own story and to reject the limiting narratives imposed upon me by non-Black academics within my discipline than it would be if I had my father's skin color, for example. Still, empowering myself by staking claim to the right to tell the story of my Black body is worth celebrating all the same. I am making my Black voice heard within the discipline of which I have been and continue to be a student; this gives me Joy.

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Crediting Black ethnographers and paying tribute to Hurston

Let me be clear about the fact that I am by no means a trailblazer in the way of being a Black native ethnographer. There have been many Black ethnographers, including native ethnographers, who have paved the way for me to be able to engage in this kind of native ethnographic research. Candidly, my biggest role model as a Black woman engaging in native ethnographic research is Zora Neale Hurston. Marion Kilson writes, “Two fundamental value orientations underlay all Hurston's writing: an emphasis on individualism and an orientation towards achievement. These values not only served as external standards of judgment but as internal motivations which both compelled and enabled her to resolve the central conflicts of her existence as American black woman through her ethnographic writing.” (Kilson 1960: 112) I find that this captures the essence of Hurston as a highly-accomplished Black female academic. Hurston left her all-Black town of Eatonville, Florida - which she describes in her autobiography, *How It Feels to Be Colored Me*, as “the little Negro town of Eatonville, Florida... exclusively a colored town” (Hurston 1928: 1) - to study at a historically-white institution, Barnard College. (Columbia University 2004) I can only imagine the sort of powerful culture shock which Hurston must have experienced upon leaving Eatonville for Columbia University, an Ivy with an incredibly waspy history. I myself have been the only Black person in several different rarified academic environments, and I know that being outnumbered in this way can be painfully lonely. Yet, in spite of the difficulties which she must have faced as a Black woman at an elite, predominantly-white institution like Barnard, Hurston was able to use her Black voice and her Black intellect to achieve excellence at Barnard through her native ethnographic research.

W. E. B. Du Bois, another Black ethnographer to whom I owe immeasurable credit as a continuous source of inspiration for me as a Black ethnographer, would likely refer to Hurston as a “university woman,” a singular, she/her gendering of the classifier “university men” which Du Bois uses in his book *The Souls of Black Folk*. (Du Bois 1907: 84) Now, I’d like to make it clear that I do not agree with Du Bois’ argument that “of the million black youth, some were fitted to know and some to dig; that some had the talent and capacity of university men, and some the talent and capacity of blacksmiths.” (Du Bois 1907: 84) I believe very strongly that all Black people are equally intellectually capable, and that the varying degrees to which we are granted access to a formal education of high quality has a tremendous impact on how we set our career goals and spend our working lives. However, I still find value in Du Bois’ thinking about “university men” as Black people who have the “talent and capacity” for academic life. Hurston had “talent and capacity” in spades, and she used these born intellectual abilities to tell stories of black Life.

What I admire most about Hurston is the fact that she claimed her Black, southern hometown with pride, and she took the people with whom she grew up seriously enough to use them as interlocutors. In *Mules and Men*, she writes, “I hurried back to Eatonville because I knew that the town was full of material and that I could get it without hurt, harm or danger.” (Hurston 2008: 2) Because she had grown up in Eatonville and she knew so many of her interlocutors personally, Hurston was confident that she would gain access to a wealth of ethnographic material in Eatonville without going to too much trouble; that she did. The native ethnography that she wrote as a result of using her hometown as her fieldsite is one of the richest, most captivating ethnographies that I have ever read. She did not run away from her

roots in the face of the opulent wealth that she encountered at Barnard. Instead, she wrote her peers, neighbors, aunties and uncles from Eatonville into the discipline of Anthropology.

Hurston's commitment to the fact that the people that she already knew very well would be "full of material" as subjects of ethnographic research has directly inspired my own process of seeking out interlocutors for my senior project. It was from Hurston that I learned that some of the most complex and generative ethnographies can be written about people that are very far from strangers: the people right at home.

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Methodology

I took inspiration from Hurston and decided to request ethnographic interviews of people with whom I was already well acquainted in my personal life, who have medically-imposed dietary restrictions. Because I have several food allergies, and some of them are quite inconvenient or difficult for me to avoid in public spaces - such as my airborne allergy to curry - I have formed friendships with several people around a shared struggle with the logistical challenges of navigating around food danger in day-to-day life. I felt confident while I was proposing my senior project to the Institutional Review Board that because Hurston had gathered so much material from people that she had known for many years, I would be able to have rich, fruitful conversations with people that I have known for years as well - this proved to be even more true than I had imagined.

I emailed each of the eight individuals with medically-imposed dietary restrictions that I had originally thought of as potential interviewees while writing my proposal, and I requested one thirty-minute-long ethnographic interview from each of them. Much to my luck, all eight of

them agreed to engage in an ethnographic interview with me. I held all eight of these interviews via Facetime or Zoom,¹ depending upon the preference of a given interlocutor, during the summer of 2020. I also transcribed all eight of these interviews and took notes on them during that same summer. When I proposed my project to the Institutional Review Board, I stated that I would conduct interviews with the managers/owners of three eateries near my hometown in New Jersey which I as a person with food allergies know to accommodate food allergies and which offer allergen-free options on their respective daily menus. I conducted these three interviews, all over Facetime, during the summer of 2020 as planned. However, because the interviews in which I engaged with friends and classmates of mine who suffer from food-related medical conditions were so very rich, I ultimately decided to omit the discussions that I had with the managers/owners of eateries from my project, so as to give full attention in my work to the respective internal and external experiences of my interlocutors.

The Covid-19 pandemic has certainly impacted and shaped the ways in which I have been able to conduct fieldwork for this project. Because of quarantining, lockdowns, and general smart social distancing, I have been unable to conduct participant observation in the ways in which I had envisioned. This might have looked like visiting a food allergy support group in person and sitting in on some of their meetings; it might also have looked like attending a cookout or a dinner party in order to watch and listen as attendees interacted with one another around food - or in avoidance of danger foods. As much as the pandemic has inhibited me in terms of my ability to conduct in-person ethnographic research, the lack of formal participant observation has motivated me to pour all of my energy into understanding the (virtual)

¹ Due to Covid-19, my ethnographic fieldwork was conducted entirely virtually, over Facetime and Zoom. This virtual ethnographic fieldwork reflects the virtual moment throughout which this senior project was written.

ethnographic interviews that I was able to carry out. Ultimately, I am quite pleased with the ways in which my project has changed and evolved over the course of these two semesters. It has been fascinating, and something of a gift, to get to engage in ethnographic research during this historic moment.

The Covid-19 pandemic has also shaped the ways in which I've sourced supplemental material for this ethnographic research project. I've been intentional about supplementing my academic sources - namely, peer-review ethnographic research - with a variety of online sources, ranging from viral videos to food blogs. It has been important for me to incorporate these sorts of online sources into this senior project, in that this has allowed me to amplify contemporary voices in my writing and to broaden the scope of my ethnography to include the voices of people across the globe with whom I have been unable to meet in person due to the social distancing which has been characteristic of this year. Creating space in this native ethnographic research project for online sources in a moment of almost entirely online socialization captures the *zeitgeist* of this year of doing ethnography in a global pandemic. Of course, I also value the role of academic sources in abstracting and synthesizing material into theory that can be reapplied elsewhere. Altogether, the thoughts, feelings, and lived experiences which my interlocutors have shared with me in our respective ethnographic interviews; the firsthand social accounts that I've found online; and the academic material supporting it all, form a complementary whole, and ultimately allow us to understand more comprehensively the lived experiences of sufferers of food-related medical conditions.

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Historicization

Food allergy prevalence in the U.S. has grown significantly in recent years. Food Allergy & Anaphylaxis Connection Team writes, “Food allergy is a rising, global epidemic. The greatest rise in the prevalence of food allergies is in the US and other industrialized countries around the world. The number of people with food allergy in America has doubled each of the last decades.” (Food Allergy & Anaphylaxis Connection Team 2021)² Within this overall rise of food allergy prevalence within the U.S., “between 1997 and 2008, the prevalence of peanut or tree nut allergy appears to have more than tripled in U.S. children.” (Food Allergy Research & Education 2021)³ Because food allergies are becoming so much more prevalent in our society here in the U.S., it is all the more urgent that we engage in the work of understanding food allergy experiences and how food allergy sufferers feel. To better understand food allergy suffering is to better understand over 32 million members of our society. (Food Allergy & Anaphylaxis Connection Team 2021)⁴ Other food-related medical conditions from which some of my interlocutors suffer are on the rise in the U.S. as well. Autoimmunity, for instance, seems to be growing more prevalent in the U.S. “In a study published April 8 in *Arthritis and Rheumatology*, the researchers found that the prevalence of antinuclear antibodies (ANA), the most common biomarker of autoimmunity, was significantly increasing in the United States overall and particularly in certain groups. These groups include males, non-Hispanic whites, adults 50 years

² The Food Allergy & Anaphylaxis Connection Team webpage is not paginated, so I am unable to provide a page number for this citation.

³ The Food Allergy Research & Education webpage is not paginated, so I am unable to provide a page number for this citation.

⁴ The Food Allergy & Anaphylaxis Connection Team webpage is not paginated, so I am unable to provide a page number for this citation.

and older, and adolescents.” (U.S. Department of Health & Human Services)⁵ Tai, one of my interlocutors who suffers from an autoimmune disease which brings about their medically-imposed dietary restrictions, is a non-woman, non-Hispanic adolescent; this means that Tai fits into several of the “certain groups” which saw an increase in the aforementioned study. Understanding autoimmunity and the ways in which it impacts the ways that you eat - and do not - is also becoming increasingly urgent work. Moreover, celiac disease is an autoimmune disorder (The Celiac Disease Foundation 2020)⁶; working to better understand celiac disease is part of what it means to work to better understand autoimmune disorders as a broad category of medical conditions.

There’s a history in the West of physicians treating people with food allergies - whether these food allergies are self-reported by patients or formally diagnosed by physicians - with a mentality that I liken to gaslighting.⁷ For one thing, if a patient of the early twentieth century sought medical assistance around their self-reported food allergies, and the “unreliable skin tests” (Smith 1976: 188) with which they were provided by physicians did not show proof of a food allergy, then patients were dismissed by physicians and written off as not having food allergies - all medical trust was placed in faulty medical infrastructure, these skin tests. Even more pertinent to this senior project, though, is the fact that Western clinicians of the early twentieth century did not acknowledge the very *real* points of intersection which exist between the emotional difficulties and logistical difficulties which sufferers are caused by their food allergies.

⁵ The U.S. Department of Health & Human Services webpage is not paginated, so I am unable to provide a page number for this citation.

⁶ The Celiac Disease Foundation webpage is not paginated, so I am unable to provide a page number for this citation.

⁷ According to the Cambridge Dictionary, “gaslighting” is “the action of tricking or controlling someone by making them believe things that are not true, especially by suggesting that they may be mentally ill.” (Cambridge Dictionary 2021)

“Unwilling to acknowledge that the link between allergy and mental disturbance might flow in both directions, clinicians either deemed patients to be suffering psychosomatically or, in contrast, failed to recognize that stressful situations could exacerbate an allergic reaction.”

(Smith 1976: 188) An integral aspect of the work which this ethnographic research project does is underscoring and analyzing the interconnectedness of emotional challenges and logistical challenges in day-to-day life as an individual with a food-related medical condition such as having a food allergy. As we sit with the words of my eight interlocutors throughout this project, it will become readily apparent that a myriad of emotions show up for sufferers of food-related medical conditions around the various medical needs and dietary restrictions with which we must grapple in our everyday lives. By writing off the points of intersection between “allergy and mental disturbance,” and failing to recognize the fact that food allergies can contribute to emotional difficulties (and quite possibly, vice-versa), Western physicians like “Theron Randolph”⁸ (Smith 1976: 188) were rejecting and denying the emotional complexities of living with a food allergy. In this senior project, I am working to complicate food allergies as a kind of medical condition. I am proving that there is always a social side to food-related medical conditions - food allergies are no exception. The social aspect of food-related medical conditions have long gotten lost in the medical sphere; this project disrupts the narrative of food-related medical conditions which overlooks the social and the emotional, with the understanding that food-related medical conditions and the ways in which sufferers live with them day-to-day are influenced by the external social happenings in our society.

⁸According to SNAC, Theron Randolph “was an early allergy specialist and one of the founders of the Clinical Ecology movement..” (SNAC 2021)

In *The Illness Narratives*, Kleinman problematizes the ways in which “the biomedical system” has traditionally taught physicians to only think about illness in biological terms, neglecting to give serious consideration to the ways in which the mental and the emotional affect how we as “patients” feel. (Kleinman 1988: 9) He writes, “The everyday priority structure of medical training and of health care delivery... turns the gaze of the clinician, along with the attention of patients and families, away from decoding the salient meanings of illness for them, which interferes with recognition of disturbing but potentially treatable problems in their life world. The biomedical system replaces this allegedly ‘soft,’ therefore devalued, psychosocial concern with meanings with the scientifically ‘hard,’ therefore overvalued, technical quest for the control of symptoms.” (Kleinman 1988: 9) I owe a great deal to Kleinman and to the discipline of Medical Anthropology at large in undertaking the project of writing this native ethnography on food-related medical conditions. In *The Illness Narratives*, Kleinman underscores the failures of the part of physicians to think holistically about what it means and looks like to have an “illness.” One of the central projects of this native ethnography is to take an intersectional approach to talking about food-related medical conditions, one which gives attention to the social and the emotional, aspects of living with a medical condition which are so often overlooked in the “biomedical system” (Kleinman 1988: 9) and in our society at large.

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Food Sharing and Social Life

Falk writes, “Eating together (com) the same bread (panis) transforms the eaters into companions.” (Falk 1994: 15) The idea that sharing food with others is a means by which to build interpersonal relationships - and to cultivate and maintain a social life - is central to

understanding the work that this project will do. This project explores the question of what being barred from sharing food with others by virtue of having medically-imposed dietary restrictions restricts and defines the ways in which a sufferer moves through shared spaces and interacts with other people in their day-to-day life. This project thinks through the effects which not being able to share food with others has on a sufferer's emotions and the ways in which they conceive of their social interactions.

Mintz and Du Bois write, "Next to breathing, eating is perhaps the most essential of all human activities, and one with which much of social life is entwined... Food serves both to solidify group membership and to set groups." (Mintz and Du Bois 2002: 102 - 109) The fact that food and its consumption are so central to human life makes it both productive and necessary to unpack the sorts of feelings and thoughts which show up for an individual sufferer around being medically unable to partake in food-sharing activities and social gatherings involving communal eating. If you cannot eat what the people around you are eating and share "bread" with them, (Falk 1994: 15) you cannot achieve the kind of social belonging that is attained through the sharing of food with others in a group. (Mintz and Du Bois 2002: 102 - 109) Having medically-imposed dietary restrictions makes it very difficult for you as a sufferer to eat your way into a social group. Janet Carsten writes that "Malays on the island of Langkawi... become complete persons, that is, kin, through living and consuming together in houses." (Carsten 223: 1995) According to Carsten, eating food with the other members of your household as a person living on the island of Langkawi is a practice which makes you and the people with whom you're sharing food family. My interlocutors and I are all people who, by virtue of being sufferers of various food-related medical conditions, are medically-unable to eat

certain foods. When these foods are being consumed by the people around us/ in our households, we cannot partake in the group consumption of these foods. This native ethnographic research project creates space for thinking about and sitting with the emotions and feelings which show up for the individual sufferer around being barred by one's food-related medical condition from eating the same foods as others, and from being a part of a group food consumption experience.

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Christina Sinclair Jones

Content Warning: eating disorders

## **Chapter II: Narrativizing and Thinking Through the Internal Experiences of Four Interlocutors**

“While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind - in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive... The term stigma, then, will be used to refer to an attribute that is deeply discrediting,” (Goffman 1986: 2-3)

Erving Goffman famously defines stigma as an “attribute that is deeply discrediting.” (1986: 3) I understand a “discrediting” attribute to be one which harms a person’s reputation or which does a person an injustice. In thinking about the fact that stigma is, according to Goffman’s definition, “an attribute,” I begin to raise the question of whether or not having medically-imposed dietary restrictions is itself an attribute. If we take having medically-imposed dietary restrictions to be an attribute, then Goffman’s definition of stigma begins to resonate. After all, my food allergies certainly make me “different from others.” Plenty of people are physically able to eat the foods that threaten my life and cause me serious harm; this sets me apart from them. My food allergies also render my ability to fully participate in social situations revolving around food fairly “weak,” as I can almost never partake in the sharing of food with the people around me. With this in mind, Goffman might very well classify my food allergies as a “stigma” from which I suffer.

I find it productive to think through the potential for medically-imposed dietary restrictions to be thought of under the classifier “stigma.” Goffman’s understanding of stigma and what its implications are for a sufferer of stigma afford me a framework through which to look at and to discuss the internal experiences of four of my interlocutors in this chapter. Embarrassment; shame; the desire to cover oneself from the perception of others; avoiding dining at restaurants; not wanting to tell others about one’s medically-imposed dietary restrictions; and feeling like a burden on others were all brought up by my interlocutors during our respective ethnographic interviews. If we take having medically-imposed dietary restrictions - which is what all four of the interlocutors whose words and experiences are shared in this chapter have in common - to be a stigma, then it becomes generative to think through the ways in which stigma shapes the respective internal experiences of these four individuals. Matthew Clair writes that “for Goffman, stigma is a general aspect of social life that complicates everyday micro-level interactions.” (2018: 1) This seems to hold true for my interlocutors and it certainly holds true for me. The “everyday micro-level interactions” in which we are simultaneously navigating social dynamics and food safety can be the interactions which cause us the most anxiety or grief. Moreover, closely examining the “everyday” at a “micro-level” scale is the work of cultural anthropology that I find to be the most important and the most valuable.

This brings me to my purpose in writing this chapter. By giving voice to the different ways in which four of my interlocutors internally experience their respective medically-imposed dietary restrictions - what Goffman might call the “stigma” that manifests itself differently for each of them - I am imploring readers of this chapter to give thought to the struggles which sufferers of food-related medical conditions face daily. In writing this chapter, I seek to preserve

and to give formal written voice to the words and lived experiences of my interlocutors, respectively. This is my way of crediting my interlocutors and validating their emotions, self-talk, and the ways in which they react within themselves to the difficulties of having to live with medically-imposed dietary restrictions as social beings with social lives. I strongly believe that everyone should read and receive the words of my interlocutors, and that everyone should be intentional about trying to better understand the impact that having medically-imposed dietary restrictions can have on a person's social life.

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## **Interviews**

### **I. Jane**

During our interview together, Jane shared that her food allergies cause her to eat out with others very seldomly because she feels “embarrassed and embarrassing” in restaurant dining situations. Now, Jane and I have been friends for several years and I know her to have several severe food allergies. She opened up to me very quickly during our interview and shared, “I feel like some kind of spectacle or something... It just seems like a thing that people can ‘ooh’ and ‘ahh’ at.” Right away, upon hearing the word “spectacle,” I began to think about the public nature of spectacle. In order for Jane to be made into something of a spectacle, she must be in a social setting, around other people. Spectacles do not occur when a person is alone; spectacles require an audience. For instance, when Jane is eating at a restaurant with a dining companion, that dining companion becomes the audience that can experience the spectacle of Jane having to maneuver around her food allergies in order to place an order. She explained that she needs to “triple-check” with her server about which oils are used in the pan in which her food is prepared

whenever she dines at a restaurant. She feels that this is something of a chore. I would argue that Jane's triple-checking of what is in her food at a restaurant is her food allergy ritual. In a piece on "the rights of particular persons to be included in specific rituals," Ian Reader makes the argument that "rituals are mechanisms through which expressions of inclusion and exclusion can be articulated and manipulated." (Reader 2016: 307) Within this framework of thinking about ritual, Jane is as a result of having food allergies being denied inclusion within/being excluded from the group of restaurant diners who are able to eat without engaging in the ritual of triple-checking. The "triple-check" functions as a kind of mechanism through which Jane's food allergies are highlighted, and made perceivable to others.

Now, what the words "embarrassed," "embarrassing," and "spectacle" all share in common is the idea that one is perceivable to others. In order to feel embarrassed, Jane must be around other people, and she must have an awareness of the fact that she can be seen and perceived by others as a person with medically-imposed dietary restrictions. The people around her are free to form their own opinions of her as they please. This brings us back to the fear of being perceived as a spectacle, a performer for an audience of sorts. The fear of being thought of as a spectacle might explain why Jane tends to avoid dining in restaurants: if she does not dine in restaurants, where she can be perceived and even judged by other people as a person with food allergies, she cannot be made to feel like a spectacle. Spectacles cannot occur in private spaces where one is alone. Therefore, if she eats alone at home instead of eating out, there is no chance for her to be made to feel like a spectacle.

Jane made a point of telling me that she has been preparing all of her meals for herself while being in quarantine, as opposed to dining at restaurants, having meals delivered to her

house, or getting curbside pickup outside of her building. Limiting the food that she eats to food that she has prepared herself has made her feel “safe,” to use her word, in a way that eating restaurant food does not. Now, cooking for yourself as a person with food allergies affords you a great deal of security. When you cook for yourself, you have total control over what you are putting in your body, so there is no need to fret over whether or not the pasta you’ve ordered is *actually* gluten-free, or whether or not the veggies you’re about to eat were cooked in peanut oil. Cooking for yourself leaves very little room for anxiety about being physically safe around food. You have total control when you cook for yourself, and it leaves little room for anxiety over physical food safety. With this being said, there is more to the safety that Jane has felt as a result of eating in her home than simply physical safety: not having to carry out her food allergy ritual in restaurant spaces has given Jane a form of safety from the judgement of others. She shared that her mother is the only person with whom she has eaten in over five months, and that her mother does not ask questions of her or trouble her about her food allergies. With her mother, Jane’s food allergies simply *are*; they do not need to be discussed or given attention. With only her mother present at her meals, there is no audience for whom Jane and her food allergies could be made into a spectacle. There is no server with whom she needs to triple-check that what she will be eating will not harm her, and there are no other diners to ask questions that make her feel uncomfortable. Eating alone makes it possible for Jane to eat without needing to worry about how she is being perceived by others.

Jean-Paul Baldacchino writes, “The body is trained to conform to a we-image. Whether in fashion, subcultural styles or even fetishized national costume, the body is often dressed as a site for agency in an eidetic of belonging. As locus for body praxis, the body of belonging could

be a theatre of cruelty and barbarous mutilation but it could also be the site for the practices of everyday life.” (Baldacchino 2011: 97) For Jane, her body becomes “the site for [her] practices of everyday life” (Baldacchino 2011: 97), in that she stays inside of her home - physically keeping her body inside, at home, instead of taking her body outside of home - in order to shield herself from the feelings of embarrassment that so often show up for her around dining at restaurants. Jane is quite literally using her body to perform in her everyday life the act of avoiding being made out to be a spectacle. There is tremendous irony in this performance, as Jane is in essence performing the state of not being a performer. Still, this irony warrants close analysis and attention. Jane is implicitly acknowledging the realness of her medical needs around food by eating at home to keep herself physically safe, while also implicitly acknowledging the realness of the social limitations of having food allergies within a restaurant setting. She stays home so that she does not have to be made to feel unusual, or as though she and the medical needs of her body are anything out of the ordinary. Her performance is one of being ordinary - ordinary is unremarkable, and unremarkable is antithetical to the spectacular.

Let us revisit the words “embarrassed” and “embarrassing” which Jane used during my interview with her to describe how she feels in restaurant settings because of her food allergies. I take the word “embarrassed” to mean that Jane is being caused to feel badly by her food allergies, while I take the word “embarrassing” to mean that Jane is causing the people around her to feel badly. She told me that she doesn’t like asking her server to triple-check all of the oils used in the pan in which her meal has been prepared, even though she needs to do this for her own safety. Now, it is quite possible that in carrying out the “triple-check,” she might cause her server to spend more and attention on taking her order than they might on taking other people’s

orders, simply because they must be particularly careful and detail-oriented when serving Jane so as to protect her from exposure to her allergens. This in itself, feeling as though she is burdening the server, might very well be contributing to the embarrassment that Jane experiences.

Sociologist C. Lee Harrington writes that “embarrassment is seen as reflecting social incompetence. As such, members make routine attempts to repress embarrassment in the self and to deny embarrassment to self and others.” (Harrington 1992: 203) It feels productive to put this concept in conversation with the fact that Jane feels both embarrassed and embarrassing as a person with food allergies in social situations, and therefore avoids eating at restaurants.

Choosing to forgo the chance to dine at a restaurant with and around others is a means by which she attempts to “repress” and “deny” embarrassment for herself and the people around whom she would be dining. In thinking about Harrington’s claim that “embarrassment is seen as reflecting social incompetence,” subtlety comes up for me as a factor which might also contribute to the embarrassment that Jane experiences in restaurant settings. After all, having her server “triple-check” that her order is accurate and safe - that is, having her server check her order neither once, nor twice, but three times - is anything but subtle.

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## II. Hanna

As I was wrapping up my interview with Hanna, a close friend of mine, I made a passing remark about how I often find myself trying to hide the fact that I’m not eating from others when I’m at parties. Her face lit up as if she had never heard anyone tell her this before, and she told me that she tries to hide her medically-imposed dietary restrictions too. She told me, “You don’t want to go to a social event and bring that up. So it’s like, how can I cover myself and how can

people not notice that I'm not eating at a dining table? ... You go, 'Oh, I'm not hungry... You don't want to be the center of attention with this topic.'" What I take away from this is that Hanna tells the people around her at parties that she's not having anything to eat. This is an attempt to direct the attention of the people around her away from the fact that she is not eating, and a means by which Hanna asserts her own narrative around her inability to share in the food that is available.

I know from my own personal experiences with not being able to eat the food available in social settings that not eating can invite uncomfortable questions and comments from others. I was once confronted by an entire friend group following a cookout that I attended - and where I was unable to eat anything because everything in sight either contained or was prepared with at least one of my allergens - for supposedly having an eating disorder. Unbeknownst to me, the four of these friends huddled up together after the cookout to talk about the fact that they "never see [me] eating anything when [I] go out, and it's worrisome," to quote one of them. Though this group of people confronted me about their concerns out of a place of genuine care and concern for my well being, I was really hurt by the accusation that I had to have an eating disorder simply because I wasn't eating. I also found myself getting defensive. These people knew so little about me that they did not even know that I have life-threatening food allergies, yet they were making major assumptions about me and my own state of mental wellness. That is what was most upsetting for me about being accused of having an eating disorder: I felt entirely misunderstood. I was also really frustrated by the fact that food allergies were so far from their minds that it seemed as though the idea that I might have a food allergy, or some sort of food intolerance, had never occurred to them as a possible explanation of my behavior around food.

The accusations that I have faced from others regarding my own reasons for not eating when I am outside of my own home have caused me to think about the judgement - stigma - that surrounds eating disorders as a possible reason for which Hanna and I both find ourselves trying to hide the fact that we are not eating from others. Though I did not ask Hanna directly about whether or not a fear of being thought to have an eating disorder has played a role in her own desire to hide or downplay the fact that she is not eating out - I was afraid that asking such a question might trigger her - I find it productive to think about the stigma that shows up in our society around eating disorders. Alex Kroudis of the National Eating Disorders Association writes, “An eating disorder is difficult enough to battle on its own, and the stigma associated with them makes the journey to becoming a warrior that much harder. The stigma that accompanies eating disorders strips an individual of their quality of life and... causes someone who struggles with an eating disorder to be fearful of negative perception by family and loved ones as well as embarrassment about their behaviors regarding the disorder.” (2018)<sup>9</sup> Now, let me be clear about the fact that I am in no way comparing the stigma that surrounds medically-imposed dietary restrictions with the stigma that surrounds eating disorders. I simply intend to show that because there is so much stigma associated with disordered eating, which for some people looks like eating very little or nothing (in social situations and in private settings), people with medically-imposed dietary restrictions who eat very little or nothing in social situations where the people around them are unaware of the fact that they suffer from a food-related medical condition, and therefore have medically-imposed dietary restrictions, might be assumed to have an eating disorder. Maybe, even if this is subconscious, we people with

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<sup>9</sup>This excerpted passage by Kroudis comes from a website for the National Eating Disorders Association. This website is not paginated, so I am unable to provide a page number in citing this source.

medically-imposed dietary restrictions fear being connected with the judgement associated with disordered eating, and we try to hide the fact that we are not eating in social situations in order to evade this sort of judgement.

Now, let us think about the idea of perceptibility as it pertains to Hanna. When Hanna says that she wants to cover herself and make it so that other people do not notice that she is not eating during a social event, she is essentially expressing a desire to make her medically-imposed dietary restrictions imperceptible to the people eating around her. If people could not perceive that she is not eating, or in other words, if she were to make herself imperceptible to the people around her altogether, there would be no cause for her to fret over trying to cover herself. Hanna is very upset by the fact that she has an autoimmune disease which causes her to have to cut out all sources of protein, as well as many carbohydrates. She opened up about this, sharing “Man, you don’t know the efforts that I’ve gone through and all the times that I’ve cried about this.” Having to change her diet so drastically at an adult age - like me, Hanna grew up being able to eat anything and everything as a child - and being excluded from sharing food with others makes her sad. She also told me that she resents her autoimmune disease and that she avoids talking about it as much as she can because being reminded of it brings her down.

When Hanna makes a concerted effort to cover herself from the perception - and consequently, the potential judgement - of others and to hide her empty plate from view, she is performing affective labor. She tries to behave and move in ways in social situations involving food so as to make the people around her feel more comfortable and more at ease: if the fact that she is medically unable to eat any of the food being served becomes imperceptible to the people with whom Hanna engages, these people do not have to worry and raise questions which feel

burdensome for her to receive, such as whether or not she is okay, or why she cannot eat what they are eating. Shiloh Whitney says that this affect, which in Hanna's case is the affect of being comfortable and having her medically-restricted eating covered from the perception of others, "is never consumed without remainder, without by-product." (Whitney 2016: 280) In other words, even if she successfully carries out the affective labor of covering herself and her empty plate while in a given social situation, she bears the burden of the by-product that is produced by her affective labor. For Hanna, this by-product is crying in the privacy of her own home, following social events, over her autoimmune disease and the ways in which it separates her from the people around her. Being medically unable to eat along with others brings her grief, grief that she works to keep from others, but grief that she herself must face and cope with on her own.

With the knowledge that Hanna resents her autoimmune disease and all of the direct implications that it has for her diet, it is easy to understand why Hanna wishes to cover herself as a person who cannot eat what is being served in social situations. Surely, if she does not like confronting her own medical issues around food, she would not want others to turn their attention toward these very same issues. Wanting to make it so that the people with whom she is sharing a dining table cannot see that she is not eating is a means by which Hanna is trying to diminish the perceptibility of her medically-imposed dietary restrictions. If she were able to make her empty plate imperceptible to onlookers, she would be making her medical issues around food imperceptible, momentarily. On the contrary, when the people around her perceive the fact that she is not eating, Hanna exposes herself and brings attention to her autoimmune disease. Telling people that she is not hungry is a means by which she tries to reclaim some of this imperceptibility. She does not want to be labeled as "the girl that can only eat, like,

strawberries and bananas,” as she puts it. Labels such as these can only be assigned to her if she becomes perceptible to others as having medically-imposed dietary restrictions. Hanna’s desire to evade labels from others seems to be the root cause of her desire to cover herself.

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### III. Finley:

When I met with Finley for our interview about her food allergies, I asked her to describe the ways in which she feels that her food allergies impact her interpersonal relationships. She told me that even though she would in theory like to go out to eat with her friends, she often finds herself staying at home and missing out on restaurant trips because she feels that there is a risk that she will be exposed to her allergens in the restaurants that her friends choose. Finley goes on to say that when she asks her friends to reconsider their restaurant choices and to pick a place where she can safely eat, she feels like she is being a burden on the group. “I definitely feel like I’m inconveniencing them,” she says, “and I don’t like getting so much attention about it either.” The “it” to which Finley is referring is the fact that she has food allergies. What I found to be the most poignant part of our conversation was that for the most part, she does not find herself feeling unhappy about her food allergies. It is only when “people start emphasizing” or asking questions about her food allergies that she feels upset.

Finley’s tendency to avoid eating outside of her home is due to the fact that because she has food allergies, she must carry out the work of dealing with safety logistics, advocating for herself, and even answering questions that make her feel uncomfortable in order to safely exist in restaurant spaces. This work is unavoidable for her, and it includes asking her friends to dine in a restaurant that is safe for her, as opposed to the restaurant that they had originally chosen. Still,

asking her friends to change their plans makes her feel as though she is bringing negativity and weight to the group. Therefore, Finley chooses not to feed her emotional needs for social interaction and spending time with friends in order to avoid facing the emotional challenges that show up for her around restaurant safety logistics. Her own self-talk around her food allergies prevents her from dining at restaurants with her friends, a key bonding activity and a kind of weekend ritual for the group. She is not present at dinner for all of the jokes that are made, new life updates that are shared, secrets that are told, et cetera. In this way, she loses the opportunity to take part in the making of memories as a collective with her friends. Not wanting to feel as though she is a burden to her friend group causes Finley to miss out on important aspects of what it means to be a member of the group at all.

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#### IV. Tai

During our interview together, Tai expressed to me that even when they have access to their own, separate meal while eating with others, not being able to eat the same meal that everyone else is eating causes them to feel excluded. Tai does not have food allergies; they have such severe Inflammatory Bowel Syndrome (IBS) that for over two years, they were required by their gastroenterologist to eat according to the FODMAP diet. Interestingly enough, Tai no longer follows the FODMAP diet - they are the only individual out of all eight interlocutors with medically-imposed dietary restrictions that no longer eats with a restricted diet - and this allows to speak retrospectively about their social experiences around medically-imposed dietary restrictions in a unique way.

One thing that Tai asked that I make known in this project is that they take immense pride in their Jewish faith. Shabbat dinner is one of the most important parts of the week for them, as it is a time reserved for connecting with community members through faith. To state the obvious, communal eating is a key component of Shabbat dinners, as they are “dinners,” and during a dinner, one communes with others to eat as a group. Tai shares, “I remember going to Shabbat dinners and I couldn’t eat anything, so I would have to bring my little tupperware of my cut-up chicken, and my rice and my green beans, and it was just so, so sad too, because I think eating is such a communal activity that really brings people together, to be eating the same thing.” A really important part of what it means for Tai to feel fully-included and fully-involved during Shabbat dinners is being able to eat and share dishes with others - simply eating random dishes around others, without sharing in eating the same dishes as other people are eating, does not make Tai feel included or satisfied. During their two years of following the FODMAP diet, Tai had to forgo meals that others were eating during their favorite time of the week, Shabbat dinner. This meant that Tai’s medically-imposed dietary restrictions kept them from enjoying a key part of how they understand Shabbat dinners to bring people together: eating the same dishes as everyone else at the table is eating. There is an argument to be made which holds that when a person’s medically-imposed dietary restrictions prevent them from being able to eat spontaneously with a group and to eat what others in the group are eating, this person is prevented from experiencing “a feeling of group belongingness.” (Julier 2013: 187) This is to say that Tai might have found themselves feeling left out or “sad” because following the FODMAP diet kept them from connecting with their community members during Shabbat dinners through a dish-sharing experience.

Tai told me that because they had to bring their own meals, prepared ahead of time, “I couldn’t be as spontaneous. Everything had to be much more calculated.” This brings up an aspect of attending a communal dinner which might be easy to overlook: spontaneous eating. If Tai had not been restricted by the FODMAP diet, they might very well have been able to merely show up to Shabbat dinners and eat whatever was being served on a given night, without needing to think about preparing their own special meal or figuring out which ingredients were contained in various dishes. This is what it looks like to eat spontaneously. However, Tai’s medically-imposed dietary restrictions caused them to have to cook ahead of time and to bring their own, separate food with them before attending a Shabbat dinner. This kind of pre-planning pre-preparing is antithetical to spontaneity. Put simply, having to follow the FODMAP prevented Tai from being able to eat spontaneously during Shabbat dinners, and this caused Tai to feel “so, so sad.”

To conclude our interview together, I asked Tai how they felt when they had to explain to people that they suffered from IBS, and had to follow a rigid diet necessitated by their IBS. In responding to this heavy question, Tai said something very poignant: “It was something I didn’t want to tell someone when I first met them, especially when I didn’t know them... I felt that way because IBS was so associated with shitting yourself, so it was embarrassing to talk about.” They went on to explain that in their own self-view, having IBS “came with so much baggage” that it was a difficult condition to open up about with other people - especially strangers. What Tai is doing here is identifying the stigma that they have experienced from other people regarding their food-related medical condition, and this stigma is “shitting.” Sharing with others that they suffered from IBS made Tai feel deeply uncomfortable because they had in their own mind

begun to conceive of IBS and “shitting” as being rather inextricably connected. It isn’t hard to imagine that opening up to strangers about the ways in which you shit - or struggle to shit - might make you feel uncomfortable. Tai’s feelings are perfectly valid, as well as understandable. Still, I would like to think about why we as a Westocentric society have come to think about shitting as an uncomfortable or private topic of discussion.

In *History of shit*, Laporte argues that we in the West - I use “we” to be intentional about including both myself and my interlocutors in this discussion of the West - have been socialized to associate shitting with intimacy. (Laporte 2002: 28) We have been taught to release bodily waste in the home, an intimate space, as opposed to in the street, a public space. This is a means by which shitting has been domesticated in our society; after all, the home is the domestic sphere and the street is not. Laporte claims that the “domestication of waste” (Laporte 2002: 28) has caused us to stigmatize releasing bodily waste in the public space of the street. We have been taught to think that shitting in the street is socially wrong. Now, in order to shit in your home, as opposed to in the street, you must normalize the smells and perceivable traces of your own excrement, and you must also regularly face the smells and perceivable traces of the excrement released by the other members of your household. In the street, there is more anonymity than in the house. My thinking is that in the street, you do not have to deal with the afterlife of your own excrement, and you might also be able to avoid dealing with the excrement of the same few people - the other members of your household - on a daily basis. Still, the street is a public space, where people outside of your family or chosen family experience your shitting and can pass judgement on the ways in which you shit, how regularly you shit, how your excrement smells, et

cetera. The idea that shitting is private and is something to which strangers ought not to bear witness is what Laporte makes thinkable.

I find that Laportean thinking about a hierarchy of where it is socially acceptable to shit is applicable to the fact that Tai felt uncomfortable when they had to discuss their IBS with strangers. I believe that Laporte would argue that Tai has been taught to view strangers as the wrong people with whom to discuss their shitting. After all, strangers are people who do not belong to Tai's family or to their domestic sphere. They do not shit in Tai's bathroom, nor do they come into contact with their shit. As people outside of Tai's home, they are not rendered suitable as people with whom Tai can share details of their home life - which includes the ways in which they do or do not shit.

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## **Conclusion**

My goal in writing this chapter has been to give formal written voice to the emotions and feelings that show up in social situations for four of my interlocutors around their respective medically-imposed dietary restrictions. Upon reading this chapter, it is my hope that it will be quite clear to the reader that there is no one internal experience shared by every individual with medically-imposed dietary restrictions. Every sufferer of a food-related medical condition experiences their unique medical needs around food differently, but each and every internal experience with medically-imposed dietary restrictions is valid and deserves acknowledgement. This chapter recognizes that stigma finds its way into the respective experiences of each of these four interlocutors; stigma is a kind of easily observable trend that shapes the internal experiences of each of these individuals. Moreover, this chapter has also called attention to a kind of

awareness that each of these interlocutors have that they are able to be perceived by others in various social situations, and are therefore subject to judgement - or social stigma - from other people.

I remain committed to preserving the words that my interlocutors use to describe the emotions and thought processes that show up for them around their own respective medically-imposed dietary restrictions. It is for this reason that dedicating this chapter to narrativizing and creating space for the internal experiences of these four individuals is so important to the work of this project as a whole: taking in the words and emotions that these four interlocutors have shared is a powerful and necessary step to take in working to understand just how it feels to have your social life impacted by medically-imposed dietary restrictions. Unfortunately, the interviews in this chapter indicate that much of these four interlocutors' respective internal experiences with medically-imposed dietary restrictions have been negative. It almost feels as though my interlocutors are engaging in a kind of critical self-talk, in which they reinforce in their own minds the idea that they are embarrassing; or that they ought to hide their inability to eat what the people around them are eating; or that they should not meet their friends for dinner at all because their needs are too burdensome for the group; or even that it will feel too uncomfortable to discuss the medical condition from which they suffer with others. One could argue that by engaging in this critical self-talk, and by imagining that they are being perceived negatively by others, my interlocutors are stigmatizing themselves. This is to say that these four individuals are creating a dialogue within their own minds and bodies which holds their respective food-related medical conditions to be "an attribute that is deeply discrediting," (Goffman 1986: 2-3) instead of an attribute that just *is* a part of who they are. Now, I have

certainly engaged my own mind and body in this kind of negative self-talk. To this day, I often find myself thinking unkind thoughts such as, *You're going to ruin all of the plans*, or, *No one likes that flavorless, everything-free cake you brought. They're all just pretending to like it for your sake*. I suppose that entertaining thoughts such as these might be viewed as a way in which I stigmatize myself around my food allergies. I completely understand why my interlocutors might be having unkind thoughts around their respective medically-imposed dietary restrictions, and I empathize with them. Still, I think that there is something to be said for the idea that we can reframe the kind of self-talk in which we engage around our respective medically-imposed dietary restrictions. A question worthy of reflection is whether or not my interlocutors are being perceived negatively in the ways they imagine by the people with whom they interact. In other words, the question of whether or not other people feel as bothered or burdened by the respective medical needs that my interlocutors have around food is worth considering. In raising this question, I am by no means suggesting that we qualify or question the realness of my interlocutors' respective internal experiences. I am merely trying to create space for the possibility that the external experiences of my interlocutors - that is, the ways in which other people experience them and form opinions about them - may not be as harsh or unforgiving as their internal experiences can be. What if the external experiences of people with medically-imposed dietary restrictions are neutral? What if the people with whom we interact are entirely indifferent to our needs and our respective rituals? These rhetorical questions feel important to raise and to think through.

It is important to note that the purpose of this chapter has not been to do the work of thinking through the external experiences of my interlocutors around their respective

medically-imposed dietary restrictions. By this I mean that the aim of this chapter has not been to engage in ethnographic research about, or to narrativize, the ways in which people who find themselves interacting with these four interlocutors think and feel about these individuals and their respective food-related medical conditions. The ethnographic research that I have conducted for this chapter has not been motivated by a desire to posit an answer to the question of whether or not people at a dinner party or a restaurant do indeed look down upon, laugh at, or feel burdened or embarrassed by the needs that my interlocutors have around food. To spend time in this particular chapter on figuring out how other people view these four interlocutors would be to do my interlocutors a tremendous disservice. Their respective internal experiences deserve to be the focus of this chapter, and I have remained committed to the idea that these internal experiences need to be narrativized and documented for others to read as a standalone chapter. Dedicating a chapter to the internal experiences of four of my interlocutors - without derailing these internal experiences to corroborate them with the external - is inextricably linked with my overall purpose in writing this project: empowering my interlocutors and amplifying each of their voices.

The next chapter of this project will center something which I contend is indeed knowable: the fact that a person with medically-imposed dietary restrictions must always be aware of the potential dangers presented by food in the physical spaces in which they socialize and through which they move. I will argue that the space around you as a sufferer of a food-related medical condition directly affects your social experience. After all, if you must

preoccupy yourself with thinking about whether or not you are physically safe in a space, you are deprived of the energy and attention that you might have been able to give others.

The upcoming chapter will complement this first body chapter on internal experiences naturally, as physical spaces are inherently external. By thinking analytically about the ways in which the logistical challenges of moving through physical spaces affect the respective social lives of my interlocutors, this second chapter will allow us to shift our focus from the internal to the external.

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Christina Sinclair Jones

Content Warning: anaphylaxis; dying; bullying; Covid-19

### **Chapter III: Spaces**

“People with a food allergy typically walk around with a little bit of fear all the time. ” -  
Robert A. Wood, M.D., Director of the Pediatric Allergy Clinic, Johns Hopkins Medical  
Institutions, Baltimore, MD

For a person with medically-imposed dietary restrictions, everyday movement in spaces shared with other people can be accompanied by intense fear. The health threats posed by what I will refer to as “danger foods,” the foods that are medically off-limits for a sufferer of a food-related medical condition, are very *real* and very scary. As we all know, all people need to eat food of some sort in order to survive; this means that food can be found just about anywhere where there are people. When your physical safety is jeopardized by exposure to certain foods - whether this exposure be airborne, by skin contact (Tan Et. al 2001: 583-6), or through ingestion - maneuvering around these foods becomes a necessary daily practice. There are many unknowns when it comes to the danger posed by other people around food. When you are alone in a space, you don't have to fret over which foods anyone else might be preparing or eating, the food traces with which you could be brought into contact by another person, etc., for you have complete control over which foods are making their way into the space. However, when you are sharing a space with at least one other person, you no longer have the ability to regulate which foods get brought into the space because you cannot control the behaviors of anyone but yourself. You can never be one-hundred percent confident that a person with whom you're sharing space has had zero contact with your danger foods whatsoever because you can't live in another person's body

or follow their every move. Even the most well-meaning of people can unintentionally put you in a position to be exposed to your danger foods - this reality is unnerving, put euphemistically.

Because you are the only person whose behaviors you can fully control, you learn very quickly as a person with a food-related medical condition to take very good care of yourself around your food needs. You become your own spokesperson, advocate and bodyguard - self-reliance is key. Day-to-day life for people like my interlocutors and me is in part characterized by a constant carrying out of preventative labor as a means of working to self-protect around food danger. The forms that this self-protective, preventative labor takes for each of my interlocutors differs from person to person, but what is consistent is for all of my interlocutors is the fact that they are the ones being forced to take responsibility for working to keep themselves safe from danger food exposure. The people around them are not actively working to mitigate the risk of exposing others to food danger through their behaviors. Instead, the onus falls on sufferers of food-related medical conditions to self-protect and to do the work of maintaining their own safety, without assistance or care from other people.

What I wish to underscore in this chapter is that in our society, we sufferers of food-related medical conditions are encouraged - if not required - to internalize the neoliberal ideals of serving one's own best interest and prioritizing one's needs above others', to the point where we internalize the idea that it is our job to do the work of protecting ourselves from food danger. I will use this chapter to draw parallels between the self-protective work in which sufferers of food-related medical conditions must engage to keep themselves safe from exposure to their danger foods, and neoliberal ideals. Neoliberalism is a set of social, economic and

political ideals that emphasize rugged individualism. Under the neoliberal model, the individual hones the skill of self-regulation and learns to accept personal responsibility for taking care of themselves and maintaining their own well-being. Within the spheres of finance and politics, one effect of the individual's learned ability to self-regulate under this neoliberal model is that the individual must work to maintain their own competitiveness in relation to others. "For neoliberals, the individual is conceived as an unattached, self-responsible market player... For neoliberals, society is an environment in which a new kind of individual is formed, whose *modus vivendi* is focused on self-entrepreneurship and the obsessive acquisition of resources to achieve success in a competitive system." (Pendenza and Lamattina 2018: 100) Obsessively acquiring and safeguarding resources are means by which an "unattached" individual makes it their top priority to fulfill their desires and serve their own best interest. (Pendenza and Lamattina 2018: 100) As a self-identified "unattached" individual, you're not thinking of yourself as a member of a community with collective needs, nor are you working to serve these collective needs (Pendenza and Lamattina 2018: 100) - you're behaving in ways meant to benefit you, without regard to the people around you.

In living in accordance with the neoliberal emphasis on moving through the world with your own best interests as top priority, you as a neoliberal (Pendenza and Lamattina 2018: 100) are placing the needs and wellbeing of others below your own. Under neoliberalism, you're not encouraged to assign greater value to your group identity than to your individual identity. Neoliberalism teaches each of us to see ourselves as self-sufficient individuals who should work to get what we want, without the need to rely on others for help or support. So many of us in our society become so preoccupied with working to care for ourselves that we do not leave room for

caring for others. There is a lack of compassion under neoliberalism which keeps us from having empathy and courteous consideration for our fellow community members. It is because “neoliberalism’s foundations support an overarching ethic of individual autonomy and individual responsibility” that there is so little room left for collective responsibility and collective care. (Wrenn and Waller 2017: 495) Individualistically-minded living as an ethic does not encourage or celebrate collective responsibility. Neoliberalism, and the sort of self-righteous individualism that neoliberalism inspires, provide a generative frame through which to think about the individual responsibility to self-protect which sufferers of food-related medical conditions shoulder. I use neoliberal ideals of “self-entrepreneurship” and self-regulation (Pendenza and Lamattina 2018: 100) to underscore the fact that in our society, sufferers of food-related medical conditions learn to be our own protectors. In a society where you the individual come first, unless you suffer from a food-related medical condition yourself, you’re not likely to regulate and restrict your own behaviors around food with the goal of limiting your chances of exposing others to food danger. Even though food allergies, for instance, have become incredibly common in the U.S.<sup>10</sup>, there’s a lack of compassion and understanding in our society among non-sufferers for people with food-related medical conditions. I believe this lack of collective care is due in large part to a lack of widespread understanding among non-sufferers of just how laborious daily life is for people for whom certain foods represent *real*, urgent danger. Under a neoliberal model, you don’t need to give thought to or try to understand medical conditions by which you are not personally affected. We aren’t called upon to actively relate to one another’s struggles in our society.

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<sup>10</sup> According to Food Allergy Research & Education, approximately 32 million Americans suffer from food allergies, a figure which includes approximately 5.6 million children under the age of 18 years.

A question I get all too often which speaks directly to a misunderstanding of food allergies and other food-related medical conditions is what I like to call “The EpiPen Question.” Upon learning that I have food allergies, many if not most people only have one question for me: “Do you have an EpiPen with you?” Once I confirm that I do indeed have an EpiPen with me, the person asking the question tends to drop the topic of my food allergies altogether, as if the fact that I’m equipped with an EpiPen eliminates all cause for concern for my safety and comfort in a space. Under the “Important Safety Information” section of the official EpiPen website, it says that if you inject yourself with epinephrine, you need to “get emergency help right away,” as “only a healthcare professional should give additional doses of epinephrine if you need more than two injections for a single anaphylactic episode” (EpiPen 2021).<sup>11</sup> The company which makes the EpiPen itself is making it clear that epinephrine is not a drug to be taken lightly. “The EpiPen Question” brazenly overlooks the sheer power of the EpiPen, and just what a drama it is to use the EpiPen. More importantly, though, the “EpiPen Question” misses the mark altogether on what it means to give active consideration to the holistic wellness of another person. Only caring to talk about a person’s food-related medical conditions in terms of whether or not this person is equipped with a drug reserved for true life-or-death emergency limits the narrative of living with a food-related medical condition to two possibilities: surviving or dying. When a conversation about food allergies starts and ends with “The EpiPen Question,” there is no effort being made to better understand the health implications of a sufferer’s food allergies outside of trying to make sure that they will not die, nor is there any regard for this sufferer’s comfort within a space.

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<sup>11</sup> This webpage is not paginated, so I am unable to provide a page number in this citation.

In writing this chapter on spaces and the various forms in which everyday self-protective work shows up for my interlocutors, respectively, I seek to highlight the fact that my interlocutors are the ones owning the responsibility of keeping themselves safe from exposure to their respective danger foods. I use neoliberalism as a frame by which to think through the idea that in our society, it is socially acceptable for sufferers of food-related medical conditions to be their own protectors, as opposed to being protected by the people around them. By unpacking the ways in which the collective does not tend to look after the individual sufferer's needs around food danger, I demonstrate the lack of community care and consideration given to individuals with food-related medical conditions by the people with whom we share space.

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## **Fear**

A classmate of mine, Brendan, has had a life-threatening peanut allergy since he was two years old. Traveling to China with our orchestra last winter was the first time that he had ever been outside of the U.S., and one of the only times that he had ever taken a flight. "Planes are hard 'cuz they serve nuts sometimes," he told me, "and that's the only reason I hadn't been on a plane 'till I was eighteen, because my allergies used to be airborne." Brendan was only able to undertake the long journey to China and back because his peanut allergy had evolved from when he was younger, such that he was no longer airborne to peanuts by the time of our trip. His peanut allergy was airborne for most of his life, and it prevented him from flying for most of his life. It was only at the age of eighteen that Brendan was able to fly for the first time; even then, he played it safe by beginning with short, domestic flights - flying to China was a big step for

him. Flying can be incredibly daunting for people like Brendan who suffer from an airborne food allergy, in that it's nearly impossible to exit an airplane in the case of a severe allergic reaction. You cannot simply parachute out of an airplane or jump out of the nearest window if you've been exposed to your allergen - you're trapped in a closed space in the sky.<sup>12</sup> Airplane travel is notorious among food allergy sufferers for its particular logistical challenges. It's much easier to exit a vehicle that is on the ground, such as a subway car or a bus, than it is to exit an airplane flying over 30,000 feet in the air<sup>13</sup> in the case of an emergency. There are all sorts of blogs and op-ed pieces written by and for food allergy sufferers which give tips on how to most safely fly as a person with food allergies,<sup>14</sup> simply because there is so much fear and anxiety in traveling without a guaranteed exit plan. Brendan described being able to fly for a total of over seventeen hours to China as something of a miracle, and it is, considering that just two years ago, taking a short domestic flight seemed too great a risk for him to take given his then-airborne peanut allergy.

## **Bullying**

When Brendan and I first began our ethnographic interview together - after having exchanged "So good to see you"s and "Hope you and your family've been healthy and safe"s - I

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<sup>12</sup> Even if the pilot of an aircraft were to stage an emergency landing in the case of a passenger like Brendan having an anaphylactic reaction, the time that it would take to land the aircraft and to get emergency medical workers onto the aircraft once it's touched down in order to begin treating this passenger, it might be too late - with anaphylactic shock, every second counts, considering that "there is a risk of symptoms getting worse or another reaction happening minutes ... later." (Armitage, MD 2020)

<sup>13</sup> Commercial flights tend to fly between 31,000 and 38,000 feet above the ground. (Hacobian 2018)

<sup>14</sup> A few examples of such pieces include: "Flying with Food Allergies: Legal and Medical Concerns" on the Kids With Food Allergies: A Division of the Asthma and Allergy Foundation of America webpage (Kids With Food Allergies: A Division of the Asthma and Allergy Foundation of America 2021); "At 30,000 Feet, Why We Can't Count on Epinephrine Vials on an Airplane" on the Allergic Living webpage (Mandelbaum 20191); and "When an Airline Served Nuts on My Flight, I Almost Died in Front of My Kids" on the Good Housekeeping webpage (Powell 2018).

asked him to speak on whether or not he feels that his food allergies impact his ability to socialize with others. He sharply exhaled as if to prepare himself for a long-winded response and then let out a muffled, “Oooof.” I knew in asking this question that it might conjure up some uncomfortable feelings for Brendan, or cause him to feel rather vulnerable, in that I was asking him to get personal with me about his own social skills. While I waited for his response, I felt myself cringing and sort of biting my lip uncomfortably - I felt awkward and slightly guilty for asking him to speak on something so intimate. Brendan looked away from the screen and then back at me, and gave me a look which to my thinking communicated, *I’m cringing too*. He then began to share. “I went through elementary school and everything,” he said. “Lunch in elementary school is where everyone learns to socialize, and when you’re just sittin’ at the peanut-free table every day, everyone just knows, ‘Oh, you’re *that* kid,’ and you don’t really get to socialize during lunchtime, which is the one time you can.” Brendan was known to his peers as “*that*” kid with a peanut allergy. Each lunch hour, classmates of Brendan’s who did not have a peanut allergy were free to choose where they wanted to eat within the cafeteria space. Brendan, on the other hand, had to sit at the same table each day, the “peanut-free table.” His flexibility of movement was limited as he was unable to roam about the cafeteria space and pick new tables at which to sit and strike up conversations with new people from lunch hour to lunch hour. He had to actively avoid peanuts, which made the “peanut-free table” the only place where he stood a chance of safely eating his lunch, as it was a designated peanut-free zone.

Brendan’s peanut allergy spatially othered him in the cafeteria space. He had to sit at a special table, with its own special name, kept separate from all of the other tables in the lunchroom. By virtue of sitting at the “peanut-free table,” Brendan was associating himself with

the othering sort of identity of being a peanut-free eater. You can't hide the fact that you're allergic to peanuts when you sit at the "peanut-free table" because the table itself is a site reserved for eaters with a peanut allergy - it brought visual attention to Brendan's "stigma" as a person with a peanut allergy. (Goffman 1986: 2-3)

Eating at the "peanut-free table" became a hypervisible lunchroom display of Brendan's peanut allergy, and it invited unthinkably cruel bullying into his life. The lunch aide in the cafeteria would make all of Brendan's classmates wash their hands before leaving the lunchroom for class, and would tell these children that they were washing their hands in order to keep Brendan safe from peanut exposure. His classmates became resentful of the fact that they were being inconvenienced for his benefit, and in turn, they began to mock him mercilessly for his peanut allergy. One child in particular took the bullying further than any of Brendan's other classmates. Brendan recounted a particularly chilling encounter with this child, to whom he referred as "this one kid," in which, "this kid was eating peanut butter and he, like, chased me around with a spoon after he ate." I must have looked at Brendan with disbelief, as I was having trouble comprehending that any child could be so cruel as to threaten another child's life as a sort of sick game. After chasing Brendan around with peanut butter, the bully told him that he wanted to watch him blow up "like a frog." Not only was this bully taunting Brendan with the food that had the power to kill him by airborne exposure alone - he was also waiting to see the consequences of his actions unfold. Blowing up "like a frog" would equate to a horrific kind of public death for Brendan, in which the peanut butter with which he was being chased would cause him to implode. Being bullied so severely as to have his health put in jeopardy must have been terrifying - traumatic - for Brendan. This was a near-death experience, and one which

happened right in his own school cafeteria, where he as a student was meant to be protected by the lunch aides working to monitor the students' lunch hour. This kind of traumatic event of being bullied by your peers is not the kind of experience that only matters in the moment in which it occurs, but one that fundamentally shapes your subjectivities.<sup>15</sup>

The fact that Brendan as a sufferer of *airborne* food allergies was not provided with a separate, entirely peanut-free room in which to eat his lunch, but was instead placed at a table within the very same cafeteria space in which other children were eating peanuts, speaks to a lack of understanding of the very nature of airborne food allergies.

Children with food-related medical conditions are trusted to be able to effectively manage risk of exposure to their danger foods and to negotiate their own safety for themselves in their day-to-day lives - the responsibility to self-protect around food danger is not unique to adult sufferers. We see this in the fact that Brendan was trusted to be able to keep himself seated at the "peanut-free table" during his lunch hour as an elementary school student, instead of wandering around the lunchroom to play and socialize with children at other tables. No matter how many lunch aides were present during his lunch hour, if Brendan had decided to abandon his post at the "peanut-free table" and sit elsewhere, he could be made sick very quickly by exposure to peanuts at any of the other tables in the cafeteria space. "Severe allergic reactions" can occur "within seconds" of exposure to an allergen. (U.S. National Library of Medicine 2021)<sup>16</sup> Even the

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<sup>15</sup> Stopbullying.gov says that "bullying can... have negative, lasting effects on a person's development, the way they interact with others, and how they perform in school." (Stopbullying.gov 2021) Even now, as an adult, Brendan feels that he's, as he put it, "not as good at socializing" as he might have been had he not been bullied so severely as a child for having food allergies.

<sup>16</sup> The U.S. National Library of Medicine's website is not paginated, so I am unable to provide a page number for this citation.

quickest decision to abandon his self-protection to sit or play with a peanut eater could have grave consequences for Brendan. Ultimately, if he decided to make this sort of decision to leave the “peanut-free table” and expose himself to peanuts, it’s not certain that any of the lunch aides would have been able to act quickly enough to save him from danger. It was up to Brendan to decide for himself, each and every day, to stick with his safety protocols and remain within his peanut-free zone - the cost to his social life notwithstanding.

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### **Preventative Labor Around Food-Related Medical Conditions in Day-to-Day Life**

Fear is a response that the body has to “stressors,” and one of the stages of experiencing fear is “exhaustion” (Rosenberg 2017).<sup>17</sup> Everyday movement in everyday spaces brings with it the dangers posed by food for sufferers of food-related medical conditions. People like my interlocutors and me can’t afford to let our guards down when we are around other people because we must constantly be anticipating the potential food dangers with which we could be presented by the people around us. You’re always working to stay alert and to keep your eyes open for sightings of your danger foods in navigating food danger. You cannot afford to slip up, as slipping up could mean the difference between living and dying. Never being able to let your guard down around other people is exhausting - you’re constantly working to keep yourself safe, while managing intense fear. As Stjerna Et al. write in a study on situated risk as it relates to managing your food allergies as a child, food allergies have “no cure or preventative treatment... The only way to manage the condition is therefore careful avoidance of the offending foodstuff

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<sup>17</sup> AJMC’s webpage is not paginated, so I am unable to provide a page number for this citation.

and treatment of reactions when they occur.” (Stjerna Et. al 2014: 130) Actively avoiding food danger is the closest that sufferers like my interlocutors and me can get to guaranteeing our own safety.

The work of spotting and actively steering clear of exposure to danger foods is preventative labor. In talking with my interlocutors about the self-protective preventative work in which they engage in their respective daily lives, I’ve come upon four main forms that preventative labor takes for them. I will use the thoughts and experiences that my interlocutors explore each of these four forms of preventative labor below.

#### I. Advanced Planning

In conducting my ethnographic interviews, I noticed that all eight of my interlocutors spoke about the respective strategies that they’ve developed for identifying the food danger with which they could be faced in a certain space ahead of time, so that they can equip themselves with what they need to be as safe as possible upon entering said space. They are each so accustomed to having to single-handedly navigate the risks that come with sharing spaces with other people that they have created their own rituals of identifying food-related risks from space to space, in order to make their self-protective work a little easier. The forms in which the work of advanced planning shows up varies among my interlocutors. Some of my interlocutors do research to vet certain spaces ahead of their arrival, in an attempt to avoid entering into dangerous spaces. Others equip themselves with safe snacks before leaving home, in case they are left without access to safe food options in a space. Even though they each have their own

unique advanced planning rituals, all eight of my interlocutors share the desire to eliminate as much food-related risk as possible when sharing space with other people.

For Jane, advanced planning takes the form of reading online reviews that customers leave about restaurants at which she is considering dining. When she doesn't see a complaint in the reviews about "an allergy thing," by which she means some sort of negative encounter with a server and/or someone from the kitchen related to food allergies, it "calms [her] down." Her thinking is that if no other food allergy sufferer has written in with a bad food allergy experience at a given restaurant, then she as a fellow food allergy sufferer is unlikely to have a poor experience at this restaurant around her own food allergies. There's solidarity in this; Jane trusts fellow sufferers so much that she's using their input as criteria for whether or not to risk eating at a certain restaurant. Her system of searching for and relying on input from fellow food allergy sufferers is also a means by which Jane recruits external assistance in carrying out her self-protective work, within a community of other individuals with food-related medical conditions engaging in their own self-protective work around food danger. She's looking to other people who have already dined at the restaurants that she is considering to give honest assessments of the safety level of a restaurant space, so that she can avoid having to find out the hard way that a space is unsafe, on her own.

One of my interlocutors, Marcus, has the gene for celiac disease; even though he did not have actively-presenting celiac disease when he was last tested for the autoimmune disorder (The Celiac Disease Foundation 2020)<sup>18</sup> at fourteen years of age, actively-presenting celiac disease

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<sup>18</sup> The Celiac Disease Foundation's webpage is not paginated, so I am unable to provide a page number for this citation.

will, as he put it, “come up at any point of [his] life.” His father and siblings, on the other hand, have actively-presenting celiac disease, so their family has always been strict about maintaining an entirely gluten-free household. Marcus’ family home is the one space in his life in which no one is eating or handling gluten around him, and everyone in sight is eating gluten-free foods. One lesson which his mother taught him and his siblings when they were children, and which has stuck with Marcus into his adulthood, is that they must pack along gluten-free safe snacks whenever they leave home. “It’s really my mom ingraining this in me... just gotta bring at least a gluten-free snack with me everywhere... It’s pretty much in my mind, I’m not guaranteed to be able to eat anything... I’m always packing something gluten-free with me,” he told me.

Marcus’ mother is acting out of a good place; she, as his mother, wishes to nurture her child and to make sure that he never has to go hungry. Her thinking is that if he brings his own food with him when he leaves home - food that he has already carefully vetted and deemed safe - then he will have something to eat no matter where he goes. The fact that Marcus’ mother has found it necessary to “[ingrain]” in her children that they need to be responsible for providing themselves with safe foods to eat when they leave home speaks to a lack of widespread care and accommodation for gluten-free eaters in our society. Celiac disease is hardly a rare medical condition in the U.S.<sup>19</sup> - it’s not a far-out concept that anywhere where food is being served, gluten-free options should be made accessible to people who are medically unable to eat gluten. Nevertheless, the possibility that Marcus as a gluten-free eater will be left without access to gluten-free food items in a particular space is so strong that he must provide himself with food accommodations to cover his bases, just in case the people around him do not do this work of

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<sup>19</sup> “Experts estimate about 2 million people in the United States have celiac disease.” (National Institute of Diabetes and Digestive and Kidney Diseases 2021)

providing him with safe food to eat on their own. There is certainly comfort and empowerment in the fact that packing a safe snack when leaving home means that Marcus does not need to rely on anyone else for access to safe food. Still, I find it upsetting that Marcus has had to learn that he has to compensate for other people's lack of consideration for his dietary restrictions. It's not his fault that he has celiac disease - why should it be on Marcus to provide himself with accommodations for a medical condition from which he did not choose to suffer?

Hanna, an interlocutor whose internal experiences we sat with in Chapter II, makes budgets before taking trips with her friends. In these budgets, she sets aside funds with which to pay for her special, expensive allergen-free foods during her travels. During her semester abroad, she found herself paying several Euros more for each meal than all of her friends were paying, each time that the group dined out. Because of her autoimmune disease, Hanna had to purchase specialty food items which were both vegan and gluten-free, while her friends were able to buy inexpensive street foods without giving thought to ingredients - Hanna's specialty food items consistently run up her tab! "If you're with a group, you have to go with the flow and go with others, and it's not always what you want and what you need, so you have to be flexible in that way, but in being flexible, it's also money, and also the possibility that you don't get a chance to eat because there's nothing for you to eat," Hanna explained. Here, as in the previous chapter, we see that Hanna's intention is to be "flexible" enough to go along with her friends' plans, and to draw as little attention to her medically-imposed dietary restrictions as possible. The tension lies in the fact that Hanna's medically-imposed dietary restrictions make it necessary for her to go out of her way to find and to purchase allergen-free foods with which to safely feed herself, while her friends are medically able to choose foods freely and at their own convenience. Hanna

has grown so accustomed to having to pay more than the people around her when eating in groups for allergen-free food items that she knows to budget in added eating expenses when calculating how much she will need to spend on her meals, in comparison to her friends.

A group of Swedish scientists conducted a study to determine the “household costs” of having at least one “objectively diagnosed allergy to staple foods” for parents of children or adolescents with food allergies. They circulated “the Food Allergy Socio-Economic Questionnaire,” in which “84 children (0-12 years) and 60 adolescents (13-17 years) with objectively diagnosed allergy to staple foods (“cases”) and age- and sex-matched controls (n = 94 children; n = 56 adolescents) were compared.” (Protudjer Et al. 2015: 68-75) Given the results of this questionnaire, the conclusion was drawn that “amongst cases, total household costs were higher by €3961 for children and €4792 for adolescents versus controls ( $P < .05$ ), and were driven by direct (eg, medications) and indirect (eg, time with health care professionals) costs.” (Protudjer Et al. 2015: 68-75) Having to buy allergen-free and/or low-ingredient foods; paying for medical equipment with which to treat yourself upon being exposed to danger foods; and having to pay for hospital visits and appointments with physicians in connection to danger food exposure, contribute significantly to the added expenses of living with medically-imposed dietary restrictions. Allergen-free foods tend to be so much more expensive than allergen-containing foods (Protudjer Et al. 2015: 68-75) that paying more for your food than people without medically-imposed dietary restrictions as a sufferer of a food-related medical condition is viewed as something of a given. It is incumbent upon her as an individual sufferer of a food-related medical condition to pull together the funds with which to feed herself,

irrespective of cost. Budgeting toward this reality is how Hanna works to bear the burden of her expensive food needs.

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## II. Adapting Environments

So much of everyday risk management revolves around cleaning. This cleaning includes scrubbing or wiping down surfaces whenever you wish you to sit at a table, or eat your meal off of a countertop; washing your hands upon shaking the hands of another; and even attempting to purify the air in a space by opening windows and doors. Cleaning is physical work. You quite literally put your body into the labors of making a space safe for you. FARE (Food Allergy Research & Education) finds cleaning surfaces to be such vitally important work for food allergy sufferers that they've dedicated an entire page of the "Resources" section of their website to discussing "Cleaning Methods" (Food Allergy Research & Education 2021)<sup>20</sup> providing food allergy sufferers with a list of instructions to follow in order to "prevent the unintentional transfer of residue or trace amount of an allergic food into another food" (Food Allergy Research & Education 2021).<sup>21</sup> Some of the instructions that they give include: "Treat all surfaces that come into contact with food in kitchens, classrooms and other locations where food is prepared or eaten;" "Disinfect frequently touched surfaces (e.g., playground equipment, door handles, sink handles, drinking fountains) within the school and on school buses;" and "Clean and sanitize food preparation equipment, such as food slicers, and utensils before and after use." (Food

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<sup>20</sup> The Food Allergy Research & Education webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>21</sup> The Food Allergy Research & Education webpage is not paginated, so I am unable to provide a page number for this citation.

Allergy Research & Education 2021).<sup>22</sup> The common thread among each of these instructions is that they call upon the individual food allergy sufferer to do the work of cleaning shared surfaces themselves in order to self-protect. There is no request being made of anyone but the individual food allergy sufferer to regulate their sanitation habits around food preparation and consumption. The fact that FARE, an organization that is highly regarded within the food allergy community as a reliable source of helpful tips on how to make food allergies liveable, centers its cleaning instructions around the food allergy sufferer as the person doing the cleaning speaks to just how widely accepted it is in our society that people with food allergies need to do the work necessary to stay safe from food danger, on their own. In this cleaning context, this quite literally translates to having to clean up after other people in order to keep yourself safe as a food allergy sufferer.

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### **Fictive Vignette**

John Douglas - Mr. Douglas to his assistant - is on the A train headed down to 42nd Street for work. He's on time, which seems to him something of a miracle, as his youngest, Aaron, threw a real fit over breakfast about having to get dressed for school. Dressed in a brown suit with a tie in robin's egg blue, Mr. Douglas feels rather sharp. He's got a cup of coffee in his right hand and a weathered briefcase in his left, and as the train squeaks to a stop at each station, another droplet or two of the hot, brown joe spills out of the top of the cup (Mr. Douglas didn't

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<sup>22</sup> The Food Allergy Research & Education webpage is not paginated, so I am unable to provide a page number for this citation.

close the lid tightly enough). It was such a struggle to get Aaron to put on his uniform that morning that he didn't get a chance to eat breakfast before heading out for the day.

When the train screeches to a stop at Port Authority, he walk-pushes past a train performer who's been dancing to Jackson 5 oldies to get off at his stop. He glances down at his watch and slows his pace upon seeing that he's still got a few minutes before his day begins. As he climbs the stairs to get up to street level, he catches a sweet whiff of candied nuts from a cart on the street. His wife hates it when he eats them because they're so "high in sugar," and, "Lord only knows how they're mad," but he decides to treat himself to a bag of them because his kids were getting on his last nerve, he missed breakfast, and his wife isn't there to see him sneak the sugary snack. The cashews look good but Mr. Douglas goes for his usual order: the peanuts. Ahh, they're delicious. As he continues on his walk to the office, he chows down on big handfuls - it's been forever since he's gotten to eat these street nuts. The meeting he's got coming up this afternoon is making him a bit nervous because it's with a potential client, and he knows that if he screws this one up for the company, he'll be on even worse terms with his boss than he is now. He's also a little worried about his daughter, Emma; she's had a rash on her face for several days, and he hopes it's nothing serious.

Mr. Douglas' office building is right up ahead. He decides that he'd better finish off his bag of nuts before he gets inside because he wants to seem professional, and it might be a bad look to be eating a snack that he bought on the street at work; he wants it to at least seem like he's so well put together that he had a full, sit-down breakfast with his family. A couple of handfuls later and he's finished the bag. He tosses it into the closest garbage can and then heads for the heavy doors at the main entrance. A woman he's met on the fourth gets close to the door

so he grabs the door knob and turns it open for her. He greets her with a smile and a “Good morning” as boisterous as he can manage. Mr. Douglas is dreading answering his emails because that client from last week might have written him to say that he will not be moving forward with their agreement. If that happens, how will he ever face his boss?

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I’ve written the fictive vignette above in order to act out an everyday city scene: a businessman taking the subway to work, stopping for a snack, and opening the door for a colleague on his way into the office building. This sort of scene might seem altogether unremarkable as it is so very ordinary. However, the fact that this sort of scene plays itself out so often is what makes it so worthy of attention. Mr. Douglas bought peanuts on the street, which already sets off warning alarms in the minds of anyone like my interlocutor, Brendan, who has an airborne peanut allergy. If Mr. Douglas could smell the peanuts in the air well enough to be tempted by a waft of them before he even reached street level, a person who cannot so much as be exposed to a small trace of peanuts, happening to be walking by the cart on that street, could easily have been made gravely ill. More important than the fact that there was a street vendor selling peanuts on the sidewalk, though, is the fact that Mr. Douglas opened the door to his shared office building with the same hands that he’d used just seconds before to finish off the bag. He didn’t think to wash or sanitize his hands before opening the door for the woman that he worked with, and he left his peanut traces all over the door knob. If someone with a peanut allergy by skin contact were to open that door after Mr. Douglas contaminated it with little bits and pieces of his morning snack, they would be at risk of having an allergic reaction. A study conducted in 2013 found that peanut residue can last on surfaces for as long as 110 days.

(Watson et al. 2013: 7) That means that if the door knob that Mr. Douglas touched immediately after having eating big handfuls of peanuts was not thoroughly cleaned, it could remain a hazard to anyone with a peanut allergy by skin contact for as long as fifteen business weeks!

Mr. Douglas is not alone in being wholly unaware of the ways in which the food that he's been eating and touching might cause harm to individuals around him who have food-related medical conditions. The possibility that someone with a peanut allergy by skin contact might touch that same door knob within the next fifteen weeks to come did not occur to Mr. Douglas. What I seek to do is to use Mr. Douglas as a character through which to speak to the larger issue within our society of not accepting personal responsibility or accountability for the wellbeing and safety of others around food danger, which I attribute to the sort of individualism that is integral to American mythology of individual rights and entitlement. Here in the U.S., we are prone to adopting the habit of mind which holds that the government cannot take from us the things that we value, whether this is guns for defenders of the Second Amendment, (Legal Information Institute 2021)<sup>23</sup> to a tasty street nut breakfast treat for morning commuters. The U.S. as we know it today was built, quite literally, out of a place of incredible entitlement; the white colonizers who stole the land upon which this nation has been settled from Indigenous peoples, who are the denizens of this land, felt entitled to take this land and to use it for their own benefit. With a history as violent and deeply entrenched in theft as we have in the U.S., it is no surprise that Americans today live very individually-minded lives, in which getting what you want with the sort of arrogance that comes with the belief that no one can tell you to do otherwise, becomes an everyday ethos.

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<sup>23</sup> The Cornell Law School Legal Information Institute website is not paginated, so I am unable to provide a page number for this citation.



In thinking specifically about hand washing as it relates to touching the same surfaces as other people, I find that there is a striking parallel to be drawn between hand washing related to food safety, and hand washing related to Covid-19 safety. In the current moment, hand washing as a means by which to avoid catching and spreading Covid-19 has become so widely regarded as important in our society that musicians of all levels are even making children's songs<sup>24</sup> dedicated to making twenty-second-long hand washing routines (Centers for Disease Control and Prevention 2021)<sup>25</sup> a little more fun. People of all ages are now thinking, talking, and singing about hand washing as it relates to Covid-19. There's a bizarre sense of novelty surrounding hand washing in the face of this global pandemic; it feels as though this is the first time that many people in our society are being intentional about thoroughly washing their hands. For people with food-related medical conditions, though, thorough and consistent hand washing has always been a necessary daily practice. We must constantly be aware of what our hands are touching, be it a restaurant table on which a danger food might have been served two minutes before we were seated, or another person, who might have touched and eaten a danger food without washing their hands before a meet-up. With this constant attention to what our hands are touching comes the constant need to thoroughly wash our hands. In washing our hands, we're working to wash away the myriad of potential food risks which show up for us in our everyday lives - before, during, and after the Covid-19 global pandemic.

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<sup>24</sup> One such song that has gained particular popularity since it was uploaded onto Youtube in March 2020 is "Wash Your Hands with Baby Shark: Baby Shark Hand Wash Challenge" from the official "Pinkfong! Kids' Songs & Stories" Youtube Channel, which currently has over 26 million views.

<sup>25</sup> The CDC's webpage is not paginated, so I am unable to provide a page number for this citation.

In drawing a parallel between living day-to-day with a food-related medical condition and living day-to-day in the face of the global Covid-19 pandemic, mask wearing stands out to me as a practice which forces us all to look at our lack of active care for the collective as a society. Mask wearing serves the purpose of protecting the people around you from you and from what you might be carrying. When we wear a mask (or two!), we are helping to take care of our community: we're doing the work of moving through spaces with a mask in an effort to preemptively shield others from the harm that we could potentially cause them. Before individual states issued official mask wearing mandates which made it legally obligatory to wear a mask in shared spaces - as of March 26, 2021, "thirty-three state governments currently require people to wear face coverings in public to curb the spread of COVID-19" (Markowitz 2021)<sup>26</sup> - many people in the U.S. were hesitant to wear a mask, or refused to wear one altogether. Vargas and Sanchez have found that "the number one reason given by Americans who are not wearing a mask is that it is their right as an American to not have to do so." (Brookings 2020)<sup>27</sup>

Inconveniencing yourself by wearing a piece of fabric around your nose and mouth which changes the ways in which you breathe and talk to others, as a means by which to protect other people from you, seems to be in opposition to the sort of neoliberal, individualistic American ethos which holds that I come before you. The idea that I should inconvenience myself for your benefit instead of for my own is anything but neoliberal - put hyperbolically, you're hurting yourself for the gain of others, instead of competing with others for your own betterment. In an effort to encourage more people in the U.S. to wear masks, the CDC began to publish articles detailing the ways in which the individual mask wearer is also benefited by their mask wearing

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<sup>26</sup> This article by Andy Markowitz is found on the AARP website, which is not paginated; therefore, I am unable to provide a page number for this citation.

<sup>27</sup> The Brookings webpage is not paginated, so I am unable to provide a page number for this citation.

(Centers for Disease Control and Prevention 2021).<sup>28</sup> It's typical of our society that we are hard-pressed to perform labor with the goal of mitigating risk, unless we are mitigating risk for our own benefit. We see this in the widespread resistance among Americans to mask wearing, just as we see this in the lack of collective care for individuals with food-related medical conditions.

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### III. Asking Questions of Others

Because we cannot regulate or control the behaviors of anyone other than ourselves, we cannot be sure of whether or not a person with whom we are sharing space has eaten, handled, or come into contact with any of our danger foods. This where asking questions of the people around you becomes really helpful as a person with a food-related medical condition: you ask questions of others so that you can better assess the level of risk that you're taking on by being in a space with these people, and make informed decisions about the types of situations in which you wish to put yourself. The questions which individuals with a food-related medical condition might ask of others can be anything from "Did you eat gluten today?" to "Have you touched almonds in the past hour?" You're trying to pick up on bits and pieces of information that you can use to keep yourself safe in a space. Just as non-sufferers of food-related medical conditions like our fictive character Mr. Douglas tend not to think to disinfect a door handle that they've just touched in case someone with a food allergy by skin contact should touch that same door handle after them, non-sufferers also tend not to think to, say, have their cars washed after eating lunch

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<sup>28</sup> The Centers for Disease Control and Prevention webpage is not paginated, so I am unable to provide a page number for this citation.

on the road in case a friend with an airborne food allergy gets into the car, or to steer clear of using peanut oil to make fries at a cookout in case one of their guests has a peanut allergy.

There's a mindlessness in the ways in which many people who do not suffer from food-related medical conditions handle food and bring food with them into shared spaces. The lack of self-reflection on the part of non-sufferers around their own engagement with food makes it necessary for a sufferer to ask questions in order to ascertain just how much or how little food risk they are taking on in a given space.

During my ethnographic interview with Brendan, I asked if he would comment on the extent to which he finds that his peanut allergy affects his dating life. He told me that when he's on a date with someone with whom he is not well acquainted and he wants to kiss them - namely, first dates - he has to ask this person what they've eaten that day so that he can determine whether or not he can safely engage them in this level of physical contact. Brendan says that having to ask his dates about the foods that they've eaten leading up to their date, and doing this sort of detective work, "kills the whole spur of the moment" aspect of sharing a kiss with someone. We all know how first dates go: when you've just begun to date a person, you need time to get to know each other, and to learn each other's likes, dislikes, wants and needs - including medical needs. For people like Brendan for whom so much as kissing someone who has ingested one of their danger foods can cause serious harm, one of the most pressing pieces of information to disclose during the early stages of dating is the fact that you cannot be exposed to certain foods. Brendan explained that he likes to be as subtle as possible when asking his dates about the things that they've eaten leading up to the potential kiss. Instead of coming out right and asking what he really wants to know, which is whether or not the person he's dating has

eaten peanuts since they last brushed their teeth, he asks leading questions such as, “What’d ya have for lunch today?” In asking these indirect questions of his dates, Brendan is performing a kind of subtlety which comes with neutral question-asking as a means of merely making conversation with someone. There is nothing casual or neutral about assessing whether or not you could be killed by kissing someone. Yet, Brendan has had to learn that asking indirect questions of his dates is the most effective way in which he can get an idea about whether or not kissing someone is safe, while being subtle enough about making this calculation that he doesn't make them feel uncomfortable.

Not only is Brendan doing the inquisitive work of asking questions of his dates in order to assess and manage risk: he’s also working to make his questions more palatable for these people. In addition to wanting to come across as subtle in carrying out his question-asking work, Brendan also tries his best to be “nonchalant” about this work. Nonchalance seems a curious goal in a life-or-death context. Nonchalance implies a free, breezy lack of care and concern - considering that it’s a means by which he negotiates his physical safety, Brendan’s question-asking work strikes me as anything but nonchalant. The sort of double-agent work that Brendan is doing when he both asks questions of others in order to keep himself safe, and edits these questions in an effort to come off as nonchalant or subtle, seems exhausting; it also seems lonely. Brendan is single-handedly managing the decision of whether or not to kiss his date, while also single-handedly working to make this person feel at ease as he engages in his stealthy self-protective work. The double-agent work in which Brendan feels he must engage in order to share a mere kiss with another person speaks to the pervasiveness of neoliberalism in everyday food allergy management. Brendan is so accustomed to having to look out for himself around his

food allergies that he even finds it within himself to look out for the people with whom he's interacting while doing this self-protective work without help from these people.

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#### IV. Accepting the Uninhabitability of a Space - The Last Resort

As a person with a food-related medical condition, you become accustomed to having to pass up opportunities to socialize, travel, network, gather with others, etc. in exchange for keeping yourself safe around your danger foods. Fun becomes secondary to safety, and when the fun that you're after involves being in a space where you face the risk of being exposed to your danger foods, you have to make peace with the fact that this fun is inaccessible to you. When advance planning, adapting environments, and asking questions of others all fail to provide you with a sense of security about putting yourself in a certain space, you have but two options if you wish to protect yourself: leave the space if you are already in it, or do not enter it at all if you aren't. Saying "no" to going somewhere, or leaving a space after you've already arrived, is a bummer. I cannot count the number of times that I've showed up to a space for a social gathering I've been looking forward to, only to find that this space presents me with so much food-related risk that I simply cannot stay. There's a kind of "FOMO" (fear of missing out) that comes with this; you feel like your medical condition is keeping you from being a part of something that appeals to you. Still, learning to accept the fact that some spaces are simply uninhabitable for us as people with food-related medical conditions is essential for self-protection. Being able to resign your desires to what you medically need allows you to continue to put yourself and your physical safety first, and consequently, to be the best advocate for yourself that you can be.

In Chapter II, we learned that Finley often stays home when her friends are dining out at restaurants so that she can avoid having to change the group's plans in order to pick a restaurant that makes her feel safe. In talking with her about her fear of missing out - her friends are out making memories together while she's at home by herself - I asked Finley whether or not she ever has to rearrange or cancel her social plans because her food allergies make a space uninhabitable for her. To this, she exclaimed, "Oh yeah, definitely!" She went on to say, "I think a couple of times, I've just went home." Finley has learned how to leave her friends and the memories that they're making behind in order to keep herself safe. However, knowing how to say "no" to certain spaces doesn't make it any easier to actually put this skill into practice in moments when your danger foods are barring you from enjoying other people's company.

For Tai, another interlocutor whose internal experiences we sat with in Chapter II, part of what it means to accept the uninhabitability of a space is to simply forgo eating altogether in spaces where none of the food available seems safe. In an attempt to not miss out on any of the social aspects of being in various spaces with friends, coworkers, fellow Jewish community members, etc., Tai will often stay put in a space where they don't feel entirely comfortable, for leaving the space means missing out on social interactions in which they wish to partake. When all of the food that's being served in a space is unsafe for Tai, they will choose the discomfort of not eating - even if it means watching the people around them enjoy their meals or snacks - in order to feel socially involved. In talking about these sorts of scenarios in which not eating was the only means by which they could make the space at all inhabitable for themselves, Tai said, "There were times where I was just like, 'I don't wanna eat anything; I don't want anything to hurt me. Everything hurts.' More than once, I went to the doctor and I was just like, 'I can't eat

anything.’ ... I was just really afraid to eat. Wasn’t fun. Wasn’t good for my mental health.”

When Tai finds themselves in spaces where they feel that the food available stands to “hurt” them, they’re left to negotiate the difficult choice between leaving a space but being able to safely eat, and staying put in a space but having to refrain from feeding themselves, entirely on their own.

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## **Conclusion**

Having to learn the skill of self-regulation as a means of keeping yourself safe from exposure to food danger is a lot to ask of an individual sufferer, and it’s unfortunate that we sufferers of food-related medical conditions have to do so much work on our own in order to stay safe around our danger foods. Nevertheless, learning to be fully self-sufficient in regulating the food that you eat and to which you’re exposed isn’t entirely negative. There’s a powerful mindfulness<sup>29</sup> around food which comes with needing to be keenly aware of which foods you are taking in, so as to protect your physical safety and wellbeing. I wish to provide an uplifting story about this sort of mindful eating in concluding this chapter on self-protective work and self-regulation around food. In wrapping up our ethnographic interview together, Marcus shared with me that living with medically-imposed dietary restrictions - in his case, being gluten-free - “kind of forces you to always be looking at nutrition facts, and really be mindful in that way.”

This sort of optimistic look at rigid self-regulation around food intake for sufferers of

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<sup>29</sup> “Mindfulness is the capacity to bring full attention and awareness to one’s experience, in the moment, without judgment. Mindful Eating brings mindfulness to food choice and the experience of eating. Mindful eating helps us become aware of our thoughts, feelings, and physical sensations related to eating.” (The Center for Mindful Eating 2021)

food-related medical conditions inspired me to think about self-protective eating as a generative, empowering means by which to show your body Love.

Having to be aware of exactly what is in all of your food for medical reasons forces you to think about what's going into your body, as opposed to mindlessly eating foods without giving thought to whether or not you wish to use the ingredients that these foods contain to fuel yourself. Honing the skill of self-regulation around food and eating puts you in a position to be intentional and disciplined about feeding yourself. Food is power - it's a source of sustenance. Food is also an important source of Joy! There is pleasure to be gotten from eating something which satisfies you. When you're able to tap into what your body is asking you for in terms of nourishment and food Joy, you can be self-sufficient in feeding your body what it wants, and giving yourself satisfaction.

Mindful eating is empowering: you're able to practice self-care by intuitively eating the foods that give you a boost. Being selective about what you do and do not eat is a way of showing yourself the sort of protective care and consideration that translates to self-love: moment to moment, you're working to give yourself the best foods possible for your body and its ever-changing needs. The narrative around eating changes from simply eating to eat, to eating what your body tells you it wants - you learn to engage in dialogue with your body and to be introspective about assessments which foods will bring you comfort and power. Mindfulness around food and eating entails connection between body and self. When you connect with what makes your body feel well in a holistic sense, you can gently and kindly experiment with eating in order to identify the foods which make the greatest positive contribution to your overall

wellness. Mindful eating is about reciprocity and acts of care. By feeding your body foods that will give it love, you thank your body for being the beautiful space which allows you to be all that you are and to do all that you do, and you give your body the foods that will best support it in continuing to show up for you.

Even though the work of keeping yourself safe around food danger is onerous, ceaseless, and taxing for an individual sufferer, it brings with it the immense benefit of making mindful eating an everyday practice. In learning to take care of and protect your body on your own, you stand to develop a caring relationship with your body, one in which you learn to steer clear of the foods that will harm you and actively take in the foods that will bring you Love. As much as the self-protective work which becomes necessary as an everyday commitment and practice for people like my interlocutors and me is about fending off danger foods, it is also about gifting yourself power foods. By giving thought to the foods that will make you feel well, you open yourself up to the possibility of eating as a practice of self-adoration and Joy.

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Christina Sinclair Jones

Content Warning: anti-Black racism; Covid-19; police brutality; death

### Chapter IV: Race

In conceptualizing my senior project, I decided that I did not want to include race as a topic of discussion in my native ethnography. As a mixed-race Black woman attending a predominantly white institution, I've had to engage in all sorts of conversations about race during my time at Bard, both inside and outside of the classroom. These conversations have exhausted me. I've found peers and faculty alike looking to me to be a teacher of all things Black for non-Black people, and it's made me incredibly uncomfortable - just because I am Black doesn't mean that I can speak for all Black people. Blackness is not universal; each and every Black experience is unique. I wanted to write this native ethnography on medically-imposed dietary restrictions with color and vibrance, without needing to discuss race in order to be understood.

Nevertheless, as I began conducting ethnographic interviews with my interlocutors last summer, I started to take note of a pattern that was showing up in several of these interviews: my interlocutors were bringing up their own whiteness in discussing their respective medically-imposed dietary restrictions with me! Marcus, for instance, told me in responding to my question about the role which having celiac disease plays in where he decides to eat outside of home, "I get made fun of a lot in friend circles and romantic life for being the white dude who can't eat gluten." Being vocal about his food needs and playing an active role in picking an eatery with gluten-free options seems to make Marcus' whiteness stand out to his friends. They find humor in the fact that he is a "*white dude* who can't eat gluten," as opposed to simply being a "*dude* who can't eat gluten." Patrick, another white man, spent time abroad in Myanmar and

found that his allergic reactions to peanuts which were grown in Myanmar were less severe than his allergic reactions to peanuts imported from the West. As he put it, the “running joke with friends there” was that Patrick “can’t have Western nuts.” It was as though the West - the traditionally-white world - posed a more severe sort of risk with regards to peanut danger than Patrick was faced with in Myanmar. Patrick shared that in Myanmar, he was the white Westerner who could not physically tolerate peanuts from the West, and his Myanmar friends found this incredibly comical. He felt “nervous” when dining at “Western restaurants” in Myanmar because foods imported from the West contained the scarier, more dangerous peanuts. When Patrick dined at Myanmar restaurants, on the other hand, he was eating dishes prepared with locally-grown peanuts, and he felt a sense of security - these Myanmar peanuts were safer than the Western ones. Ironically enough, considering that Patrick was born and raised in the U.S., the West meant danger for him in a way which Myanmar did not, in terms of peanut exposure.

At first, I simply could not understand why several different individuals, who are entirely unrelated to one another, and with whom I was having unique conversations about the food-related medical conditions unique to each of them, all brought up their own whiteness/positionality as a white Westerner. I did not ask any questions of my interlocutors about race, nor did I bring up my Blackness or their whiteness. In truth, I wanted to avoid talking about race altogether during these ethnographic interviews. I made a concerted effort in writing my interview questions to exclude race from our conversations, and I refrained from mentioning my own racial positionality or alluding to the social happenings of the summer of 2020 as I spoke with my interlocutors. Therefore, the fact that several of my interlocutors still took it upon

themselves to bring up their own whiteness in opening up to me about their respective lived experiences as sufferers of food-related medical conditions is striking and significant - therein lies the puzzle which grounds this chapter. The fact that several individuals with no relation to one another whatsoever each felt moved to talk about their whiteness during a conversation about medically-imposed dietary restrictions means that for some of my interlocutors, race plays a role in shaping everyday movement and social interactions in living with a food-related medical condition. I will use this chapter to think through this puzzle, and to explore various points of intersection between race and food-related medical conditions. In order to honor my interlocutors and to make this project as comprehensive as possible in terms of covering and sitting with all that my interlocutors shared with me during our ethnographic interviews, I find it necessary to think analytically about race as something which continues to impact the ways in which several of my interlocutors conceive of their respective food-related medical conditions.

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### **Social Context**

How you feel about your body's needs and the ways in which you take up space in adherence with these needs are directed by the social context of the world around you. Having a medical condition doesn't happen in a vacuum. The way that your medical condition makes you feel is influenced by what's going on in your society, and the feelings that show up for you around your condition are inherently put in dialogue with the feelings that show up for you around your own societal positionality in a historical moment. To gain a comprehensive understanding of how my interlocutors were feeling during our respective ethnographic interviews, I find it important to think with intention about the timing of those interviews - their

social timing - so as to recontextualize the feelings and thoughts that were shared with me during these conversations. The summer of 2020 was, put euphemistically, memorable. Often times, when people refer to a summer as “one to remember,” they’re looking back on it with fond memories of ultra-American things like watching fireworks at the beach, eating well at a cookout - or a barbeque, depending on who you ask<sup>30</sup> - and having swimming parties with friends and family, be they at a pool or a neighborhood swimming hole. I want to be very clear about the fact that I am in no way looking back on the summer of 2020 with fondness or nostalgia. In fact, it was a summer which traumatized me and the entire world, as it marked a moment of multiple pandemics: the Covid-19 pandemic and the pandemic of anti-Black racism, to name the two that have influenced me most directly in writing this chapter. Sadly, this moment of multiple pandemics has proven to be anything but fleeting, as we still find ourselves entrenched in the global despair and suffering brought about by the Covid-19 pandemic that people worldwide have been fighting for over a year, and racism is alive and well. Still, what made the summer of 2020 particularly strange in the U.S. was the temporary period of racial reckoning which so many white, self-proclaimed allies<sup>31</sup> underwent over the course of a few hot months.

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<sup>30</sup> If you read between the lines here, I’m already separating quintessential Black American experiences from quintessential white American experiences; Black folk say “cookout,” while white people say “barbeque.” I prefer the term “cookout” myself.

<sup>31</sup> I’ve chosen to refer to the white Americans who did not choose to deny the realities of anti-Black racism. (E.G: Trump supporters; people involved in white supremacist hate groups, those who showed up to Black Lives Matter protests to verbally or physically accost protestors; etc.) These white Americans are the sort of people who wrote “BLM” in their Instagram bios, linked their personal social media bios to the “<https://blacklivesmatters.carrd.co/>” URL, put up “Black Lives Matter” signs in their front yards, and took to performing their self-proclaimed allyship in hypervisible, public ways. By calling these white Americans “self-proclaimed allies,” I wish to draw attention to the fact that the hypervisible, public aspects of the sorts of performances of solidarity with Black Americans which is characteristic of the summer of 2020 point to an awareness on the part of the white person performing these solidarity acts that they will be seen by others. There’s a selflessness in my own personal definition of an ally, a person who works to effect change without wanting to be thanked and repaid by anyone, let alone acknowledged; an ally is, to me, a person who does the right thing simply because it is right, without expectations. That is exactly why I find the online and front yard sort of allyship to be so off-putting: there’s a desire on the parts of people using “BLM” banners as Facebook cover photos, or wearing a “Black Lives Matter” t-shirt, to be seen and acknowledged by others, almost as if doing these simple gestures warrants gratitude and reverence. I shall refer to anyone who

During this unique and temporally-bounded period, many white Americans wrote about, posted about, made art about, cried because of, marched in the streets to fight, and had meetings to discuss the privileges that they are afforded in our white supremacist, Eurocentric society, as well as their own internalized prejudices and biases. Plenty of U.S. companies and organizations issued statements of solidarity with the Black Lives Matter movement. These statements often took the form of lengthy emails circulated to entire email listservs to proclaim to staff members and customers that their company or organization's leaders do not condone anti-Black racism. Something that I found peculiar, not to mention unnerving, in the midst of the circulation of such solidarity statements (of which I as the only Black intern at an entirely white-run company was on the receiving end) was that so many of these statements focused on the murder of George Floyd specifically. I remember listening to the CFO of the organization for which I was interning tell all of us staff members and interns during a weekly meeting that she was outraged and horrified by the crime that was committed against George Floyd and his family. As I watched my corporate superiors nod their heads and paint their faces with expressions of deep sorrow and grief, I was taken aback by just how shocked these white people seemed by the fact that a Black King was murdered by the police in the U. S. of A. Now, I was heartbroken and shocked along with the rest of the world by the murder of George Floyd - each and every murder of a Black person is one murder too many, and yet another stinking and unerasable blood stain on the rotten record of white civilization. However, I was just as heartbroken and shocked by the murders of

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performs acts of solidarity with the desire or expectation to be thanked and given bonus points as an ethical being as a member of the classifier I'm using in this section, "self-proclaimed allies." These people are fair weather supporters of racial justice; they surfaced out of the metaphorical woodwork during the summer of 2020 to support a cause that has needed supporting since the inception of this nation, simply because it served their best interest by helping them to create a certain, quasi-curated image for others to see in which they are some sort of proud, outspoken racial justice worker.

Breonna Taylor, Ahmaud Marquez Arbery, David McAtee, Chris Beaty, Italia Kelly, Calvin L. Horton Jr., James Scurlock, and so, so many more of the Black siblings that I will never have the opportunity to get to know here in the earthly realm because they were stolen from us all. (Chughtai 2021)<sup>32</sup>

At least 164 Black Americans were murdered by the police during the first eight months of 2020 alone (Cohen 2020)<sup>33</sup> - many of these murders took place long before the summer months came, and long before the self-proclaimed allies who cried over the murders between the months of May and August woke up or cared. Every Black life that is stolen is equally outrageous, equally gut-wrenching, equally heartbreaking, and equally shocking to us Black folk; the loss of a member of our community is a loss that stings and burns as if it were the loss of our own parent, cousin, best friend, teacher, neighbor, grandmother, auntie, unc, big brother, little sister, godmother, teammate, band member, favorite coworker... or even of ourselves. By the same token, every murder of a Black person is equally damning for the individuals responsible, as well as for white civilization at large. The murders of our kind are nothing new to us Black folk. We grow up in the U.S. being taught by our elders to not stay out past a certain time, to greet white people - particularly white adults - with respect and to maintain strong but respectful eye contact with them, and to, "Yes sir," "No sir," cops. Racism and the fact that I am Black in a country that was built upon the practice of stealing land and lives from Black, Brown and Indigenous people, have been two of the most fundamental facts of my life for as long as I can remember; the same goes for every single brother or sister that I have ever known. Though the

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<sup>32</sup> This interactive list of names of Black people murdered by the police in the U.S. during the infamous 2020, created by Alia Chughtai through Al Jazeera, is not paginated; therefore, I am unable to provide a page number for this citation.

<sup>33</sup> CBS News published an article by Li Cohen in 2020 in which I found this information. The CBS News website is not paginated, so I am unable to provide a page number for this citation.

murder of George Floyd was nauseatingly horrid and caused my eyes to spring tears and my hands to clench into fists, I was, sadly, unsurprised by the fact that yet another Black King had been murdered by the police. They've been killing us for as long as we have been in this country, in any and every brutal way imaginable; that's exactly why I found the sudden pity for Black folk and enthusiasm about activism which came from white people last summer - though these sentiments dissolved quickly - so strange and so uncomfortable: we Black folk have understood our plight all along, so why did it take white people such a long time to wake up? *What did the murder of George Floyd do white people that no other Black murder had done?*

For us Black folk, the temporary social media activism of last summer has already become something of a community joke. It was incredibly bizarre to witness from the outside both the sudden influx of infographic regurgitation on social platforms, and the equally-sudden end to this sort of temporarily-incessant stream of online conversations and information-sharing regarding anti-Black racism. At the end of the summer of 2020, the swift return to racially-unconcerned normalcy among white self-proclaimed allies showed up on social media in forms like bikini pics, uncomfortably-large group photos at the family lakehouse, photos of clouds from the window of an airplane headed to the Islands, and videos of people dancing or playing drinking games at house parties disguised as small indoor gatherings. I remember attending a socially-distant 26th birthday celebration in my hometown for Breonna Taylor, and seeing at least one-hundred white people in attendance who I had never before seen at events honoring Black people. A close friend of mine was there with me, and as we gave each other a look, she said as quietly as she could manage while wearing a KN95 mask and keeping her distance, "How long are they gonna keep this up?" An almost amused, yet jaded, lack of trust in

the sustainability of the racial justice work that our white counterparts were undertaking was a widely-felt sentiment among Black people, all summer long. I had hoped that the momentum<sup>34</sup> as so many optimistic leftists were calling the energy-charged sense of urgency that activists and self-proclaimed allies alike were bringing to their work, would last; though I had a gut feeling that it wouldn't, I was surprised that white burnout happened within the same summer that the reckoning had begun. National news channels stopped covering the protests, or insisted on referring to them as "riots."<sup>35</sup> White book clubs stopped reading books by Black authors, or programming discussions of anti-Black racism altogether.<sup>36</sup> White friends of mine stopped texting to ask how I was doing, a gesture which really touched me and made me feel seen while it lasted. Gofundmes stopped receiving reparation payments. Black businesses lost out to the man once more. The changes we saw in our white friends, neighbors, colleagues, family members, coworkers, bosses, and favorite celebrities gave some Black folk a sense of optimism - albeit hesitant and at times doubtful - that we as a country might actually make some progress. When the changed behaviors and the concerned white attentiveness reverted back to mindless

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<sup>34</sup> An entire blog on Medium.com, entitled "Momentum," has been dedicated to thinking about and reflecting on the momentum that the Black Lives Matter movement gained during the summer of 2020.

<sup>35</sup> Johnny Magdaleno wrote an article in the *Indianapolis Star* in entitled "Report: BLM protests turned to riots after IMPD fired chemical agents on demonstrators" (Magdaleno 2021)

<sup>36</sup> Until mass white burnout happened as the summer of 2020 neared its end, self-proclaimed allies were reading books about race with new fervor. I watched as my Black father, the only Black person on his team, was required to read *Waking Up White, and Finding Myself in the Story of Race* by Debby Irving with a group of white colleagues and to discuss the book with them, which in practice translated to an exhausting obligation to become the teacher of blackness and all things Black for this group of supposedly well-meaning white people. *Waking Up White, and Finding Myself in the Story of Race* is a book written by a white woman, for white people, and it's something of a racial coming of age story in which Irving narrativizes her journey of discovering and coming to terms with her own white privilege as a grown woman - this fact alone speaks to the privilege that Irving possesses, as someone who can take something of a personal growth journey in order to conceive of her own racial identity, as opposed to living in a white supremacist society as a Black person and having to learn the implications of being Black for how you are treated by non-Black people very early on in childhood. Listening as my father's colleagues put words together to form sentences like, "Gosh, I always thought that the police were the good guys," and, "But how could anyone do something like that to somebody, just 'cuz of how they look?" was eye-opening for me. It made me realize that some white people, in spite of having lived in this country for their entire lives, really do not have the slightest clue about what being Black in America entails.

movement through the world and a lack of consideration for Black Life, a profound sense of disappointment rippled through the Black community. The fact that white folk could not make it through more than three consecutive months of merely talking about how it feels to live the lives that we've lived every day since we were born reminded us yet again that we are other in this country; this realization was painful, as well as irritating.

In thinking retrospectively about the ways in which my interlocutors might have perceived me during our respective ethnographic interviews last summer, I am reminded of the fact that I as an ethnographer am a position subject. As such, I profoundly shape the impressions of my interlocutors. It's possible that they felt interpolated by me as a Black woman anthropologist; if that is the case, then it stands to reason that they would direct our conversation toward something with which I as a Black person would plausibly have first-hand experience: anti-Black racism. Anyone who has conducted ethnographic fieldwork knows that you as the ethnographer can prepare a list of interview questions ahead of time, and you can draw up rich and complex proposals in which you detail the questions which your project seeks to answer, but you can never be certain that the direction that you've sort of preemptively established for your project is the direction in which your interlocutors will end up taking you during your ethnographic fieldwork. As the subjects of our ethnographic fieldwork, our interlocutors ultimately have control over the ways in which our ethnographic research develops.

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### **Privilege**

All of my interlocutors and I fall under the same category: involuntary restrictive dieters. We are all people for whom food-related medical conditions have made it necessary to eliminate

certain foods - our respective danger foods - from our diets. My interlocutors all share the fact that they did not get a say in whether or not to restrict their diets in common. Now, there are plenty of people who choose, for various reasons, to eliminate certain foods from their diets without medically needing to do so; these people fall under the category of voluntary restrictive dieters. Voluntary restrictive dieters possess the privilege of being physically able to eat the foods that they've given up, a privilege which none of my interlocutors possess. In this section, I will think through privilege as it pertains to restrictive dieters, voluntarily restrictive and involuntarily restrictive dieters alike. This section will explore three different forms in which privilege shows up around restrictive dieting: the privilege of electing to stop eating foods which are medically accessible to you, foods which your body is physically able to tolerate; the socioeconomic privilege of having the funds with which to sustain a costly diet made up of low-ingredient specialty foods; and the privileges which one is afforded on account of the color of one's skin as a white restrictive dieter, voluntary or involuntary. I will use gluten-free eating as a lens through which to highlight and to examine the great disparities which exist among restrictive dieters of various categories and demographics.

The system in this country is set up to benefit and uplift white people, and to oppress and limit non-white people. By virtue of being white in the U.S., you enjoy innumerable privileges which are off-limits to people of all other races and ethnicities. Systemic racism and socioeconomic oppression are interconnected;<sup>37</sup> under capitalism, money is equated with power. Our system in the United States, a capitalist system built on white supremacy and the violent pillage of Indigenous lands, advantages white people with food-related medical conditions, while

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<sup>37</sup> Thomas Kleven writes, "The United States is systemically a highly classist and racist society, that classism and racism are interrelated and overlapping phenomena" (Kleven 37: 2009)

it puts sufferers of color at a great disadvantage; our system also values and rewards those who have the most money. As Brodtkin writes, “capitalism as an economic organization in the United States is racially structured.” (Brodtkin 2004: 76) Race and money matter greatly in our society here in the U.S. Race has an impact on what it means to live with and to interact with others around a food-related medical condition, just as it has an impact on just about every aspect of life in this country. “Race affects everything we do,” (Center for American Progress 2021)<sup>38</sup> and it determines which sufferers of food-related medical conditions are systemically privileged over others.

#### I. The Privilege of Being Physically Able to Unchoose Foods

In 2016, Hyun-seok Kim, MD, MPH conducted a study exploring the rise in the popularity of gluten-free living in the U.S. from 2009 through 2014 (Kim et al. 2016: 1715). In this study, Kim found the following: “From 2009 through 2014, the prevalence of celiac disease remained stable over time (0.70% in 2009-2010, 0.77% in 2011-2012, and 0.58% in 2013-2014) and among population subgroups, with the exception of a decrease among men. In contrast, adherence to a gluten-free diet without having celiac disease has increased significantly overall (0.52% in 2009-2010, 0.99% in 2011-2012, and 1.69% in 2013-2014) and among population subgroups, with the exception of stable trends among nonwhite participants.” (Kim et al. 2016: 1715) The fact that trends of adhering to a gluten-free diet by choice - without celiac disease - remained “stable... among nonwhite participants” (Kim et al. 2016: 1715) means that the rise of voluntary gluten-free eating occurred among white participants - voluntary gluten-free eating among “nonwhite participants” (Kim et al. 2016: 1715) did not see a rise. White voluntary

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<sup>38</sup> The Center for American Progress webpage is not paginated, so I am unable to provide a page number for this citation.

gluten-free dieters are privileged above involuntary gluten-free dieters in the ways of being physically able to eat gluten, but still giving it up, simply because they can. Even Marcus, a white man, lacks the privilege reflected in the study conducted by Kim, MD, MPH. he has no choice but to live a life free of gluten.

As a person who's had to give up gluten out of medical necessity, I often find myself wondering why anyone would choose to give it up if they didn't *need* to. Having to avoid gluten can be really inconvenient, not to mention upsetting. In thinking through the complexities of voluntary restrictive dieting, I needed to get past my own personal biases in seeking to understand why some people decide to give up gluten without being physically forced to do so. Nutritionist Carrie Forrest gives a list of reasons for which she says that anyone who does not suffer from celiac disease should consider eliminating gluten from their diet. This list includes, "Gluten can be inflammatory... even for people who have non-celiac gluten sensitivities, there may be a connection between eating gluten and swollen joints, and, "Gluten products aren't necessarily nutrient-dense." (Forrest 2020)<sup>39</sup> Forrest is attributing gluten-free living to healthfulness. In postulating that a connection "may" exist between inflammation and gluten eating, even for people who do not suffer from celiac disease,<sup>40</sup> Forrest is implying that giving up gluten might be of direct benefit to one's joints, in that going gluten-free would reduce the inflammation purportedly caused by gluten. However, Forrest reveals that it is not certain that any sort of causal relationship between gluten eating and joint swelling exists through her use of the phrase "may be." "May" speaks to potential, possibility; "may" is not synonymous with "is,"

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<sup>39</sup> The website on which this article is found, [cleaneatingkitchen.com](http://cleaneatingkitchen.com), is not paginated, so I am unable to provide a page number for this citation.

<sup>40</sup> Christopher Pomeroy, MD writes in an article about arthritis health, "When a person with celiac disease or a gluten sensitivity eats gluten (gliadin and glutenin proteins) the immune system jumps into action, causing inflammation... such as joint pain." (Arthritis-health 2016)

which speaks to definitive truth. Moreover, by saying that “gluten products aren’t necessarily nutrient-dense,” (Forrest 2020)<sup>41</sup> isn’t proving that gluten products are definitely lacking in nutrient density. Forrest is also not undertaking any sort of project of proving that gluten-free products are nutrient-dense. She is simply raising the idea that maybe, replacing gluten products with gluten-free products will contribute positively to the density of nutrients that an eater is getting from their food.

My own impression of voluntary gluten-free eating is that it stems from a belief that gluten-free eating is better for a person’s overall health than gluten eating. Erica Lindsay, a blogger on spoonuniversity.com, writes, “The gluten-free diet has become a hot trend, with purported benefits including weight loss, increased energy, and overall improved health.” (Lindsay 2021)<sup>42</sup> We know from reading Forrest’s reasons for voluntarily going gluten-free that there is a narrative of gluten-free eating which holds it to be good for one’s overall health. However, what Lindsay points out in her blog post is that “the science behind these claims” about the supposed health benefits of gluten-free eating “does not hold up.” (Lindsay 2021)<sup>43</sup> Just as there are people who advocate in favor of the possibility that voluntarily following a gluten-free diet is of benefit to a person’s health, there are also people who feel strongly that going gluten-free if you do not medically *need* to do so can negatively impact your health. In an article on gluten-free eating, two physicians - Niland, MD and Cash, MD - cite the fact that “many gluten-free foods are not enriched and may be deficient in several nutrients, including

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<sup>41</sup> The food blog website on which this article is found, cleaneatingkitchen.com, is not paginated, so I am unable to provide a page number for this citation.

<sup>42</sup> The food blog website on which this article is found, spoonuniversity.com, is not paginated, so I am unable to provide a page number for this citation.

<sup>43</sup> The food blog website on which this article is found, spoonuniversity.com, is not paginated, so I am unable to provide a page number for this citation.

dietary fiber, folate, iron, niacin, riboflavin, and thiamine” as a source of potentially-detrimental health effects which can come as a result of eating gluten-free foods in place of gluten foods.

(Niland, MD and Cash, MD 2018: 87) The idea that gluten-free foods can be nutrient deficient

(Niland, MD and Cash, MD 2018: 87) is in direct conflict with the idea to which Forrest was alluding, that eating gluten-free means that you will have a nutrient-rich diet. (Forrest 2020)<sup>44</sup>

The issue of nutrient-rich versus nutrient-deficient diets is but one of many points of disagreement among proponents and opponents of voluntary gluten-free dieting.

During our ethnographic interview, Jane spoke poignantly about the privilege of being able to voluntarily restrict one’s diet when she said, “Whenever I see people who can eat whatever they want and then choose not to, I’m like, ‘What the fuck are you doing?’” I’ve known Jane for over five years, and one thing I’ve noticed about her over the years is that she only swears when she is particularly passionate about something. The fact that she said, “What the fuck are you doing?” instead of, “What are you doing?” shows me how strongly she feels about the fact that some people turn their backs without needing to on the foods which she wants so badly to be able to enjoy. The Cambridge Dictionary defines “privilege” in multiple ways, one of which being, “a special advantage or authority possessed by a particular person or group.” (Cambridge University Press 2021)<sup>45</sup> Any person who has the physical ability to eat anything of their choosing and elects to restrict their diet is privileged according to this definition of “privilege,” in that they possess a special authority over their diets with which to restrict themselves to certain foods simply because they can, and not because they must. Understandably, Jane resents the people “who can eat whatever they want and then choose not to” because they

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<sup>44</sup> The website on which this article is found, [cleaneatingkitchen.com](http://cleaneatingkitchen.com), is not paginated, so I am unable to provide a page number for this citation.

<sup>45</sup> The Cambridge Dictionary webpage is not paginated, so I am unable to provide a page number for this citation.

are sort of waving their privilege in her face. She went on to share, “I would consider myself an adventurous eater, and so the fact that ... there are all these types of foods and cuisines that I can’t have... just makes me fucking annoyed and mad.” Seeing people pass on the adventures through various cuisines and dining experiences which she simply cannot experience is upsetting for Jane - it’s unfair that she wants but cannot have, while they can have but do not want.

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## II. Socioeconomic Privilege

Following a strictly gluten-free diet is expensive; I know this all too well. I always have the highest bill to pay whenever I go out to eat with my friends because I inevitably have to substitute menu items for gluten-free alternatives. “As the naturally GF grains and flours (e.g., quinoa, millet, teff, sorghum, buckwheat) are not mainstream items, the cost of the GF products is often more expensive than their gluten containing counterpart. The economic burden of the GFD has been previously documented in the United States (U.S.) [2], in Europe, Canada, Saudi Arabia, Iran and Chile.” (Lee et al. 2019: 1) Gluten is a staple food in the American diet; it can be found hiding in all sorts of foods, beverages and sauces, from cheesecake fillings,<sup>46</sup> to beers,<sup>47</sup> to soy sauce.<sup>48</sup> Because gluten is such a widely-used, “mainstream” (Lee et al. 2019: 1) food ingredient, it’s cheap and easy to obtain. Gluten-free substitutes are far less commonly used in the food items that are widely consumed in the U.S., and are therefore more difficult to obtain than gluten. The fact that food producers must go to more trouble in order to obtain gluten-free

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<sup>46</sup> “10 Surprising Foods That Contain Gluten” (Blasi 2019)

<sup>47</sup> “8 Gluten-Free Beers That Will Hit the Spot This Summer” (Horton 2019)

<sup>48</sup> “Which Soy Sauce Brands are Gluten-Free?” (Anderson 2020)

food items than they need to in order to obtain gluten is what causes the consumer to incur heavy shopping and dining fees: put bluntly, inconvenience is expensive.

Now, when you are gluten-free out of medical necessity (for instance, you suffer from celiac disease, or you have a food allergy to wheat), you have no choice but to purchase specialty gluten-free foods items, regardless of how expensive they are. We all need safe food with which to sustain ourselves; for people with a medical aversion to gluten, there's an added criterion which makes it so that the food needed for sustenance *must* be gluten-free. It can feel annoying, and even unfair, to have to pay significantly more for safe, gluten-free food with which to feed yourself than the people who are medically able to eat gluten spend. It feels as though you are paying a price, quite literally, for having a food-related medical condition. When you're an involuntary gluten-free eater, there's no choosing to not spring for expensive gluten-free items, simply because you're short on money, or because you would rather use your funds to buy something more exciting or fun than food. You've simply got to spend money on getting safe, gluten-free foods to eat, even though they're incredibly expensive - there's no choice in the matter. This is exactly why choosing to live a gluten-free lifestyle without medically needing to do so evidences socioeconomic privilege. The Cambridge Dictionary gives another definition of "privilege" which I find particularly relevant here: "An advantage that only one person or group of people has, usually because of their position or because they are rich." (Cambridge University Press 2021)<sup>49</sup> People who are in the socioeconomic "position" and who possess the money power needed to reliably sustain a gluten-free lifestyle, while having the "advantage" of not being medically obligated to eliminate gluten from their diet, are privileged over people for whom

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<sup>49</sup> The Cambridge Dictionary webpage is not paginated, so I am unable to provide a page number for this citation.

gluten is a danger food. It is having the money with which to determine for oneself that gluten-free living is attractive enough that it warrants paying significantly more money for food than you would if you were consuming gluten, which speaks to privilege.

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### III. White Privilege

Let us turn our attention back to the fact that the study conducted by Kim, suggests that, “From 2009 through 2014... adherence to a gluten-free diet without celiac disease has increased significantly overall (0.52% in 2009-2010, 0.99% in 2011-2012, and 1.69% in 2013-2014) and among population subgroups, with the exception of stable trends among nonwhite participants.” (Kim et al. 2016: 1715) If “adherence to a gluten-free diet without celiac disease” saw “stable trends among nonwhite participants,” yet saw a significant increase nonetheless, then we can deduce that the significant increase occurred among white participants (Kim et al. 2016: 1715). White people in the U.S. are the ones who have been going gluten-free voluntarily, and who have been quite literally buying into the narrative of “trendy” (Bucklin 2018)<sup>50</sup> gluten-free living as a healthful way of eating. This stands to reason, considering just how expensive it is to eat gluten-free. White people are the population of eaters in the U.S. who are going gluten-free by choice: white people control the wealth in our society, so they are the ones who have the money power with which to sustain a voluntary gluten-free lifestyle. After all, “the typical White family has eight times the wealth of the typical Black family and five times the wealth of the typical Hispanic family.” (Bhutta et al. 2020)<sup>51</sup> Generally speaking, white families in the U.S. are

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<sup>50</sup> This article is found on everydayhealth.com, a website which is not paginated. I am therefore unable to provide a page number for this citation

<sup>51</sup> The webpage for the Federal Reserve System is not paginated, so I am unable to provide a page number for this citation.

better-positioned financially than typical Black or Hispanic families, which means that they are more able to afford and sustain a gluten-free lifestyle than their “nonwhite” counterparts (Kim et al. 2016: 1715). The sheer fact of being born into a white family in the U.S. means that you will, statistically, have more money available to you than you would have if you were born into a nonwhite family (Bhutta et al. 2020).<sup>52</sup> The rise in voluntary gluten-free dieting among white people in the U.S. speaks directly to the economic privileges that come with being white in America.

The white privilege which shows up around voluntary restrictive dieting is in no way limited to the financial ability to afford expensive, restrictive dieting lifestyles. There is also great disparity in which racial groups suffer at the highest rates from food-related medical conditions; the kind and quality of health care that is afforded sufferers of different racial groups; which racial groups are adequately diagnosed with food-related medical conditions versus underdiagnosed, etc. Gwen Smith of Allergic Living writes, “Black Americans, and especially children, are significantly more likely than white Americans to have food allergies or asthma – or both. Food allergies can trigger anaphylaxis, and those with asthma can suffer severe attacks. These are serious diseases that require constant management and healthcare guidance – supports that, research shows, are not equally available to the Black community.” (Gwen Smith 2020)<sup>53</sup> She goes on to say that Black children suffer from food allergies and asthma at disproportionately high rates when compared with white children, and Black children are “six times more likely to die of an asthma attack than white children.” (Gwen Smith 2020)<sup>54</sup> Forming

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<sup>52</sup> The webpage for the Federal Reserve System is not paginated, so I am unable to provide a page number for this citation.

<sup>53</sup> The Allergic Living webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>54</sup> The Allergic Living webpage is not paginated, so I am unable to provide a page number for this citation.

a connection between asthma and food allergies is crucial in that food allergies can cause sufferers to experience anaphylaxis,<sup>55</sup> and people with asthma can “suffer severe attacks” when exposed to their danger foods. (Gwen Smith 2020)<sup>56</sup> In other words, having an allergic reaction upon exposure to an allergen can cause an asthmatic reaction, and this can be a death sentence for Black people.

Food allergy sufferers of low-income status or from low-income households end up spending more than food allergy sufferers of higher economic status on emergency medical services from the hospital, as opposed to spending their money on preventative medications. A study on socioeconomic disparities among children suffering from food allergies found that “children in the lowest income stratum incurred 2.5 times the amount of emergency department and hospitalization costs as a result of their food allergy than higher-income children (\$1021, SE  $\pm$ \$209, vs \$416, SE  $\pm$ \$94;  $P < .05$ ).” (Bilaver LA, et Al. 2016: 5) Low-income families are financially-burdened as is. When a child from a low-income household needs to seek emergency medical help around their food-related medical condition, it then becomes incumbent upon their family to cover the substantial costs of emergency medical services. Ruchi Gupta, MD, MPH, comments on this study by writing, ““Our findings suggest potential under-diagnosis of food allergy among Medicaid-enrolled children. Families in the Medicaid program may be encountering barriers to accessing and affording specialists and potentially life-saving epinephrine prescription.”” (Ann & Robert H. Lurie 2020)<sup>57</sup> Now, one of the groups listed under “Eligibility” on Medicaid.gov is “low-income families.” (Centers for Medicare & Medicaid

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<sup>55</sup> Allergist lists “trouble breathing” and “tightness of the throat” as two symptoms of anaphylaxis. Someone who already has compromised breathing due to asthma is ill-equipped to handle the respiratory symptoms of anaphylaxis. (American College of Allergy, Asthma & Immunology)

<sup>56</sup> The Allergic Living webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>57</sup> The EurekAlert! webpage is not paginated, so I am unable to provide a page number for this citation.

Services 2021)<sup>58</sup> If “families in the Medicaid program” are at risk of being under-diagnosed as food allergy sufferers, (Ann & Robert H. Lurie 2020)<sup>59</sup> and low-income families make up a significant portion of the “72.5 million Americans” who are dependent upon Medicaid for “health coverage,” (Centers for Medicare & Medicaid Services 2021)<sup>60</sup> then low-income families are being faced with the crisis of being denied adequate diagnoses of food allergy suffering. If an individual with food allergies is not properly diagnosed, they cannot receive adequate medical support in the ways of being afforded access to preventative medications, nor can they be referred to specialists who can help them devise a plan for everyday food danger avoidance. Without access to adequate medical support, food allergy sufferers who are under-diagnosed are left with little choice in life-or-death situations of food emergency but to seek emergency medical help at a hospital. This is where the great disparity in having to pay for emergency medical services among low-income versus higher-income food allergy sufferers comes in: low-income food allergy sufferers are the ones who are making the most emergency hospital visits, so they are the ones paying the most money for emergency hospital services.

Dr. Emily McGowan, et al. conducted a study on “an inner-city cohort of 516 children” and found that “of the kids who were at high risk for food allergy, 74% were Black and 18% Hispanic. By the age of 5 years, 9.9% of these children had developed food allergies, which was a considerably higher prevalence than the rate of 6.5% of children having food allergy in a general population survey.” (Gwen Smith 2020)<sup>61</sup> This tells us several things: it tells us that

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<sup>58</sup> The Centers for Medicare & Medicaid Services website is not paginated, so I am unable to provide a page number for this citation.

<sup>59</sup> The EurekAlert! webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>60</sup> The Centers for Medicare & Medicaid Services website is not paginated, so I am unable to provide a page number for this citation.

<sup>61</sup> The Allergic Living webpage is not paginated, so I am unable to provide a page number for this citation.

among children living in what the study refers to as the “inner-city,” Black children suffered from food allergies at dramatically-higher rates than children of all other races and ethnicities, including Hispanic children. It also tells us that children living in the “inner-city” as a whole, irrespective of race or ethnicity, suffer from food allergies at higher rates than children living in more affluent neighborhoods. This study helps make readily apparent that individuals of low-income backgrounds suffer from food allergies at higher rates than people with greater socioeconomic means, and that within populations of low-income food allergy sufferers, Black people suffer at higher rates than people of all other demographics.

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### **“That Person”**

During our respective ethnographic interviews, both Marcus and Jane brought up the idea of not wanting to be perceived by others as “that person” who asks for special accommodations around food. Marcus shared that when he eats outside of home, he tends to avoid asking servers to provide him with his own dedicated frying pan, with which to avoid gluten cross-contamination in the kitchen, for he does not wish to be a burden for his servers. “I don’t wanna look like that person who’s the gluten-free, like, kind of just, like, being really stingy and, like, I think a lot of my... actions about the way I move and speak in those settings where that stuff has to come up, like, ‘Oh, I actually need a dedicated frying pan,’ ... or, ‘Oh, I actually can’t have that because it has this little ingredient on it,’ I almost... I rather not say anything because I don’t wanna look like a certain thing that I know I’m not, but I know other people will look at me as,” he told me. Even though his father and siblings with celiac disease always make a point of asking for a dedicated frying pan when eating outside of home, Marcus doesn’t always

ask for this accommodation for himself. This is not because he needs a dedicated frying pan any less than his family members do, for he too has the gene for celiac disease; it's because it makes him uncomfortable to ask people to go to the trouble of cooking and preparing food with a special pan, just for him. To his thinking, asking for this sort of accommodation opens him up to the possibility of being seen as "stingy" by the people around him. Now, Marcus says that he knows himself to be anything but "stingy," or ungenerous. Yet, he fears being mischaracterized by others as a "stingy" person all the same. Marcus' fear of being associated with the stingy "that person" persona with which he does not personally identify keeps him from engaging in the sort of self-advocacy that would improve his chances of staying safe around gluten in restaurant settings.

During my ethnographic interview with Jane, I asked her if her food allergies impact her ability to travel. To this, she said, "I get a little nervous with airplane food. There have been times when I could've gotten a trail mix, but... also don't wanna say to the flight attendant, 'What are the ingredients in this?'" She went on to explain that having to ask a stewardess aboard a flight for clarification on the ingredients in an airline snack or meal that she's considering ordering brings up the same feeling of not wanting to be, as she put it, "that person" that she experiences when she needs to ask a server in a restaurant to "triple-check" the ingredients contained in a housedish. Asking a server to spend their time and energy on going over ingredient lists with her is what makes Jane fear association with the "that person" persona. Medically, Jane *needs* to know the contents of the food that she's considering putting in her body because of her several severe food allergies. Aboard an airplane of all places, it's of paramount importance that she is certain that none of her danger foods are contained in what she's eating,

for as we know, there is no fully-dependable emergency escape plan aboard an airplane, should one come into contact with a danger food. Nevertheless, the fear of exhibiting the needy, demanding mannerisms of a “that person” keeps Jane from ordering food altogether, simply so that she can avoid having to clarify ingredients with stewardesses. In not eating, Jane doesn’t have to order, in not ordering, she doesn’t have to ask for clarification, and in not asking for clarification, she can steer clear of any possible associations with “that person.”

As a term, “that person” is loosely-defined and somewhat elusive. “That” is a demonstrative pronoun, one of four English demonstrative pronouns, “that,” “this,” “these,” and “those” - the colloquial demonstrative pronoun “yonder” not included. (Bureau de la traduction 2021)<sup>62</sup> “That” points the speaker to the outside, whereas “this” points the speaker to the inside; the fact that Marcus and Jane both chose to use the demonstrative pronoun “that” in order to refer to the type of person with which they wish to avoid being associated shows that they are trying to create distance between the type of person that they know themselves to be, and the “that person” persona with which they do not personally identify. They each see themselves as existing outside of “*that person*,” and want to make sure that no one gets this confused.

During my ethnographic interview with Marcus, I challenged him to define the “that person” term in his own words. He was stumped! He opened his mouth to speak, but only came out with, “I guess ‘that person’ ... ‘that person’... damn. That’s a good question.” I wanted to encourage Marcus to keep trying to put words to what he was feeling, so I asked him if he ever feels embarrassed by his self-advocacy work (E.G: requesting a dedicated frying pan) when he’s around other people, and I learned that he does. “I feel a little embarrassed,” he said. “I think...

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<sup>62</sup> The Bureau de la traduction webpage is not paginated, so I am unable to provide a page number for this citation.

society has a lot to do with my not wanting to be ‘that person,’ and society and personal issues with just, like... I feel like I’m making someone’s life a little harder for having to do these extra certain things.” It feels as though for Marcus, taking on the characteristics of “that person” means being someone who asks for help and support to a point of causing trouble for other people. “That person” is on the extreme end of a spectrum of sorts of people with food-related medical conditions who are vocal about their needs around food and seek accommodations from others. It goes beyond merely asking for what you need, into being burdensome for the people with whom you interact. It’s almost as though there are different gradients of self-advocacy around an individual sufferer’s medical needs around food, wherein asking for help from others feels comfortable up until the point at which a sufferer feels that they risk burdening the people from whom they seek accommodations. Asking to be provided with his own dedicated frying pan in restaurant spaces feels like too onerous an ask for Marcus, which is why the behavior of requesting a dedicated frying pan becomes one which he associates with the troublesome “that guy” persona.

Marcus is keenly aware of - and somewhat irritated by - the fact that voluntary gluten-free dieting has seen such a dramatic rise in popularity during his lifetime. He told me that because “gluten specifically is a thing that popped up in recent years” as a food which many people voluntarily eliminate from their diets, “‘that gluten-free person’ is just a whole other specific image, different from being lactose intolerant.” This links back to what he shared with me about “society” having “a lot to do with” his understanding of what it means to be a “that person,” in that the trend in our society of increased voluntary gluten-free eating has impacted the ways in which he conceives of himself as a gluten-free eater who is involuntary as opposed

to being voluntary. Unlike voluntarily gluten-free eaters, Marcus' safety would be compromised if he were to eat gluten. By virtue of this fact, Marcus is in a different category than the gluten-free eaters who have given up gluten by choice; he understands this perfectly well. It's because he knows himself to be in an inherently different category of gluten-free eaters than voluntary gluten-free eaters that Marcus wishes to disassociate himself from the burdensome behaviors which he has observed from this group. He avoids seeking accommodations which would identify him as a gluten-free eater, like being provided with a dedicated frying pan, so that he can mitigate the risk of being grouped together with voluntary gluten-free eaters by the people around him. Marcus limits the self-advocacy in which he engages around gluten to mute his perceptibility as a gluten-free eater. By muting his ability to be perceived by others as a gluten-free eater, he is working to limit the possibility of being mischaracterized as a voluntary "that gluten-free person."

During our ethnographic interview, Jane told me that she feels as though there is a stigma<sup>63</sup> against all restrictive dieters who actively seek accommodations in restaurant spaces, involuntary and voluntary restrictive dieters alike. Because voluntary restrictive dieters often *want* the same sorts of accommodations as involuntary restrictive dieters *need*, such as a "triple-check" of ingredient lists with a server or having certain food items substituted for others, the line between accommodations that are *wanted* - accommodations requested by voluntary restrictive dieters - and accommodations that are *needed* - accommodations requested by people like my interlocutors and myself, sufferers of food-related medical conditions - becomes blurred. It becomes difficult to differentiate involuntary restrictive dieters from voluntary restrictive

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<sup>63</sup> Recall our discussion of stigma in Chapter II.

dieters without directly asking a restrictive dieter if they chose to give up a certain food or if they have a medical aversion to it. Jane does not want to risk being mistaken for a voluntary restrictive dieter; she wishes to be taken seriously as someone who is medically required to avoid her danger foods. For this reason, Jane has learned to tell servers directly that she is “allergic” to whichever food item it is that she is asking to have substituted, instead of merely asking to have her meal prepared without that food item. She has consistently found that being forthright with servers about the fact that she has an allergy, and therefore *needs* to be accommodated, causes her servers to take her more seriously than when she simply asks for an accommodation without explaining her medical need for it. “Allergic” seems to carry a kind of social currency as a classifier. Jane isn’t dairy-free because she *feels* like being dairy-free - she’s a person who is “allergic” to dairy, a classifier which warrants respect.

Clearly, protecting her own physical safety is priority number one for Jane; if her servers do not take her food allergies seriously and serve her dishes which contain her danger foods, she could be made seriously ill. Still announcing to her servers - and consequently, anyone else in a restaurant space who can hear or see this interaction - that she is “allergic” to the danger foods in question, serves a social purpose for Jane as well. She shared with me that she wants to, at all costs, avoid being seen by others to fit what she calls the “annoying trope” of “annoying white women” who cut foods out of their diets “on their own accord.” Seeing as Jane would very much like to be able to eat her danger foods but medically cannot, she doesn’t fit the description for this particular “annoying trope” of “annoying white women” with voluntarily-restricted diets. However, she is still white, and she identifies as a woman. Therefore, Jane is not entirely in the clear in terms of avoiding association by others with the broad demographic of white women

who have restricted diets, be they voluntary or involuntary. Whiteness - white womanness in particular - is integral to Jane's understanding of what it means to be a "that person." The fact that Jane is a white woman compromises her ability to self-advocate in the ways of requesting accommodations around her food allergies of servers. By making sure to say out loud for the people around her to hear that she is "allergic" to certain foods, Jane is actively working to make herself, a white woman, easily distinguishable from the white women she so strongly resents whose demanding and needy behaviors around food accommodations are at the core of her "that person."

One term that I could not seem to go a day without hearing during the summer of 2020, used to describe white women in the U.S. who knowingly used their white privilege to commit acts of hate against Black people, is "Karen."<sup>64</sup> All sorts of video footage appeared on various social media platforms last summer exposing white women behaving horrifically and being actively racist against Black people. White women of this kind earned the label "Karen," a socially-damning classifier reserved for the most bigoted white women in our society. One video which I think captures the sheer gall of "Karen" as a type of person, entitled "The Most Entitled KARENS Ever," is listed on YouTube with the following description: "The Most Entitled KARENS Ever! Which Karen do you think was the worst and went too far? Leave a Like if you enjoyed!"<sup>65</sup> The "Karens" who are featured in this despicable highlight reel of racist white

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<sup>64</sup> Dictionary.com writes, "*Karen* is a pejorative slang term for an obnoxious, angry, entitled, and often racist middle-aged white woman who uses her privilege to get her way or police other people's behaviors. As featured in memes, *Karen* is generally stereotyped as having a blonde bob haircut, asking to speak to retail and restaurant managers to voice complaints or make demands, and being an anti-vaxx, Generation X soccer mom. In 2020, *Karen* spread as a label used to call out white women who were captured in viral videos engaging in what are widely seen as racist acts." (Dictionary.com 2021)

<sup>65</sup> A YouTube video entitled "The Most Entitled KARENS Ever," uploaded on July 1, 2020.

women are all so appalling in their racist acts of entitlement that the YouTube user who put this compilation together is making entertainment for viewers out of choosing which of these racists is behaving more egregiously than the others - it's a competition of who is the worst of the absolute worst. To say that a "Karen" is a "trope"<sup>66</sup> (to use Jane's language) of white women dipping into their privileges to commit wrongdoings would be an understatement, considering that the term "Karen" has been used with such frequency over the last year - in early April 2021, I found over one million search results on Instagram alone under the hashtag "Karen." To say that a "Karen" is an "annoying white [woman]" would also be quite an understatement, considering that a "Karen" is a white woman who is so hateful in her racist, anti-Black ways that she sets out to have Black people with whom she comes into contact harmed, physically, emotionally, and/or legally.<sup>67</sup> It's safe to say that such a white woman is the epitome of the sort of "annoying," "trope" of a "white [woman]" with which Jane is so vehemently opposed to being associated by others.

A notorious epitome of a white woman acting as a "Karen" from the summer of 2020 is Amy Cooper, a white woman in New York City who unflinchingly called the police on a Black man for asking her to keep her dog on a leash.<sup>68</sup> Though this sort of egregious behavior might appear to exist on a far different plane than a white woman who is shamelessly asking a server at a restaurant to painstakingly go over ingredients - or substitute several menu items for others - without medically needing this level of accommodation, both of these scenarios exist on one

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<sup>66</sup> The Merriam-Webster Dictionary defines "trope" as "a common or overused theme or device." (Merriam-Webster Dictionary 2021) The Merriam-Webster webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>67</sup> Ashitha Nagesh writes in an article for BBC News, "A predominant feature of the 'Karen' stereotype is that they weaponise their relative privilege against people of colour - for example, when making police complaints against black people for minor or even - in numerous cases - fictitious infringements." (BBC News 2020)

<sup>68</sup> The "Central Park Karen" to whom I am referring here is the infamous Amy Cooper. (New York Post 2021)

same spectrum of white women using their white privilege to get what they want. By announcing to servers that she is “allergic” to the foods which are off-limits in her diet, a classifier which separates her from the un-allergic, voluntary restrictive dieter white women that she sees in the eateries where she dines, it feels as though Jane is working to disassociate herself from a very specific kind of “that person.” Jane’s “that person” seems to be a restrictive dieter white woman who knowingly dips into her privileges in order to serve her own best interests - Jane’s “that person” is a sort of “Karen” of restrictive dieting. “Karen” was such a culturally specific term at the time of my ethnographic interview, and a term which continues to hold significant social currency as a sort of ugly vestige of the summer of 2020, that it feels appropriate to put Karenism in conversation with Jane’s fear of being misconstrued by others as a privileged, restrictive dieter white woman who eliminates certain foods from her diet by choice. The privilege with which Jane takes issue in the ways of voluntarily restricting one’s diet as a white person in the U.S. exists on the same spectrum of white privilege as Karenism, a sort of hyperbolic manifestation of using one’s white privilege to assert power in our society.

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## **Conclusion**

This chapter has been something of a survey of the points of intersection between medically-imposed dietary restrictions and race. By centering race in this chapter, I have been afforded the flexibility with which to cover a wider breadth of material than I would be able to cover in a chapter which specifically centers, say, whiteness. Race is complex, it’s multi-faceted, and it’s messy: I am grateful to my white interlocutors for making me understand through our respective ethnographic interviews that their own whiteness plays an important role in shaping

their internal experiences around their respective food-related medical conditions. In working to most comprehensively narrativize and unpack these internal experiences, I began to think intentionally about the ways in which race - which impacts and shapes so many of our social interactions and interpersonal relationships as members of a historically-racist, white supremacist society - makes its influence felt within my community of people with medically-imposed dietary restrictions. It has become readily apparent to me that Black food allergy sufferers are given poor medical care and little to no support from physicians in terms of learning to live safely day-to-day with food-related medical conditions. This chapter has but scratched the surface on the vast disparities in the quality of medical care afforded to sufferers of different races. I plan to use my future ethnographic research projects to expand upon the research that I've conducted in writing this last body chapter on the ways in which being Black in the African diaspora directly affects sufferers' respective lived experiences around their food-related medical conditions. In conducting fieldwork for these future ethnographic research projects, I will be sure to include Black interlocutors. I'm committed to taking an intersectional approach in honoring the social - and the fact that we are always influenced by our social surroundings - in my future ethnographic work.

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Christina Sinclair Jones

## Chapter V: Looking Ahead

This senior project is only the beginning of the wealth of ethnographic material which I intend to contribute to the discipline throughout my life. Upon graduating from Bard College in May 2021, I will be moving to the United Kingdom to earn a Master of Philosophy in Social Anthropology from the University of Cambridge. At the University of Cambridge, I intend to focus research on how food allergies in particular - the focus will be narrower than simply centering food-related medical conditions at large - impact and determine the social behaviors of Black people in two diasporic cities: New York City and Johannesburg. In framing my research in relation to these distinctive but resonant cities of the African diaspora, I hope to show how the study of food allergies as a social actor can help us understand how Blackness is lived in multiple ways and places, with a focus on Black Life and Black eating in urban spaces. My intended ethnographic research at the University of Cambridge will take as its point of entry the everyday practice of eating food with others as a method of study. Ethnographic interviews will allow me to amplify Black voices in my work and to use my work as a medium through which to tell the rich, colorful, and multi-faceted stories of Black life.

“Food deserts” are geographic areas where access to affordable, healthy food options (aka fresh fruits and veggies) is limited or nonexistent because grocery stores are too far away... Approximately 2.3 million people (2.2% of all US households) live in low-income, rural areas that are more than 10 miles from a supermarket... Residents living in food deserts also have a hard time finding foods that are culturally relevant and that meet their dietary restrictions.” (Dosomething.org 2021)<sup>69</sup> The food that is made available to members of communities plagued

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<sup>69</sup> The Dosomething.org webpage is not paginated, so I am unable to provide a page number for this citation.

by food deserts comes from all over the world; food deserts aren't stocked with fresh, locally-sourced perishable produce, but preservative-filled foods which have traveled long distances and are produced to last.<sup>70</sup> There's a very strange and sinister dichotomy between the local and the faraway with respect to food deserts. People living in food deserts in the U.S. - people living in food poverty<sup>71</sup> - are forced by virtue of living in a fresh food deadzone to limit their food consumption to the foods made available to them locally in their communities, foods which come from all over the world and which are filled with all sorts of toxins<sup>72</sup> unsuitable for the human body. (Food Revolution Network 2021)<sup>73</sup> These foods are packed full of "refined grains, added sugars, and fats are generally inexpensive, palatable, and readily available in low-income communities." (U.S. Department of Housing and Urban Development 2021)<sup>74</sup> Over time, eating foods which are "high in calories and low in nutrients... may lead to weight gain and diabetes" (U.S. Department of Housing and Urban Development 2021)<sup>75</sup> - the foods from far away which are available for consumption locally act violently upon the bodies of the people consuming them, and cause harm. Moreover, having little to no access to supermarkets with a wide selection of food items makes it very difficult for community members with dietary restrictions, be they medically-imposed, religiously-imposed, ethically-imposed, etc., to find

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<sup>70</sup> "Food products purchased from [eateries and food stores in food deserts] are often processed, pre-packaged, and high in calories, fat, sugar, sodium, and preservatives. Within food deserts, availability of healthy food items, including fresh produce, meats, and dairy products is limited." (Brace Et. al 2016: 250)

<sup>71</sup> "Food poverty is worse diet, worse access, worse health, higher percentage of income on food and less choice from a restricted range of foods. Above all food poverty is about less or almost no consumption of fruit & vegetables" (Sustain 2021)

<sup>72</sup> "The food that is distributed in these communities is sub-par, and it is coming from different parts of the world. It is sprayed with toxins and poisons and picked before its time," (Food Revolution Network 2021)

<sup>73</sup> The Food Revolution Network webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>74</sup> The U.S. Department of Housing and Urban Development webpage is not paginated, so I am unable to provide a page number for this citation.

<sup>75</sup> The U.S. Department of Housing and Urban Development webpage is not paginated, so I am unable to provide a page number for this citation.

foods to eat which are in keeping with their restricted diets. “Residents living in food deserts... have a hard time finding foods that are culturally relevant and that meet their dietary restrictions.” (Dosomething.org 2021)<sup>76</sup> It’s as though the faraway - the unnatural, the preservative-ridden, and the industrial - is forced upon local people and wreaks havoc in the way of food. Foods from far away make local consumers sick; they also disenfranchise local eaters by limiting their flexibility as eaters.

I fully intend to dedicate future ethnographic research projects to underscoring and unpacking the harmful opposition between the local and the faraway in food production, and the ways in which faraway foods make it all but impossible to eat safely and reliably as a person with medically-imposed dietary restrictions. In dedicating myself to honoring Black voices, Black bodies, Black lived experiences around food eating, and Black Life, I feel that I urgently need to engage in ethnographic research which centers food deserts and the ways in which they inhibit many Black sufferers of food-related medical conditions living in urban areas.

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One of my favorite things about Anthropology as a discipline is its emphasis on the importance of precision of language in academic writing. When writing about other people and seeking to adequately put words to their experiences and stories, every term and phrase that you use as an ethnographer holds power and significance. For instance, in coming up with a phrase which I’ve implemented throughout this senior project, “medically-imposed dietary restrictions,” I sought to find words with which to describe dietary restrictions which are caused by food-related medical conditions including and/or other than food allergies. All eight of my

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<sup>76</sup> The Dosomething.org webpage is not paginated, so I am unable to provide a page number for this citation.

interlocutors suffer from some sort of food-related medical condition, and all eight of my interlocutors follow restricted diets because of their respective food-related medical conditions. However, as has been made obvious in this project, my interlocutors do not all suffer from food allergies - some have autoimmune diseases including celiac disease which cause them to have to place restraints on what they do and do not eat. I needed a term which would be all-encompassing enough to include both interlocutors who have food allergies and interlocutors who do not have food allergies, yet narrow enough to specifically focus on people with involuntary dietary restrictions brought about by a food-related medical condition. This sort of thinking led me to “medically-imposed dietary restrictions.”

Another term which I’ve used throughout this project is “sufferer,” as in a sufferer of a food-related medical condition. I came to use “sufferer” as a term to use in place of, say, “a person with a food-related medical condition,” because “sufferer” is a more succinct way of saying “person with [a certain food-related medical condition].” I’ve found in my own food allergy journey that physicians either refer to me as a “sufferer” or as a “patient.” Personally, I do not care for the classifier “patient,” as I associate it with illness and being ill. The very first example which Merriam-Webster gives when defining “patient” in a “medical” context is “cancer *patients*.” (Merriam-Webster 2021)<sup>77</sup> It goes without saying that cancer is an absolutely horrific medical condition. I in no way wish to equate cancer and, say, food allergies in any of my work, for to do so would in my opinion be both ugly and inappropriate. Therefore, I have shied away from using “patient” as a classifier with which to describe people with food-related medical conditions: I do not want to disrespect the term “patient” in all of its medical loadedness

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<sup>77</sup> The Merriam-Webster webpage is not paginated, so I am unable to provide a page number for this citation.

and with its extreme associations (E.G: cancer). Instead, I've gravitated towards the other classifier which has been ascribed to me by the physicians who have treated me over the years for my food allergies, "sufferer."

In writing this senior project, I've found myself fretting over my usage of the term "sufferer" and its hyper-negative connotations. What I am fearful of is that readers of this project will think in associating the term "sufferers" with food-related medical conditions that life as a person with a food-related medical condition is purely negative, a life characterized by suffering. As we saw with Marcus' mindful eating in Chapter III, for instance, there are plenty of positives which come with learning to be aware and in touch with one's body as an eater - having a food-related medical condition isn't all bad; my interlocutors and I are not *suffering* all of the time. In future ethnographic research projects, I will give thought to the dilemma in which I currently find myself of whether or not to use the term "sufferer" when describing individuals who have food-related medical conditions. I will also dedicate space in future ethnographic work to thinking about other terms that might work alongside, or even in place of, "sufferer." I intend to think analytically in future work about the value of having people with food-related medical conditions define for themselves their own positionalities, ascribing their own self-selected classifiers to themselves. One framework which might feel generative as a potential lens through which people with food-related medical conditions can think about and talk about our respective food-related medical conditions is the framework of disability. In my next ethnographic research project, I'd like to engage analytically with the question of whether or not it is more empowering or disempowering for people like my interlocutors and myself to think of ourselves as "disabled" for having food-related medical conditions.

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One of my interlocutors, Tai, spoke repeatedly about body image and disordered eating during my ethnographic interview with them. They spoke at length about “diet culture” and the ways in which the people in their life considered Tai’s “gluten-free,” “dairy-free” diet to be “healthier” than a diet which includes these staple foods. “I get really frustrated at how diet culture and food culture is making people think that going gluten-free will make them healthier, or that, like, going dairy-free is a good thing to do... The ways that diet culture and the ways that people are thinking about food is just really messed up,” they shared. The fact that Tai’s medically-restricted diet was so frequently linked to healthfulness by the people with whom they interact - such as by family members commenting on their medically-imposed dietary restrictions “at Thanksgiving,” a holiday which so many families in the U.S. celebrate by eating generous helpings of heavy, autumnal foods - causes me to think about orthorexia, “an obsession with proper or ‘healthful’ eating.” (National Eating Disorders Association 2021)<sup>78</sup>

While they were on the FODMAP diet, Tai’s avoidance of gluten and dairy was taken to be a sign by the people in their life that they were an eater who warranted praise for the sort of immaculate healthfulness of their diet. Tai says that other people “glamorized” their medically-imposed dietary restrictions, and held it up on something of a pedestal of disciplined, regimented healthy eating. “They wanna envy you because they don’t know how to find moderation in their life, or be happy with their bodies,” Tai shared, “They’re essentially jealous that you’re essentially being forced to have that control in your life, and there’s nothing you can do about it.” It’s almost as though the people in Tai’s life were jealous of the *medically-imposed*

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<sup>78</sup> The National Eating Disorders Webpage is not paginated, so I am unable to provide a page number for this citation.

aspect of Tai's restricted diet: because Tai medically had no choice but to restrict their diet in the ways necessitated by their IBS, there was no room for them to slip up and cheat on their diet by eating an off-limits food, unless they wanted to suffer the immediate physical consequences of being made severely ill by these danger foods. Accountability seems to come up as a key part of the relationship between how the people in Tai's life perceived their restricted dieting: these people viewed Tai's food-related medical condition as a kind of buffer which forcibly held Tai accountable at all times and kept them from eating their supposedly-unhealthy danger foods. The dysmorphia that showed up for Tai around the praise that they received from other people because of the changes in their body shape and their fluctuating weight throughout the FODMAP diet process have been damaging for them long-term. "The way that I had to think of everything as good or bad, or just be really afraid of what I was eating and what it might do to my stomach and how it might make me feel, was a pretty horrible cycle to be in... I was gratified because I was losing weight, and that's seen as a good thing." Avoiding danger foods gained significance for Tai outside of simply being a means by which to keep themselves safe: it became a means by which to maintain a certain kind of slender figure.

Hearing this makes me sad. Food avoidance for us people with medically-imposed dietary restrictions is painful enough as is, without the added pain of associating certain foods with punishment or some sort of "bad" quality. To Tai, and to any and all other interlocutors of mine who have struggled with body image along their journeys of learning to live with and operate around medically-imposed dietary restrictions, I'd like to say the following: I see you, I hear you, and everything that you've ever felt in relation to your body and its unique needs is valid; all the same, I'm so sorry that our image-obsessed "serial skinny culture" (Table Agent

2021)<sup>79</sup> has caused you to think about your food-related medical condition through a lens of beauty and aesthetic value. This particular ethnographic research project does not do the work of analyzing the relationship between food-related medical conditions; body image; disordered eating; or the ways in which sufferers are perceived or received by the people in our lives around our respective medically-imposed dietary restrictions and eating habits. However, I wish to make clear that I have really taken to heart and sat with all that Tai shared with me, and I fully recognize the importance of giving thought to body image and disordered eating within a conversation of food-related medical conditions. I intend to use future ethnographic research projects to understand the ways in which being medically unable to eat certain foods affects body image, as well as the ways in which an individual sufferer approaches eating as a practice of nourishment and care for the self.

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As a final note, I would like to thank every single one of my interlocutors for taking the leap of vulnerability over a computer screen, a medium which can feel incredibly impersonal. Even over Facetime and Zoom, my interlocutors and I connected on deeply personal levels. They gave me *the real* on their lives, and that is a gift for which I will be forever grateful.

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<sup>79</sup> The Table Agent webpage is not paginated, so I am unable to provide a page number for this citation.

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