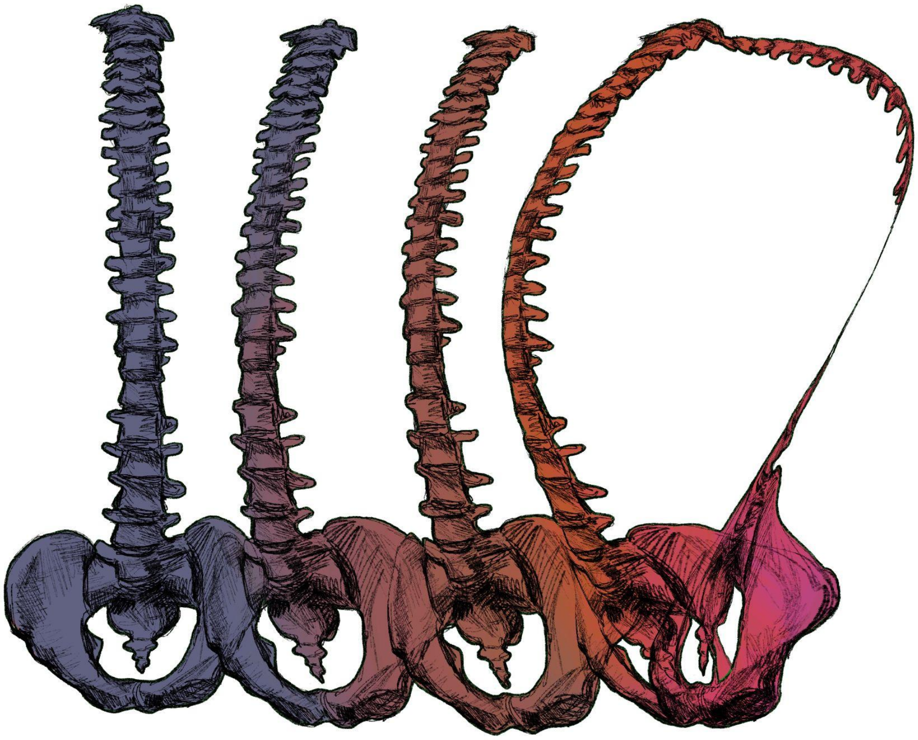
ABSTRACT

Through graphic ethnography, I analyze and represent the way individuals experience, feel, and embody the unique temporality and liminality of Ankylosing Spondylitis (AS) as a chronic, degenerative condition. To do so, I draw on my research of individuals with AS in online public spaces and nine long-form, semi-structured interviews. This work, in all its components, addresses overarching conversations about chronic illness and people's use of holistic treatments in the face of the biomedical push for pharmaceuticals. AS is a chronic inflammatory autoimmune disease marked by inflammation of the sacroiliac joints, spine, ribs, and eyes, and vertebrae fusion. It often presents in adolescence and throughout early adulthood and manifests in periods of pain and periods of remission. I use digitally-produced graphics to de-center and complicate the overwhelming hold of biomedicine's normative narratives of the "best" and "correct" modes of treatment and care, evoking an affective response to narratives of AS and experiences of chronic illness embodiment. As a generative form of analysis and representation, graphic ethnography allows me to unearth the way people's engagements and investments in holistic healing generate newfound control, agency, and power that biomedicine otherwise strips from them in light of an AS diagnosis.

Contested Healing:

Experiments in Graphic Ethnography of Ankylosing Spondylitis



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Thesis in Gender Studies

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Mama, thank you for tirelessly lending your artistic eye to the iterative, *almost* never-ending cycle of graphic revisions. And to my dad, Jaya, and Anusha, thank you for your unwavering support and excitement for my research and art.

INTRODUCTION: TAKING UP GRAPHIC ETHNOGRAPHY

Graphic ethnography is an emerging form of methodology and representation that features drawings alongside text in various formats. Medical anthropology and health humanities have picked up the medium as a fruitful and innovative site of intellectual engagement to showcase ethnographic fieldwork. The University of Toronto started a book series in 2015 entitled *EthnoGRAPHIC: Ethnography in Graphic Form*, which aims to embrace unique and creative representations of academic research. In 2007, Penn State University Press pioneered a dynamic series entitled *Graphic Medicine,* which is described as "a site that explores the interaction between the medium of comics and the discourse of healthcare."[1] Contributors include artists, healthcare professionals, academics, and comic book fans. Graphic ethnography may take on a host of forms, from illustrations interspersed with written-text, to full-fledged graphic novels depicting ethnographic narratives. In a 2015 blog post announcing the *EthnoGRAPHIC* series, Anne Brackenbury states: "there are likely as many different ways of constructing an ethnoGRAPHIC narrative as there are people creating them."[2]

Starting in Spring 2021, I undertook research with individuals with Ankylosing Spondylitis (AS), a chronic inflammatory autoimmune disease marked by inflammation of the sacroiliac joints, spine, ribs, and eyes, and the *ankylosing* — or fusion — of

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[1] "About Graphic Medicine." n.d. *Graphic Medicine* (blog). Accessed April 19, 2022. https://www.graphicmedicine.org/about/.

[2] Anne Brackenbury, 2015. "Announcing EthnoGRAPHIC: A New Series | Teaching Culture." April 20, 2015. http://www.utpteachingculture.com/announcing-ethnographic-a-new-series/.

vertebrae. I engaged with academic literature, conducted nine long-form interviews with individuals with AS who use holistic healing modalities, and undertook participant observation on online forums. My understanding of holistic healing evolved to encompass an eclectic range of healing modalities, from using medical cannabis to brewing and drinking kombucha for gut health. My engagement with many forms of graphic ethnography paired with my life-long love of illustration and experience using creative methodologies for course work helped me recognize art as the most effective and productive medium to showcase, highlight, and parse the interviews and forum posts while synthesizing palpable themes with academic literature. In this way, my work is grounded in theory, method, and practice. Through graphic ethnography, I analyze and represent how individuals experience, feel, and embody the unique temporality and liminality of AS as a chronic, degenerative condition and address overarching conversations about chronic illness and people's use of holistic treatments in the face of the biomedical push for pharmaceuticals.

The lines between research, analysis, and representation are inherently blurred in my project. The process of illustrating the graphics and combining the written text (which includes an assemblage of interview and forum quotes, along with my own analysis) was often generative, spontaneous, and iterative. I dedicated significant thought to the visual quality of the art, including the color palette, the text placement, and the size and the illustrative representation of the featured women. I used my iPad and the program Procreate to make each graphic, which allowed me to fine-tune all of the elements.

The illustrative, black-and-white quality of the person in each piece denotes the constant unfolding of illness, selfhood, and healing methods found in interviewee and forum post narratives. Contrastingly, all of the backgrounds include color, indicative of the dynamic and active relationship between one's body and the environment. As a relatively newly diagnosed person with AS, I constantly filtered the interview narratives, forum posts, and theory through my own experience. This filtering was expressed through my use of women in each graphic — similar female figures have been an intrinsic mode of personal expression vital to the art I have made throughout my life. Engaging with this reappearing figure in the graphics aided in my processes of internalizing, synthesizing, and representing my ethnographic research.

The graphics in this project act as part of the multimodal, layered process of analysis and final representation of the ethnography itself. While transcribing and reading (and re-reading) the interview transcripts, a multitude of themes emerged. The following are some of the most pertinent ones, listed in no particular order: (1) the importance of family context and influence that led individuals to use holistic healing; (2) attitudes towards traditional pharmaceuticals; (3) fears about drug side effects and doctors' framing of biologics; (4) gender and race as they relate to AS diagnosis and embodied experience of illness; (5) the importance of community support; (6) the relationship between mental health and physical pain; (7) understandings of the root cause of AS and the original onset of pain; (8) the self-directed, iterative feedback cycle of treatment; (9) notions of reflexive care; and (10) the gut as a primary site for healing.

While I coded for these themes in a traditional manner, meticulously and methodically combing through the interview transcripts, the artistic representation of the research in graphic form (as detailed in the section "Research Trajectory: Situating Reflexive Graphic Ethnography") helped elicit a nuanced, deeper understanding of the interview narratives. The process of pulling out different sections of interview quotes and synthesizing them with literature I engaged with during the illustration process helped me to think through my own embodiment and engagement with the narratives in new ways.

By focusing on the entanglements of treatment expectations, people's risk assessments, and the medical and pharmaceutical industries, I examine conceptual ideas around temporality and liminality inherent to chronic illnesses like AS, which tend to manifest in early to late adolescence, met by periods of pain and periods of remission. Interviewees' positionalities (along racial and gendered lines) came to the fore in discussing diagnosis processes and illness experiences. Notions of personal agency and control over one's body when engaging with modes of holistic healing are palpable within all the interviews, and I aimed to artistically represent these themes in various capacities.

Following this section, I invite you to engage with the graphics, which draw on and synthesize my analyses of the interviews, forum posts, and literature in order to explore narratives of chronic illness and holistic healing. A brief written description accompanies each graphic to provide analytical insight.[3] As a series, the graphics depict people's experiences using holistic healing modalities to regain agency of their health and bodies within the context of the overwhelming, global hold of the pharmaceutical

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[3] To readers who are encountering this work for the first time in digital format: You may wish to view the document in "Two Page View" for the best experience. This will allow you to see each graphic on the left, alongside its analytical description on the right.

industrial complex that often strips control from those with chronic illness. Under, "Interviewee Portraits,"[4] I detail pertinent background information on the interviewees whose stories and narratives greatly shaped and informed this project. I then offer a section, "Research Trajectory: Situating Reflexive Graphic Ethnography," to explicitly locate my research in academic literature, ethnographic research, and my positionality, providing critical background for the six graphics I created. Finally, in an Appendix, I include the paper, "Painful Objects and Fragmented Bodies," in which I phenomenologically and affectively think through pain and the embodied self. The process of analysis, deriving interview themes, and writing the paper helped me turn to the graphic form. This writing is located in the Appendix so as to not overshadow the primacy of the graphics, though it greatly informed the graphic ethnography.

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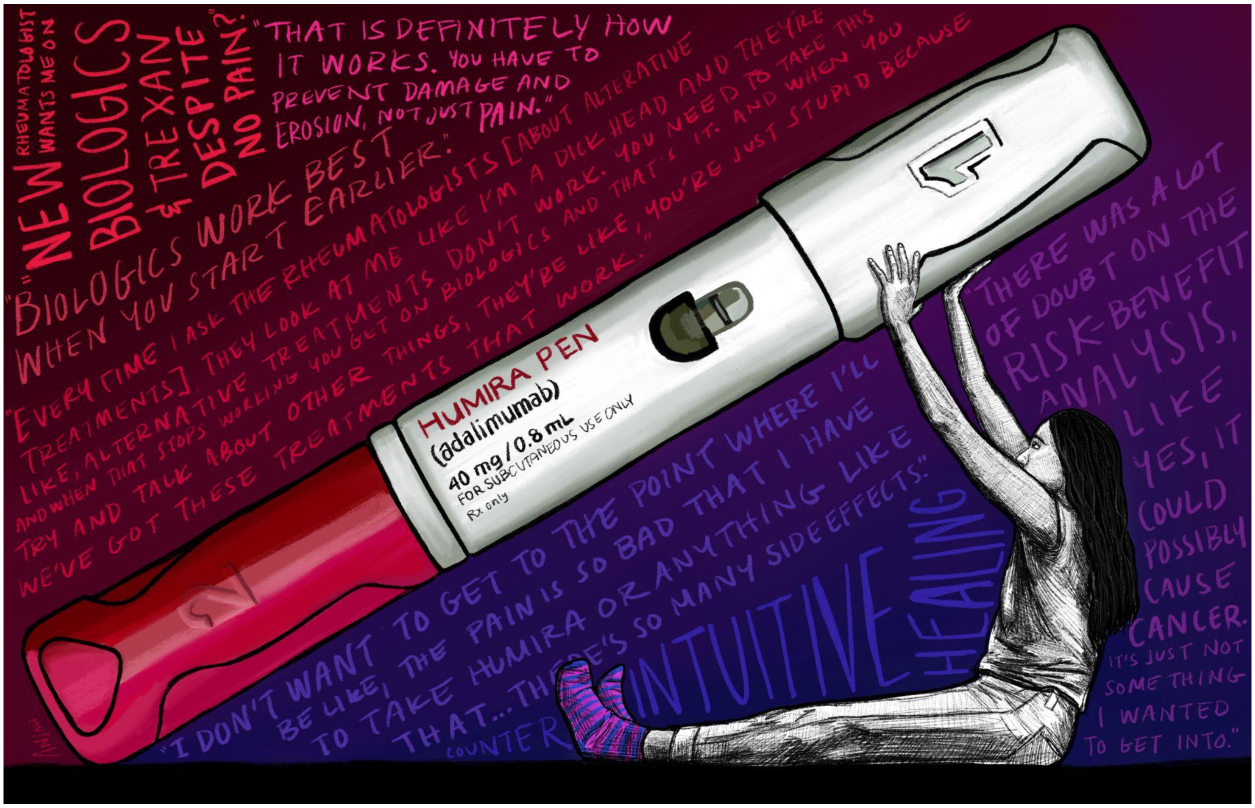
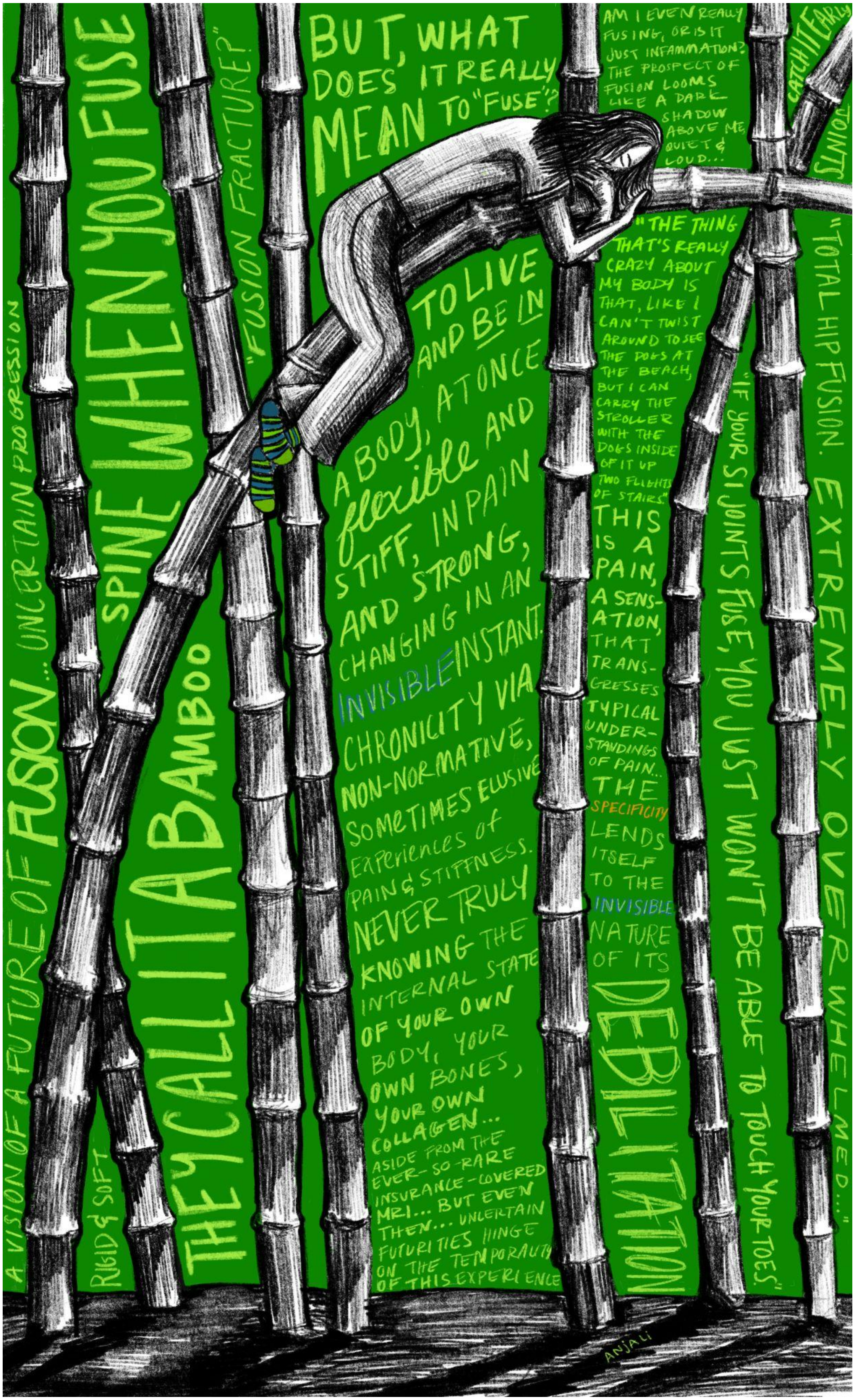
[4] I have used pseudonyms in order to protect interviewees' privacy.


CONTESTED
HEALING:
A GRAPHIC
ETHNOGRAPHY


"NEW RHEUMATOLOGIST WANTS ME ON BIOLOGICS & TREXAN DESPITE NO PAIN?"
"THAT IS DEFINITELY HOW IT WORKS. YOU HAVE TO PREVENT DAMAGE AND EROSION, NOT JUST PAIN."
"BIOLOGICS WORK BEST WHEN YOU START EARLIER."
"EVERY TIME I ASK THE RHEUMATOLOGISTS [ABOUT ALTERATIVE TREATMENTS] THEY LOOK AT ME LIKE I'M A DICK HEAD AND THEY'RE LIKE, ALTERNATIVE TREATMENTS DON'T WORK. YOU NEED TO TAKE THIS AND WHEN THAT STOPS WORKING YOU GET ON BIOLOGICS AND THAT'S IT. AND WHEN YOU TRY AND TALK ABOUT OTHER THINGS, THEY'RE LIKE, YOU'RE JUST STUPID BECAUSE WE'VE GOT THESE TREATMENTS THAT WORK."
HUMIRA PEN
(adalimumab)
40 mg / 0.8 mL
FOR SUBCUTANEOUS USE ONLY
Rx only
"I DON'T WANT TO GET TO THE POINT WHERE I'LL BE LIKE, THE PAIN IS SO BAD THAT I HAVE TO TAKE HUMIRA OR ANYTHING LIKE THAT... THERE'S SO MANY SIDE EFFECTS."
COUNTER INTUITIVE HEALING
"THERE WAS A LOT OF DOUBT ON THE RISK-BENEFIT ANALYSIS, LIKE YES, IT COULD POSSIBLY CAUSE CANCER. IT'S JUST NOT SOMETHING I WANTED TO GET INTO."

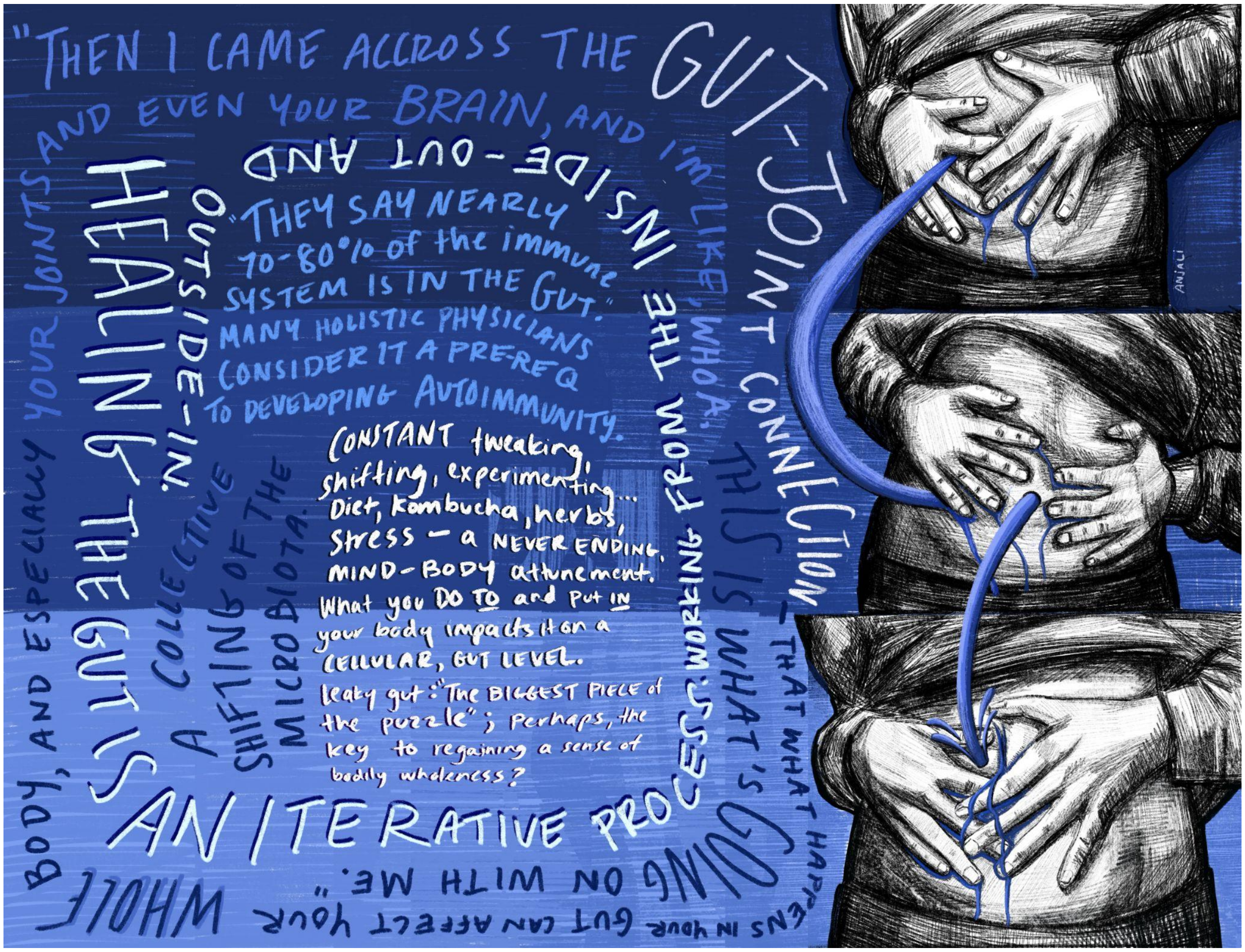
Biologic Bulldoze

This piece responds to the discourses around traditional pharmaceutical drugs like tumor necrosis factor (TNF) blocking biologics and nonsteroidal anti-inflammatory drugs (NSAIDs) that surface on forums and within the interviews. When discussing desires to utilize holistic modes of treatment and care rather than biologics, some interviewees expressed feeling shut down by their biomedical doctors. Tensions between different schools of thought around the “best” and “correct” ways to treat AS are palpable and create a stigma attached to rejecting standard biomedical treatment found in patient-rheumatologist dynamics and on forums.


A VISION OF A FUTURE OF FUSION... UNCERTAIN PROGRESSION
RIGID & SOFT
THEY CALL IT A BAMBOO
SPINE WHEN YOU FUSE
"FUSION FRACTURE?"
BUT, WHAT DOES IT REALLY MEAN TO "FUSE"?
AM I EVEN REALLY FUSING, OR IS IT JUST INFAMMATION? THE PROSPECT OF FUSION LOOMS LIKE A DARK SHADOW ABOVE ME, QUIET & LOUD...
CATCH IT EARLY
JOINTS
TO LIVE AND BE IN A BODY, AT ONCE flexible AND STIFF, IN PAIN AND STRONG, CHANGING IN AN INVISIBLE INSTANT. CHRONICITY VIA NON-NORMATIVE, SOMETIMES ELUSIVE Experiences of PAIN & STIFFNESS. NEVER TRULY KNOWING THE INTERNAL STATE OF YOUR OWN BODY, YOUR OWN BONES, YOUR OWN COLLAGEN... ASIDE FROM THE EVER-SO-RARE INSURANCE-COVERED MRI... BUT EVEN THEN... UNCERTAIN FUTURITIES HINGE ON THE TEMPORALITY OF THIS EXPERIENCE
"THE THING THAT'S REALLY CRAZY ABOUT MY BODY IS THAT, LIKE I CAN'T TWIST AROUND TO SEE THE DOGS AT THE BEACH, BUT I CAN CARRY THE STROLLER WITH THE DOGS INSIDE OF IT UP TWO FLIGHTS OF STAIRS"
THIS IS A PAIN, A SENSATION, THAT TRANSGRESSES TYPICAL UNDERSTANDINGS OF PAIN... THE SPECIFICITY LENDS ITSELF TO THE INVISIBLE NATURE OF ITS DEBILITATION
"IF YOUR SI JOINTS FUSE, YOU JUST WON'T BE ABLE TO TOUCH YOUR TOES."
"TOTAL HIP FUSION. EXTREMELY OVERWHELMED..."
ANJALI

Bamboo Spine

When your spine fully fuses, it is referred to as a “bamboo spine.” In this piece, a person wraps their arms and legs around the foremost bamboo tree, bending and curving it into a position reminiscent of a fully fused AS spine. She clings tightly to the tree, almost becoming one with it, though the potential for the stalk to spring back exists if she were to shimmy down, indicative of a fluidity and fluctuation that comes with the embodiment of chronicity. On forums, people consistently discuss their fears for the future, their questions and concerns about what their bones might look like in a month, a few years, and decades ahead. Interviewees’ surfaced discussions about the invisible nature of their pain and stiffness as it was linked to bone fusion. Within the context of holistic healing, interviewees’ and forum participants’ conceptions of the future were constantly filtered through discussions about the kinds of treatments and modes of care they engage in.


"Then I came accross the GUT-JOINT CONNECTION — THAT WHAT HAPPENS IN YOUR GUT CAN AFFECT YOUR WHOLE BODY, AND ESPECIALLY YOUR JOINTS AND EVEN YOUR BRAIN, AND I'M LIKE, WHOA. THIS IS WHAT'S GOING ON WITH ME."
HEALING THE GUT IS AN ITERATIVE PROCESS: WORKING FROM THE INSIDE-OUT AND OUTSIDE-IN.
A COLLECTIVE SHIFTING OF THE MICROBIOTA.
"THEY SAY NEARLY 70-80% of the immune SYSTEM IS IN THE GUT."
MANY HOLISTIC PHYSICIANS CONSIDER IT A PRE-REQ TO DEVELOPING AUTOIMMUNITY.
CONSTANT tweaking, shifting, experimenting... Diet, Kombucha, herbs, stress — a NEVER ENDING MIND-BODY attunement.
What you DO TO and put IN your body impacts it on a CELLULAR, GUT LEVEL.
leaky gut: "The BIGGEST PIECE of the puzzle"; Perhaps, the key to regaining a sense of bodily wholeness?
ANJALI

Leaky Guts

An iterative, cyclical form of healing came through each interviewee's narrative as they spoke about their holistic healing processes in relation to their leaky guts. The term "leaky gut" refers to the process by which the mucosal barrier of the gut becomes permeable to "antigens from the gut lumen," promoting "both local and systemic immune responses."[5] People with AS tend to have a leaky epithelium and endothelium due to "adherent and invading bacteria" that reside in their ileums, causing epithelial barrier changes.[6] The introduction of bacteria and zonulin into the bloodstream can lead to the autoimmunity that results in AS.[7] The gut is positioned as a dynamic, critical interlocutor, receiving (or not) and processing the presence and absence of different objects. A kind of *microbial kinship* emerges, in which individuals with AS exhibit similarities in their microbiota that unite them in a shared lived experience of their illness. The potential to decrease inflammation and stiffness in almost unimaginably fast periods of time resides primarily in and around one's relationship with their gut. A constant, interactive back-and-forth materializes in interviewees' narratives. Knowledge of leaky gut allows James to act on it with kombucha; Adam's gluten elimination, for example, works to revert zonulin secretions and heal the mucosal lining. In this way, a gut-mind-body relationship, symbiosis, and circle become evident.

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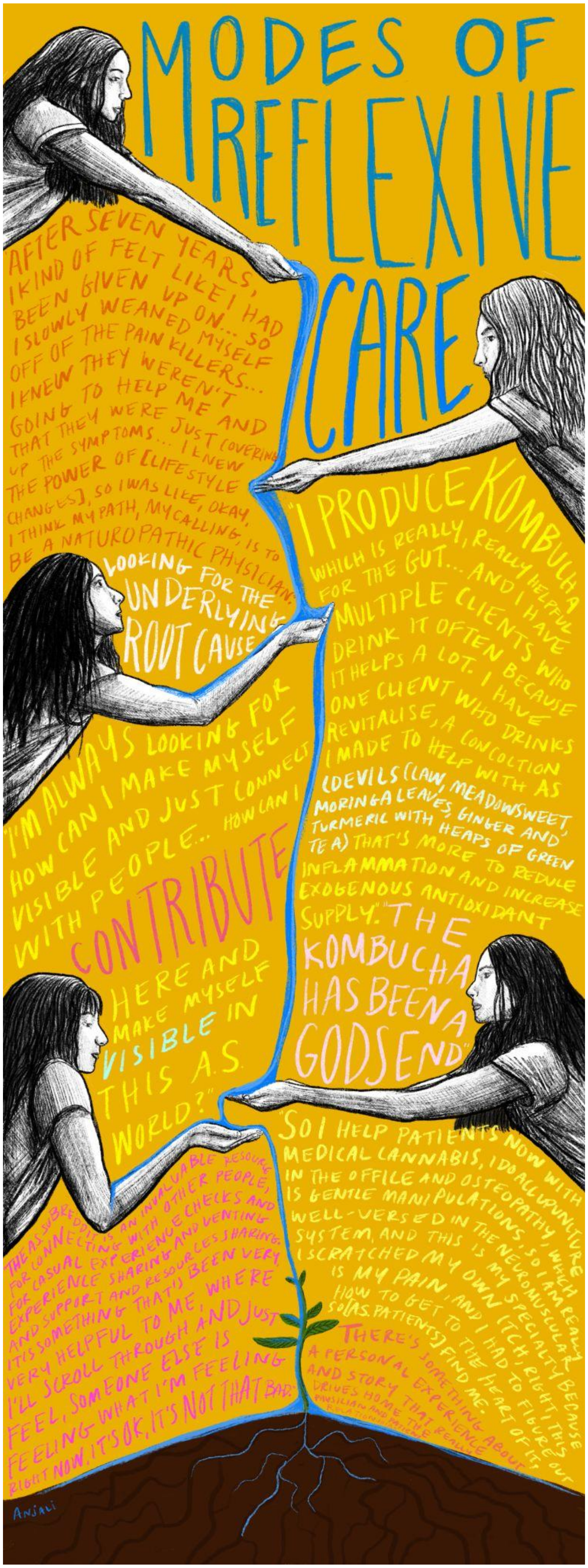
[5] Qinghui Mu et al., "Leaky Gut as a Danger Signal for Autoimmune Diseases," Frontiers in Immunology 8 (May 23, 2017): 1, https://doi.org/10.3389/fimmu.2017.00598.

[6] Francesco Ciccia et al., "Dysbiosis and Zonulin Upregulation Alter Gut Epithelial and Vascular Barriers in Patients with Ankylosing Spondylitis," Annals of the Rheumatic Diseases 76, no. 6 (June 2017): 1, https://doi.org/10.1136/annrheumdis-2016-210000.

[7] Ibid, 7.



"AFTER SEVEN YEARS, I KIND OF FELT LIKE I HAD BEEN GIVEN UP ON... SO I SLOWLY WEANED MYSELF OFF OF THE PAIN KILLERS... I KNEW THEY WEREN'T GOING TO HELP ME AND THAT THEY WERE JUST COVERING UP THE SYMPTOMS... I KNEW THE POWER OF [LIFESTYLE CHANGES], SO I WAS LIKE, OKAY, I THINK MY PATH, MY CALLING, IS TO BE A NATUROPATHIC PHYSICIAN."

LOOKING FOR THE UNDERLYING ROOT CAUSE

"I PRODUCE KOMBUCHA WHICH IS REALLY, REALLY HELPFUL FOR THE GUT... AND I HAVE MULTIPLE CLIENTS WHO DRINK IT OFTEN BECAUSE IT HELPS A LOT. I HAVE ONE CLIENT WHO DRINKS REVITALISE, A CONCOCTION I MADE TO HELP WITH AS (DEVILS CLAW, MEADOWSWEET, MORINGA LEAVES, GINGER AND TURMERIC WITH HEAPS OF GREEN TEA) THAT'S MORE TO REDUCE INFLAMMATION AND INCREASE EXOGENOUS ANTIOXIDANT SUPPLY." "THE KOMBUCHA HAS BEEN A GODSEND"

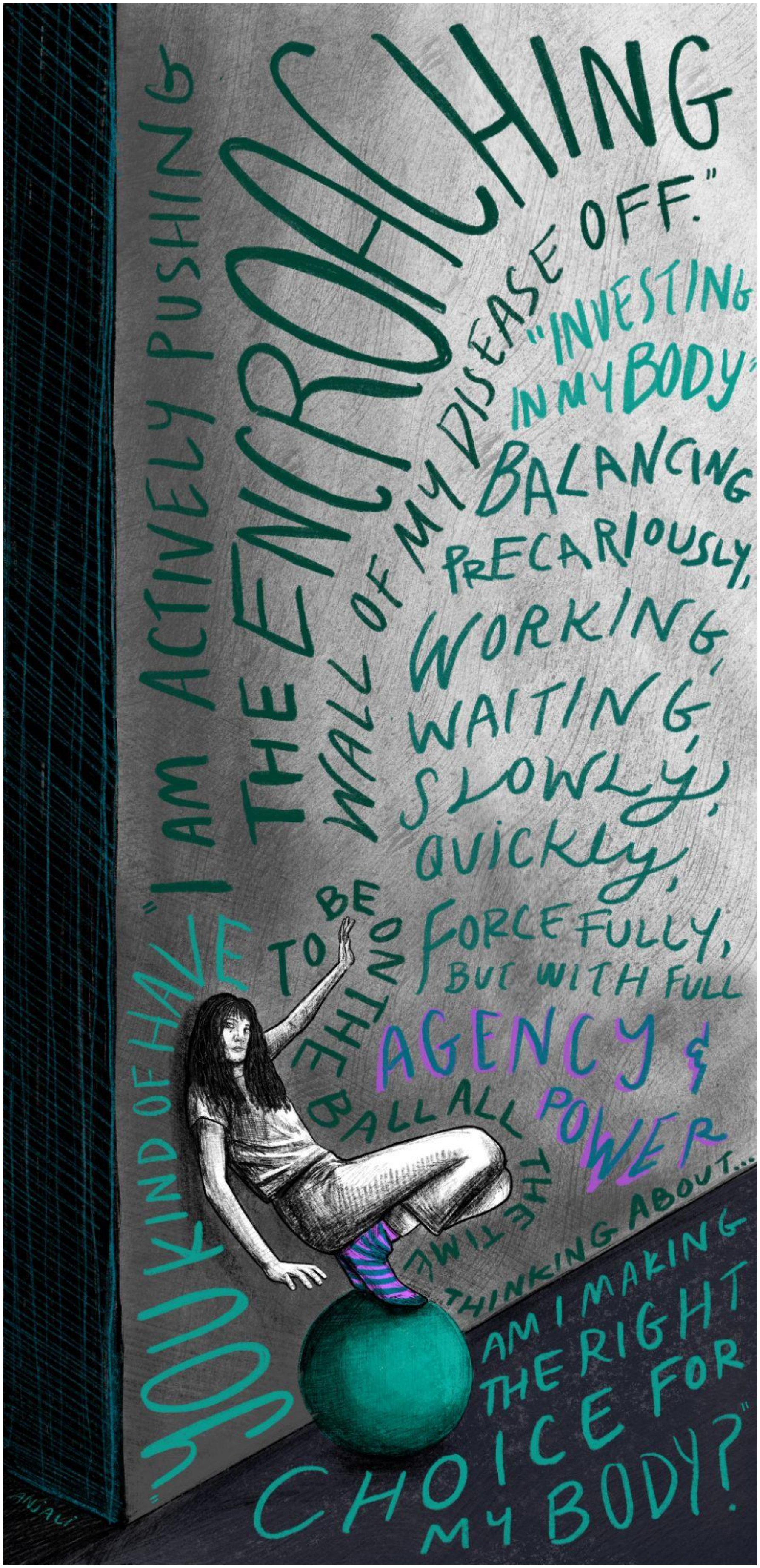
"I'M ALWAYS LOOKING FOR HOW CAN I MAKE MYSELF VISIBLE AND JUST CONNECT WITH PEOPLE... HOW CAN I CONTRIBUTE HERE AND MAKE MYSELF VISIBLE IN THIS A.S. WORLD?"

"SO I HELP PATIENTS NOW WITH MEDICAL CANNABIS, I DO ACUPUNCTURE IN THE OFFICE AND OSTEOPATHY, WHICH IS GENTLE MANIPULATIONS, SO I AM REALLY WELL-VERSED IN THE NEUROMUSCULAR SYSTEM, AND THIS IS MY SPECIALTY BECAUSE I SCRATCHED MY OWN ITCH, RIGHT, THIS IS MY PAIN, AND I HAD TO FIGURE OUT HOW TO GET TO THE HEART OF IT, SO [AS PATIENTS] FIND ME. THERE'S SOMETHING ABOUT A PERSONAL EXPERIENCE AND STORY THAT DRIVES HOME THE REALI[illegible] PHYSICIAN AND THE RELATIONSHIP [illegible]

"THE AS SUBREDDIT IS AN INVALUABLE RESOURCE FOR CONNECTING WITH OTHER PEOPLE, FOR CASUAL EXPERIENCE CHECKS AND EXPERIENCE SHARING AND VENTING AND SUPPORT AND RESOURCES SHARING. IT'S SOMETHING THAT'S BEEN VERY, VERY HELPFUL TO ME, WHERE I'LL SCROLL THROUGH AND JUST FEEL, SOMEONE ELSE IS FEELING WHAT I'M FEELING RIGHT NOW, IT'S OK, IT'S NOT THAT BAD."

Reflexive Care

Across the interviews, individuals described the various ways they care for their bodies and minds, expressing their desires to relay and pass this knowledge on to other people with AS in a multitude of forms. They exhibit what I have coined *reflexive care*, an intrinsically motivated form of care meant to benefit others. For example, Joy became a medical cannabis physician because she reaped the benefits of CBD and THC first-hand and wanted to help individuals with chronic illness achieve symptom reduction via these pathways.


"I AM ACTIVELY PUSHING
THE ENCROACHING
WALL OF MY DISEASE OFF."
"INVESTING IN MY BODY"
BALANCING
PRECARIOUSLY,
WORKING,
WAITING,
SLOWLY,
QUICKLY,
FORCEFULLY,
BUT WITH FULL
AGENCY &
ALL POWER
"YOU KIND OF HAVE TO BE ON THE BALL ALL THE TIME
THINKING ABOUT...
AM I MAKING THE RIGHT CHOICE FOR MY BODY?"
ANJALI

On the Ball

Interviewees expressed a sense of increased agency and power when taking health and healing into their own hands. A unique precarity inherent to autoimmunity and chronic conditions emerged in their narratives. Gaining “control” of their bodies and illness by way of different healing modalities requires constant experimentation, an iterative process towards balance, equilibrium, and stability. Some individuals seemed to grapple with whether they were supporting their body as well as they could in the face of uncertain disease progression, or rather, the “encroaching wall” of illness.


"Letting it land,
letting it settle,
setting it FREE
"I AWOKE THE BEAST AND NOW I MUST MAKE A HOME FOR IT"
"In the first years it was so, so present with a lot of pain. I was constantly looking for all these doctors, for what I could do. AS became a part of my identity. I felt like I was so attached to it... But it doesn't define who you are."
A NESTING PAIN
A SHIFTING ENTITY
MAKING PEACE WITH THE DRIFT

Peace with the Drift

Each interviewee surfaced various relationships to their AS and pain. A common thread was the process of coming to terms with one's illness in light of shifting, elusive experiences of symptoms. Acknowledging and accepting one's body in all forms and within ranges of pain and discomfort emerges as a critical shift in relating to AS. Moving from the fear and discomfort of diagnosis into acceptance and self-compassion opens up the possibility of new kinds of psychic, emotional healing.

Interviewee Portraits

MAX is a forty-four-year-old white, cisgender, heterosexual man from Canada who was diagnosed with AS at the age of thirty-eight. He discussed his pending ADHD diagnosis and the ways this impacted his decisions around AS treatment. When first diagnosed, his doctor urged him to start Humira, and he did so out of sheer curiosity about how it would impact his body. Because Humira reduced his pain levels so much, he became hyper-fixated on his ADHD symptoms (without the distraction of pain) and became “unable to function” in day-to-day life. After two weeks, he stopped taking Humira, explaining that he could not afford to get an infection because he works in construction. He decided to turn to different forms of treatment through a laborious, time-consuming, self-directed process in which he tested many vitamins, supplements, and diets. He described great success on a carnivore diet for the past four years in tandem with Semax (which he takes for ADHD, but also helps with pain) and cannabigerol (CBG). He has an intense attunement to the inflammation triggers for his body, even stating, for example, that if he were to dip his finger into refined sugar, his inflammation would increase, and pain would ensue.

BEN is a thirty-two-year-old white, cisgender, heterosexual man living in the US. He started experiencing acute back, foot, and knee pain when he was in his late-twenties. He was diagnosed with AS at the age of thirty and is currently utilizing medical cannabis as his primary form of treatment due to a change in insurance that made it impossible to stay on biologics. He said that his rheumatologist did not talk much about the side effects of biologics when they were first prescribed, and in retrospect, he was “overly eager” to start them due to the severity of his pain. Ben has been using CBD and THC, prolonged hot tub soaking, physical therapy, exercise, stretching, and mental health therapy to manage his AS. He expressed that all people with AS should seek therapy because it “takes a toll on you.” He talked about the importance of joining online AS communities as a vital space for people to discuss their experiences with chronic illness.

JESSIE is a thirty-eight-year-old genderqueer Black person born and raised in the US, and currently living in Spain. Jessie was diagnosed with AS nine years ago after experiencing severe pain in their back, neck, and ribs since their teenage years. They expressed a sense of self-blame for triggering the onset of AS as a result of an eating disorder that put their body under immense stress that caused gut dysbiosis. Jessie said they originally “felt betrayed by [their] body” and struggled to engage in healthy eating practices in an effort to help their body heal. They also explained that Chinese Medicine links “rigidity and perfectionism” to the development of AS, stating, ”That was me from the age of ten. If it wasn't perfect, it was a failure.” Jessie described their trepidation with biomedicine after experiencing years of sexism and racism at the hands of dismissive doctors. They took Simponi for a few months after being diagnosed before deciding to stop it in an attempt to get pregnant. They have primarily used holistic treatments ever since and emphasized the importance of strength training, anti-inflammatory diets, acupuncture, essential oils, and yoga. Jessie decided to shift career paths to become a holistic health coach after healing their relationship with food and engaging in self-directed experimentation to treat AS. Their stiffness has recently been getting worse, though, and they are debating whether or not to try out a new biologic.

JAMES is a twenty-nine-year-old white, Australian, cisgender, heterosexual man living in the South of France. He was diagnosed with AS at the age of twenty-five after experiencing intense back pain. His wife is a physiotherapist and was recently diagnosed with non-radiographic axial spondyloarthritis. James cited the importance of his wife's support in his pursuit of natural treatments for AS. He has his own kombucha business and described how he brews kombucha specifically to help with gut health. James also has a few "clients" who have AS and buy his kombucha to support digestion and gut health. He talked about the risks of biologics that deterred him from taking them and described feeling ostracized by his rheumatologist when he disclosed his apprehension toward biologics. James has a background in nutrition and dietetics from an undergraduate degree. He mentioned the importance of obtaining financial stability to equip himself to deal with worsening AS pain and symptoms.

MARTA is a thirty-seven-year-old cisgender, Hispanic, heterosexual woman living in the US. She was diagnosed with AS less than a year ago at the age of thirty-six. However, her symptoms, including stiffness and pain primarily in her left shoulder blade and right hip and leg, started about eight years ago. For years, doctors told her she had fibromyalgia and herniations, and most pushed painkillers as a form of "treatment." As someone with an "addictive personality" who became sober at sixteen for the first time, she said that painkillers "did not do [her] any good." She wakes up at four in the morning to be able to function by six with yoga and stretching. She has done acupuncture, cupping, and physical therapy and has used herbs like Arnica, a TENS unit, and hyperbaric chamber therapy to help with her AS. When describing her openness to holistic modes of healing, she cited her family's interest in natural remedies, joking, "Sopa de Fideo is going to save your life, because, Mexicans, we cure everything with food!". Her rheumatologist prescribed steroids for the pain, which she still takes. Humira did not work for her, and at the time of our interview, she had just had her second dose of Inflectra. She has experienced many side effects from the Inflectra and Humira, including fatigue, nausea, hair thinning, and brain fog, but she is optimistic Inflectra will reduce her pain in tandem with holistic treatments.

DANILO is a forty-seven-year-old cisgender white man who grew up in Croatia and is currently living in the US. He has been using diet and exercise in the form of walking

and biking as his primary treatment for AS for roughly a decade. When he was first admitted to the hospital due to severe pain and swelling in his back and hands and concerning blood panels, doctors put him on steroids and prescribed him physical therapy, which helped with his symptoms. When he moved to the US, his rheumatologist said he needed to take biologics, but he resisted this, stating uncertainties about the side effects and efficacy of the drugs. His wife helped him research and implement diet changes, and he has felt significantly better ever since. He says the book *The IBS Low-Starch Diet: Why Starchy Food May be Hazardous to Your Health* (2006) has been vital to his healing process. He still takes ibuprofen every night to manage inflammation.

LYDIA is a twenty-nine-year-old cisgender white woman from Germany. She was diagnosed with AS at the age of twenty-three while living in the US for college where she played competitive tennis and experienced the first onset of symptoms in her SI joints and lower back. When diagnosed, her rheumatologist prescribed Meloxicam, a strong NSAID, and suggested she start a biologic, but Lydia wanted to explore different treatment options after experiencing side effects from the Meloxicam. She spent two weeks inpatient at a holistic hospital in Germany on two separate occasions. She experienced immense symptom reduction from medically supervised fasting, fever-induced therapy, homeopathic medication, and physiotherapy. Lydia discussed leaky gut as the root cause of her AS and explained the process of intermittent fasting, which helps alleviate strain on the gut while subsequently reducing widespread inflammation in the body. She emphasized the importance of diet, decreased stress levels, acupuncture, osteopathy, and mental health in her "healing journey." She discussed the importance of de-identifying from the AS diagnosis, making clear her efforts to tell herself that she is not an "AS person," but rather someone who happens to have AS. Her holistic mindset and understanding of the gut cannot be divorced from the culture around health and medicine she described growing up with in Germany. She now works as a functional health coach to impart her knowledge of holistic healing gained as a person living with AS to others with chronic conditions.

ADAM is a forty-two-year-old cisgender white man who was diagnosed with AS at the age of thirty-two while in school to become a naturopath after quitting his job as a teacher. When he was ten years old, he started experiencing pain in his hips, heel, and the tendon below his knee cap, which doctors explained away by his basketball hobby. When he turned eighteen, the pain migrated to his lower back and radiated down his leg, making it impossible to walk. His rheumatologist put him on a variety of NSAIDs that gradually stopped working. He was given corticosteroids and prescribed Vicodin when the other drugs failed to alleviate the pain. From 2000 to 2007, he took two to four NSAIDs and four Vicodin daily. He started developing side effects from the drugs, including panic attacks, anxiety, digestive issues, and migraines. At twenty-seven years old, his doctor told him all of the drugs were impacting his kidneys and liver but said he had no other ways to treat him. Adam weaned himself off opioids for over a year and did research concerning the importance of diet, exercise, and vitamin supplement support. He wanted to make a difference in others' lives and says that naturopathic medicine is about getting to the true "root cause" of disease. He argued that traditional pharmaceuticals mask symptoms, and noted that biologics can worsen AS symptoms for some people.

JOY is a forty-five-year-old cisgender Asian woman living in New York City. She grew up in the Bronx and was diagnosed with AS at the age of fifteen after years of pain in her neck, back, and glutes. She grew up in a traditional Chinese household, so her parents brought her to an acupuncturist and herbalist before traditional biomedical doctors, where she received acupuncture, cupping, and needling for her pain. Her primary care doctor urged her to take samples of NSAIDs like Vioxx to help with the pain. She went to medical school in San Francisco shortly after California legalized medical cannabis, and her attending physician (an HIV and AIDS doctor) suggested she take a tincture he had made of marijuana steeped in alcohol to help with her pain. She experienced immense symptom reduction from medical cannabis and decided to become an integrative medical cannabis physician to help other individuals with chronic illnesses. She explained that cannabis does exactly what the NSAID Celebrex does, except it is a natural plant without the side effects and gut-damaging potential. She currently does hot yoga every other day and uses foam rollers, sauna, light cardio, acupuncture, and osteopathic manipulation at least twice a week. She emphasizes the importance of an anti-inflammatory diet and takes a one-to-one CBD and THC tincture three times a week at night and CBD every morning.

RESEARCH TRAJECTORY: SITUATING REFLEXIVE GRAPHIC ETHNOGRAPHY

When I was fifteen, I suddenly developed an intense, nagging, stabbing sensation in my left hip. The pain came in ebbs and flows — intense for one to two weeks at a time, so much so that I could hardly walk — and then it would spontaneously, miraculously subside. At the time, I chalked it up to overexertion during jiu-jitsu practice. But that intense, crippling sensation would spring up, unannounced every few months or so, confining me to the couch and making a mere five-foot trip to the kitchen an immense struggle. I was funneled through the healthcare system as doctors passed me off, each professing a different diagnosis (from a simple sports injury to tendonitis or bursitis that would resolve on its own). I tried month after month of physical therapy (one physical therapist boiled my pain down to "weak ankles"), hot packs, cold packs, Advil, Advil, and more Advil, but the pain always returned — loudly.

In August 2020, after five years of this unexplained, debilitating pain and appointments with dozens of stumped and dismissive doctors, I was diagnosed with Ankylosing Spondylitis. AS can be considered an "invisible illness," as permanent, internal physical manifestations (e.g., vertebrae fusion and bone marrow edema) may not cause outwardly visible changes to the body. My diagnosis came from a cheerful rheumatologist, Dr. Bern, who immediately and eagerly exclaimed that I had "textbook" AS symptoms when I pointed to my sacroiliac joints as a constant site of pain.

An-kill-lo-sing Spond-EE-li-tis, *Ank-uh-los-ing Spond-uh-litis, An-kee-lo-sing Spon-DUH-litis, An-kih-losing Spond-i-li-tis, An-ky-losing Spondylitis, Ankylosing Spondylitis, Ankylosing Spondylitis, Ankylosing Spondylitis…* I remember haphazardly repeating it over and over until the words rolled off my tongue in a semi-fluid manner, almost as if, with the click of my heels, it might just disappear … What a clunky name.

Dr. Bern explained that AS was a "man's disease," which was why my symptoms may have been overlooked all those years. After multiple rounds of blood work that told me I was HLA-B27 positive,[8] x-rays, and two MRIs, the results were finally conclusive — bone marrow edema and small erosive changes to my left SI joint as seen on the MRI allowed Dr. Bern to concretely diagnose me with AS. Luckily, she explained, all I had to do was get on *adalimumab*, otherwise known as Humira, the leading tumor necrosis factor (TNF) blocking, injectable biologic drug prescribed to treat rheumatoid arthritis, plaque psoriasis, Crohn's disease, ulcerative colitis, and AS. Dr. Bern also informed me that she had special coupons I could use to reduce the cost of the drug if my insurance did not sufficiently cover it.

The dominant system of medical care for AS in the United States relies on the prescription of conventional pharmaceutical drugs. Along with nonsteroidal anti-inflammatory drugs (NSAIDs), rheumatological guidelines regard TNF blockers as a primary or secondary mode of AS treatment. After many years, Humira was one of the top-grossing pharmaceutical drugs worldwide, pulling in $20.7 billion in 2021.[9] It is

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[8] Many people who develop AS are HLA-B27 positive, though, this is not necessary for diagnosis and development of the disease. Being HLA-B27 positive increases a person's chances of developing AS, however, only around 5-10 percent of HLA-B27 positive individuals wind up with AS (Ince 2019).

[9] Matej Mikulic, "Revenue of AbbVie's Humira 2011-2021," Statista, February 24, 2022, https://www.statista.com/statistics/318206/revenue-of-humira/.

also forecasted to be the top-selling pharmaceutical in 2022. Biologics have undeniably changed people's lives for the better with symptom reduction, remission, and increased quality of life. However, they carry a "black box warning" issued by the Food and Drug Administration as they weaken the immune system and increase the potential for serious infections and death.

When I inquired about any other ways I might be able to support my body alongside the Humira, perhaps with an antiinflammatory diet or exercise, Dr. Bern dismissively told me that there was no evidence-based data to show that any of those methods worked and that Humira was the only viable treatment. And anyway, the injections were quick, easy, and now, almost painless since the new version is citrate-free, she explained. Wary about injecting myself with a drug that increases the risks of various cancers[10] and serious illnesses,[11] may only work for a contained time, and weakens the immune system (which was particularly concerning as my diagnosis came at the height of the COVID-19 pandemic in New York City), I sought out a second opinion from another rheumatologist, Dr. Weber. She professed that yes, Humira was the smartest treatment for me, though I could wait a bit and take indomethacin, an

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[10] As of April 17, 2022, the official Humira® website states that, "For children and adults taking TNF blockers, including HUMIRA, the chance of getting lymphoma or other cancers may increase. There have been cases of unusual cancers in children, teenagers, and young adults using TNF blockers. Some people have developed a rare type of cancer called hepatosplenic T-cell lymphoma. This type of cancer often results in death. If using TNF blockers including HUMIRA, your chance of getting two types of skin cancer (basal cell and squamous cell) may increase. These types are generally not life-threatening if treated; tell your doctor if you have a bump or open sore that doesn't heal."

[11] The Humira® website also states, as of April 17, 2022 — "Serious infections have happened in people taking HUMIRA. These serious infections include tuberculosis (TB) and infections caused by viruses, fungi, or bacteria that have spread throughout the body. Some people have died from these infections. Your doctor should test you for TB before starting HUMIRA, and check you closely for signs and symptoms of TB during treatment with HUMIRA, even if your TB test was negative. If your doctor feels you are at risk, you may be treated with medicine for TB."

NSAID often prescribed for various forms of arthritis, if I did not feel ready to start the biologic injections. Worst case, my SI joints might fuse and I wouldn't be able to touch my toes, she said. Again, when I asked if there were any other ways I could work to naturally reduce inflammation and stiffness in my body before diving into biweekly Humira injections, Dr. Weber scoffed, "Listen, turmeric isn't going to stop your back from fusing."

With the prospect of continued pain and fusion hanging in the balance, it didn't quite *feel* like I had a choice or any control of my AS. In fact, when I came away from these appointments, AS took on an agency and mind of its own and I felt increasingly powerless. What kind of fool would put off taking a widely used, largely safe drug if the alternative — constant pain, a fused "bamboo" spine, and the inability to walk and bend over — was oh so dispiriting?

That August, as a newly diagnosed individual with AS, I naturally gravitated to AS–specific online forums and spaces in which people discuss their diagnosis, modes of care and treatment, and experiences taking biologics. Growing up with an Indian mother steeped in the teachings and practices of Ayurvedic medicine and with a father who is generally less concerned with the benefits of natural remedies, I was intrigued by the layered, complex, dynamic, and nuanced discourses unfolding online about AS and the most effective ways to deal with it, live with it, curb disease progression, and heal.

Contrasting stories and discussions about drug side effects, drug safety, and dwindling effectiveness struck me. For example, someone commented on an AS forum, "I think the potential side effects of a biologic need to be also balanced against the dangers of uncontrolled or not well controlled AS. AS is not just an inconvenience, it can do real damage. Eyes, organs, etc." and, "Please keep record of all your symptoms! I had cognitive problems that developed and worsened after the second infusion. I ended up with a demyelinating reaction to the biologic. Also called drug-induced lupus or MS. It presented like a stroke." Another post went,

> I was on Humira for 13 years, Simponi for 6 months, Remicade for a year, and Cosentyx for the past two years. They're unfortunately not painkillers, but the right one can help the severity a lot. I stopped Humira because it wasn't as effective as it used to be, Simponi and Remicade because they never really did much for me, and Cosentyx seems to be my new BFF for now.

If I start on biologics now, what will I have left in ten, fifteen, or twenty years? I wondered. After hectic back–and–forths with our insurance company, my mom and I were able to place the first order of Humira. And thanks to Dr. Bern's coupons, the out-of-pocket copay dropped from $250 to five dollars. A few doses sat untouched in the back of the fridge while we collectively deliberated the best route of care and treatment.

Oftentimes, while perusing the forums those first few months after diagnosis, I noticed discussions about alternative, natural forms of healing for AS get shut down and scoffed at as foolish, risky, and stupidly anti-science. For instance,

> Natural remedies don't exist … The bottom line is this: AS does what it wants. Medication prescribed by your rheumatologist has been through an enormous testing protocol. Your rheumatologist prescribes medication that she/he believes will work for you. If it works, then stay the course. If it needs tweaking or another med is indicated yadda yadda yadda.

But other pockets of healing narratives surfaced; some people wrote about how cutting out gluten, drinking more water, and strengthening the muscles around their spines drastically reduced their pain, others lauded the healing powers of tetrahydrocannabinol (THC) and cannabidiol (CBD) tinctures. One individual made a post asking,

> Has anyone gone down the route of functional medicine and gotten any results? There seems to be such a connection with gut health and autoimmune/ inflammatory diseases. Just seems counterintuitive to take medicines that have long-term gut-destroying potential. Has anyone tried functional medicine and care to share?

Someone replied, "I found tremendous relief through acupuncture but finding a really good provider is key. Also, give it some time. Regular [acupuncture] treatments are great, the benefits are cumulative." Another person said, "I've been looking into an online subscription-based functional medicine package. I am kind of desperate but hate sinking money into something that has such mixed reviews."

While endeavoring on my path to diagnosis and treatment and reading through compelling online discourses, I was simultaneously interning as a Research Assistant for Professor Jacquelyne Luce, reading and coding interview transcripts from people who self-identify as being exposed in-utero to diethylstilbestrol. The sheer power and richness of the interview narratives struck me, and I began to develop an interest in carrying out work of this kind. I worked through the themes I was finding in the interviews and literature by creating spontaneous, stream-of-consciousness "free-draws," which greatly influenced my current project. Interning for Professor Luce throughout the summer of 2020 planted the many seeds that have blossomed into the work you see here today. In the face of the overwhelming push for the use of drugs like Humira that I personally experienced, and more broadly by the pharmaceutical industrial complex, I was particularly drawn to and interested in the narratives of those who have sought out holistic modes of healing for AS. A range of healing systems fall outside of the traditional biomedical framework, including, for example, Ayurveda, Indigenous Healing practices, Naturopathy, Herbalism, and Chinese Medicine. All of my interviewees engaged in arrays of treatments, many of which originate from these kinds of healing systems but are also peripheral when thinking about what holistic healing encompasses. This can include the use of diet changes, vitamin supplement protocols, CBD, exercise, and even brewing kombucha to support their bodies and mitigate disease progression without primary reliance on pharmaceutical drugs. A few interviewees explicitly explained that they were in the process of weaning themselves off of NSAIDs.[12] One interviewee, Marta, had just started Inflectra infusions at the time of our interview and another, Ben, was primarily relying on medical marijuana because his insurance stopped covering Humira. Though they engage with forms of biomedical care, they describe various reasons for their pragmatic use of different healing modalities.

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[12] NSAIDs can often effectively reduce inflammation in the body, which helps decrease short-term pain and stiffness associated with AS, however, they lead to gastrointestinal damage that can exacerbate and worsen disease progression (Maseda & Ricciotti 2020, 2). Both short and prolonged use of NSAIDs can disrupt and change the gut microbiome by compromising the mucosal lining and creating abnormal variation in bacterial growth (Maseda & Ricciotti 2020, 2). Aside from the widespread use of NSAIDs among those with AS, over 30 million people take them daily (Sostres et al. 2013, 1). Humans are indelibly, collectively, and quite carelessly shifting our microbiota. This mass NSAID use may be a small piece of the puzzle when it comes to understanding the increasing rates of autoimmunity seen worldwide (NIH 2020).

In carrying out this project, I was curious about what motivates people to engage with holistic modes of healing and the attentiveness to the way one's environment impacts illness. I wanted to discern how an engagement with holistic healing inflects individuals' relations to their AS, pain, and bodies. My project highlights narratives of holistic healing that co-exist with the dominant medical framework that pushes NSAIDs and biologics as unrivaled forms of treatment. That said, I oscillate between the words *holistic* and *different* healing modalities and forms of care to avoid the commonly used term "alternative treatments," since this implicitly positions biomedicine and allopathy as the standard model of care. While I do sometimes use the word "treatment," this is not meant to medicalize or position my interviewees' use of various healing modalities in a biomedical context. The breadth of what constitutes holistic healing and care shifted, grew, and evolved throughout my fieldwork — while I conceptualized holistic forms of care as those that are outside of traditional biomedical frameworks and attend to the inherent relationship between all parts of the body and one's environment, I did not anticipate the many forms this can include. For example, one interviewee, James, talked about his use of kombucha to aid and support gut health, a unique way to attend to the health of the body that I would not have otherwise imagined.

Grounding in the Literature

Given the interdisciplinary nature of my research and my interest in the intersection between feminist studies, disability studies, anthropology (and everything in between), I must acknowledge the deeply interwoven and non-linear nature of many of the sources this project draws on. I immersed myself in a wide range of materials during an independent study in Spring 2021. During this time, I read literature and ethnographies about pharmaceuticals, narratives of able-bodiedness and cure, shared kinship networks, models of holistic healing, and more.

In what follows, I highlight a selection of literature that is most important to contextualize the direction of my final project. I work to disentangle what I conceptualize as a highly intertwined assemblage of thought and ideas. For example, the offerings of feminist embodiment and phenomenology help elicit my application and understanding of Critical Medical Anthropology (CMA) in the context of holistic healing and chronic illness narratives. All of this is situated in the broader complex of biomedicalization and pharmaceuticalization. Though I engage with and parse distinct schools of thought in the following paragraphs, they are not meant to be thought of in a hierarchical, stratified manner. In the graphic representations of my research that follow this introduction, I aim to swiftly and strategically re-tangle, knot, twist and muddle the neatness of the literature presented here.

Understanding the pharmaceutical climate, entrenched in notions of and aspirations for greater health and wellness foregrounds the ideas about holistic healing that I engage with in my work. *Global Pharmaceuticals* (2006), edited by Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, puts forth a series of essays on the ethics, marketing, and practices of the pharmaceutical industrial complex that first sparked my interest in discourse of this kind. In the opening chapter, “The Pharmaceutical Nexus,” Petryna and Kleinman detail the way pharmaceutical marketing drives drug company profits, highlighting how illnesses are valued and treated differently. Cross-cultural contexts inflect the global pharmaceutical trade and have broader implications for the way drugs impact one's ability to attain and maintain health and wellness. Chikako Takeshita's "The IUD in Me: On Embodying Feminist Technoscience Studies" (2010) complements pharmaceutical market discourses with her semi-autobiographical account of "ideal drug users." She argues that her use of IUDs as a "consenting and safe" user incorporates her into the "global socio-technical network that upholds the IUD as a favorable planning method,"[13] thereby enabling larger processes of social engineering "designed to sustain the viability of contraceptive technologies."[14]

Normative understandings of how to "best" treat AS, purported by biomedical doctors and many people on AS–related forums, are entrenched in the pharmaceutical industrial complex, and stigma exists for those who circumvent these standard forms of treatment. Joseph Dumit's *Drugs for Life* (2012) discusses the way doctors are targeted as "gatekeepers" to the drug market due to their status as the primary prescribers of medicine, helping to outline notions of patient risk to make sure consumers *stay* on drugs. Using these works as a grounding frame provides vital insight into the marketing and creation of an ideal user for biologic drugs, which are so widely prescribed as a first or second mode of treatment for AS.

My project is situated in a body of scholarship that addresses biomedicalization and the examination of power relations in biomedical health systems, which can be understood through the framework of Critical Medical Anthropology (CMA).[15] In "A

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[13] Chikako Takeshita, "The IUD in Me: On Embodying Feminist Technoscience Studies," Science as Culture 19, no. 1 (March 2010): 9, https://doi.org/10.1080/09505430903558021.

[14] Ibid, 14.

[15] Hans A. Baer et al., "A Dialogue between Naturopathy and Critical Medical Anthropology: What Constitutes Holistic Health?," Medical Anthropology Quarterly 26, no. 2 (June 2012), https://doi.org/10.1111/j.1548-1387.2012.01203.x.

dialogue between Naturopathy and Critical Medical Anthropology: What Constitutes Holistic Health?" Hans Baer et al. (2012) critically argue that biomedicine, which is the current *world medical system*, is fundamentally rooted in and promotes the "hegemony of capitalist society in general and the corporate class through the developed and developing worlds."[16] Naturopaths who co-authored the piece describe naturopathic views of health and health care as emphasizing "a broader view of health than just the absence of disease," dubbing the fundamental tenets of naturopathy as "vitalism, the inherent healing power of the body; and holism, the interconnectedness of mind, body, and spirit."[17] These are concepts that the majority of my interviewees seek in their pursuit of holistic healing modalities. While a few of them may not specifically categorize their modes of care within naturopathy, these tenets of healing are palpable in their illness narratives. *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (2010), details the biomedicalized objective to "control" and "molecularize" life within the normative framework of "how life can be/is to be lived."[18] All of my interviewees spoke to notions of fluctuating agency and control of illness within holistic and biomedical contexts.

Experiences and narratives of chronic illness and chronic pain are complex, layered, insightful, jarring, and inherently affective and phenomenological. Though not explicitly positioned in this manner, the research of medical anthropologists such as Arthur Kleinman, Nancy Scheper-Hughes, and Mary-Jo DelVecchio Good, addresses

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[16] Ibid, 243.
[17] Ibid, 247.
[18] Adele E. Clarke et al., "Biomedicalization: A Theoretical and Substantive Introduction" in *Biomedicalization: Technoscience, Health, and Illness in the U.S.*, ed. Adele E. Clarke et al. (Durham & London: Duke University Press, 2010), 7.

questions of affect and phenomenology.[19] Drawing on works like Elaine Scarry's *The Body in Pain: The Making and Unmaking of the World* (1985), disability scholars like Eli Clare, and feminist science and technology studies literature like Annemarie Mol's *The Body Multiple* (2002), I engage with questions and stakes of embodiment as they relate to pain and people's use of non-biomedical healing modalities. Pain's inexpressibility in language necessitates objectification — which Jean Jackson (1994) describes as the pain sufferer's view of their pain as a separate entity — and births the biomedical frameworks within which categorical conceptualizations of pain and chronicity emerge.[20]

Notions of the "lived body" put forth by phenomenologists push back against biomedicine's "Cartesian legacy" and objectification of the "medical body."[21] Phenomenological frameworks help unearth desires to restore bodily unity and holism in light of otherwise fragmented understandings of chronic pain and illness. For example, Jackson's "Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands" (2005), dissects the way chronic pain sufferers disrupt the mind-body dualities that mark the allopathic conceptualization of illness. In a similar vein, Scarry's *The Body in Pain* (1985) explores the complexities of pain, making the critical argument that pain "shatters" language.[22]

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[19] Katherine J. Morris, "Chronic Pain in Phenomenological/Anthropological Perspective," in *The Phenomenology of Embodied Subjectivity*, ed. Rasmus Thybo Jensen and Dermot Moran (Cham: Springer International Publishing, 2013), 167.

[20] Jean E. Jackson, "Chronic Pain and the Tension between the Body as Subject and Object," in *Embodiment and Experience: The Existential Ground of Culture and Self* (Cambridge University Press, 1994), 203-204.

[21] Gay Becker, "Phenomenology of Health and Illness," in *Encyclopedia of Medical Anthropology*, ed. Carol R. Ember and Melvin Ember (Boston, MA: Springer US, 2004), 125, quoted in Morris, "Chronic Pain in Phenomenological/Anthropological Perspective," 171.

[22] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985), 5.

I also recognize that my research — indebted to a lineage of medical anthropologists like Kleinman and Good — can be understood and positioned in a deeper genealogy of work that extends the critical contributions of phenomenologists like Maurice Merleau-Ponty, Martin Heidegger, and Jean-Paul Sartre.[23] I am interested in embodied experiences of pain and what they reveal about the logics of choosing certain treatments and healing modalities over others. Because AS is a chronic illness, marked by temporally and liminally complex experiences of symptoms, phenomenological frameworks help contextualize my interviewees' desires to restore bodily unity and holism via holistic healing modalities in light of otherwise fragmented understandings of chronic pain and illness.

Ida Madsen's ethnographic piece, "People Made of Glass: The Collapsing Temporalities of Chronic Conditions" (2021), draws heavily on phenomenology, discussing how osteogenesis imperfecta (OI), marked by bodily fragility, causes "psychophysical experiences of temporal collapse"[24] that emerge in her interviewees' narratives. She also draws on psychoanalytic literature to delve into the mind-body connection and draws out the way the psychophysical aspect of OI creates a "haunting," phenomenologically informed temporal experience. OI, as a disease denoted by increased bodily fragility and broken bones, directly contrasts AS, which is distinguished by the rigidity of bone fusion. However, Madsen's analysis of OI is a fruitful and generative point of reference used when coding the AS interviews. For example, the collapsing of the past and future into the present found in OI interview

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[23] Morris, "Chronic Pain in Phenomenological/Anthropological Perspective," 167.

[24] Ida Vandsøe Madsen, "People Made of Glass: The Collapsing Temporalities of Chronic Conditions," Anthropology of Consciousness 32, no. 1 (March 2021): 10–11, https://doi.org/10.1111/anoc.12131.

narratives maps on to the experience of AS, which can be managed in the present to mitigate future disease progression, and is presently dictated by one's past. Notions of temporality are central in my interviewees' narratives because they are constantly engaged in healing processes with complex futurities of disease prognosis and progression on the horizon.

Much of my ethnographic research took place in online spaces where illness narratives constantly unfold, as individuals with AS convene to discuss their experiences. Engaging with literature on communities of people with shared biologies is, therefore, important to my project. Biological citizenship, a term coined by Adriana Petryna in *Life Exposed: Biological Citizens After Chernobyl* (2016), and therapeutic citizenship, as described by Vinh-Kim Nguyen in *The Republic of Therapy* (2010), speak to varied ways of conceptualizing kin, which I engage specifically in my work on leaky gut. In "Among the Metavivors: Social Media and Illness Narratives of Stage IV Breast Cancer Patients" (2018), Susan Jacobson analyzes how social media acts as a site for people with stage IV breast cancer to converse, share their illness narratives, and subsequently sidestep and break down traditional pathways of medical knowledge production. Through an ethnographic engagement with four individuals with metastatic breast cancer, Jacobson unveils the ways social media shifts and facilitates illness narratives, giving space to materialize experiences of suffering, exchange information, share and articulate stories, and include a "network of readers, responders and reciprocal influencers."[25] I draw on this literature to inform my engagement with

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[25] Susan Jacobson, "Among the Metavivors: Social Media and Illness Narratives of Stage IV Breast Cancer Patients," Catalyst: Feminism, Theory, Technoscience 4, no. 1 (May 7, 2018): 3, https://doi.org/10.28968/cftt.v4i1.29631.

AS forums and the multitude of ways people utilize them, sharing personal experiences, providing support to one another, and multilayered discourse between posters and responders about modes of treatment, symptoms, and illness narratives.

The Fieldwork

Following an exploratory approach to feminist ethnography, this project centers individual narratives of AS. Starting in the summer of 2021, I recruited interview participants by posting messages on various AS forums, reaching out to people directly, and through snowball sampling. For the sake of privacy and anonymity, I choose not to specify the names of the forums that I engaged with, and I also refer to my interviewees using pseudonyms. I conducted nine long-form interviews with individuals with AS and carried out participant observation by immersing myself in online spaces where people with AS convene to discuss their experiences living with chronic illness and chronic pain. I transcribed and analyzed the interviews and forum posts for varying themes and ideas using a flexible coding scheme. The majority of my interviewees use treatments *outside* of standard biomedical protocols for AS, including herbs, supplements, diet changes, exercise regimens, naturopathy, acupuncture, and more. Two interviewees who have AS are also healthcare practitioners; Adam is a doctor of naturopathy, and Joy is an integrative medical cannabis physician.

Interview protocol questions included those about the kinds of treatments people have used since being diagnosed with AS and the reasons they decided to pursue them. In addition to posing questions about their experiences living with AS, I asked the healthcare practitioners a variety of questions about how they became involved in AS treatment, their perspectives on different treatment models, and appropriate users. The interviews varied in length, some lasting forty minutes, and others, an hour and a half. All of them took place remotely, over Zoom. While I used a detailed interview protocol, I also let interviewees lead and subsequently shape the direction of our conversations.

Situating this project in gender studies offers me the ability to engage with a blend of feminist science studies, health humanities, disability studies, and medical anthropology. My engagement with these varied — yet very interrelated and tangled — areas of study were integral to the makings of the final project in the form of graphic ethnography. Gender studies' commitment to unique and multimodal research methods to challenge the ways knowledge travels and with whom the "authority" lies nurtured this project in all of its stages, from conception to conclusion.

APPENDIX

Painful Objects and Fragmented Bodies:

Ankylosing Spondylitis and the Use of Holistic Treatments to Restore Bodily Unity

Verbalizing and Interpreting Painful Objects

It is April 2021, and I am beginning ethnographic research, sitting in front of my laptop, the screen crammed with search windows, scouring AS forums and support group sites.[26] I read through the responses to a forum post entitled, “My back hurts all the time[,] too.” The post goes:

> So a lot of my friends/co-workers like to chime in that they are also in a lot of back pain … I struggle to describe what AS pain feels like... and I am not sure why because I live with it daily … (stiff, deep, knocks the wind out of you, hard to breathe in deeply) … nothing really sums it up for me. How do you all describe the feeling of your pain?

The poster’s articulation of an inability to pin down and verbalize their pain relates to Scarry’s central argument in *The Body in Pain: The Making and Unmaking of the World*

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[26] Throughout my research, online forums, like the one I lifted the following quotes from, have emerged as places to concretely visibalise and verbalize pain (whether or not these descriptions wholly encompass people’s lived experiences of AS pain and symptoms that are otherwise invisible). Drawing on Victor Turner’s (1969) use of the Latin term *communitas* to describe liminal, cognitively disorienting experiences that intensely tie people together (360), Jean Jackson (1994) argues that individuals with chronic pain often seek out *communitas* to “facilitate mutual understanding” (213). The Ankylosing Spondylitis Facebook page has over 35,000 followers, and the Reddit forum has over 10,000, and countless more AS–specific online communities exist. One poster on the AS subreddit wrote, for example, “[this forum] feels like…the only place i can go to where my pain feels validated. the ppl in my life dont rlly understand how it feels and it gets so frustrating trying to explain.” Spaces like this have their own, distinct “cognitive-affective” styles and makeups, and in ways, serve as clear, concrete, ‘legitimate’ objects and archives of AS pain and AS experiences, which all of my interviewees discussed using and engaging with at some point in time (Jackson 1994, 214).

(1985). Pain "shatters" and "destructs" language.[27] Scarry writes about pain with a focus on the "unmaking" of the world via torture and warfare, and "making" of the world via imagination, artifacts, and religion. Katherine Morris (2013) challenges the lack of specificity in the (un)making of the "world" rhetoric, arguing that it seems as though people with chronic pain are "wordless" in their embodiment of pain unless they "remake" their worlds.[28] As Scarry argues, "the capacity to experience physical pain … differs from … every other bodily and psychic event, by not having an object in the external world."[29] Within this poster's narrative, the objectlessness of pain comes to the fore. In fact, as I sit here typing this, a constant, nagging, piercing, nerve-y, aching pain radiates from my SI joints, though my pain's lack of object makes it hard to sum it up in an accurate capacity …

When it comes to verbalizing one's pain, which this poster calls on others to do, its "lack of object" manifests in various ways. Replies to the forum post include: "I … describe [my pain] as being stuck in a vice – a weight pressing from the bottom up and the top down, crushing me vertically and grinding my lower back against my pelvis with every step" and, "The way I have found to describe it is: imagine if someone inflated a balloon in every joint in your spine." Both descriptions enact what Scarry describes as "language of agency,"[30] in which the posters narrate how "the feeling of pain entails the feeling of being acted upon," in this case, by the outside world (e.g., a vice or via another person "inflating a balloon" in their spine).[31] Language of agency

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[27] Scarry, *The Body in Pain*, 5–6.
[28] Morris, "Chronic Pain," 172.
[29] Scarry, *The Body in Pain*, 161.
[30] Ibid, 13.
[31] Ibid, 16.

objectifies an otherwise objectless experience of pain.[32] In thinking through agency and pain as object, I am reminded of an interviewee, Jessie, a genderqueer, Black person, who told me, "the pain can fluctuate but there's no getting rid of it, you know, it's just something that – I awoke the beast and now I've had to make a home for it." In this narrative, Jessie professes a strong sense of personal agency, stating that they "awoke" the painful object, dubbed, "the beast." Though not the same type of imagery evoked by the first two quotes, a subject-object divide emerges, and this pain metaphor parallels Mol's (2002) argument that "illness is something being done to you, the patient. And something that, as a patient, you do."[33] The images these descriptions conjure up work to combat the "flatly invisible"[34] nature of pain by creating imaginative representations of the severity and intensity of pain, accessible to most outside interpreters of the information.[35]

As Scarry explains, "the only state that is as anomalous as pain is the imagination. While pain is a state remarkable for being wholly without objects, the imagination is remarkable for being the only state that is wholly its objects."[36] Enacting a language of agency to describe pain capitalizes on imaginative capacities. Imagining is

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[32] Jackson, "Chronic Pain," 203.

[33] Annemarie Mol, *The Body Multiple: Ontology in Medical Practice*. Science and Cultural Theory (Durham: Duke University Press, 2002), 20.

[34] Scarry, *The Body in Pain*, 12.

[35] Drawing on Mol's discussion of disease *interpretations* in "The Body Multiple" (2002), I use the term "interpreter" here; "patients," or people with illness, are constant interpreters of their own experiences, and so are those that they convey their experiences to (in Mol's piece, these are doctors). Furthermore, Mol uses the word *perspectivism* to describe the notion that all people — patients and doctors alike — bring their own perspective to experiences of illness by attributing "meaning to what happens to bodies and lives" (2002, 10). Mol argues that perspectivism (and the interpretative process that ensues) makes doctor and patient equal, "but to say this is also to reinforce their division, because the interpretations doctors and patients give must differ, linked as they are to the specific history, interests, roles, and horizons of each group" (2002, 10). Here, one can argue that configurations of *pain*, like disease, "*recede* behind the interpretations" (2002, 12).

[36] Scarry, *The Body in Pain*, 162.

the "last resource for the generation of objects,"[37] and if one fails to imagine — and subsequently *interpret* — the pain of another, "'hearing about pain' may exist as the primary model of what it is 'to have doubt.'"[38] To doubt another's pain is to *contribute to* and generate the delegitimization associated with 'invisible,' chronic illness. This process of delegitimization, often rooted in the complexity of conveying one's pain, can generate stigma associated with chronicity. For example, in response to the original poster's question about how to best describe one's AS pain, one person responded by stating, "I think the thing that has always mentally bothered me the most (other than the AS) is when you explain your problem and they respond with 'but [you] look fine'. Almost like they think I'm lying." The explanation of their 'problem' (i.e., AS) fails to sway or convince their listeners and interpreters who reply doubtfully (e.g., 'but you look fine'), delegitimizing and stigmatizing the experience of pain. While much of one's suffering often comes from the experience of debilitating, constant, aching, stabbing, sharp, chronic (etc.) pain, disbelief, and/or rejection, by and from family, friends, doctors, and others incites a unique kind of suffering and isolation.

AS is a liminal illness; people with it inhabit a unique and strange place in the vast world of pain and embodied experience, further complicating narratives of pain and compounding stigma. AS symptoms can manifest quickly, last on and off from days to weeks to months to years, and dissipate rapidly. However, the potential for progressive bone fusion always exists. In "Stigma, Liminality, and Chronic Pain," Jackson (2005) explains the relationship between these three entities. Liminality is

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[37] Ibid, 166.
[38] Ibid, 4.

twofold: Victor Turner conceptualizes it as "betwixt and between,"[39] often associated with "negative affects" which "slip" through and "elude" classifications "that normally locate states and positions in cultural space,"[40] and Mary Douglas, whose version of liminality succeeds that of Emile Durkheim, and is concerned with "'matter[s] of being out of place,' or 'category mixing.'"[41] People with AS exhibit "inappropriate pain behavior"[42] in that they experience pain in varying, temporal ways (long, short, intense, subtle), and their pain and symptoms often manifest in youth.

For example, Jessie told me, "that's the thing that's really crazy about my body is that, like I can't twist around to see the dogs at the beach [because of the pain and stiffness] but I can carry the stroller with the dogs inside of it up two flights of stairs without a problem." They frame this narrative as a "crazy," non-normative experience, indicative of the way their pain transgresses typical understandings of pain, perhaps one that consumes the body or one that lasts for a contained amount of time and heals. The specificity of Jessie's pain (e.g., trouble twisting, but not carrying a heavy stroller) feeds into the invisible nature of its debilitation.

Additionally, the liminal complexities of AS often make diagnosis a challenging and demoralizing process. Otherwise "healthy" teenagers presenting with acute and chronic back pain, for example, disrupt normative notions of youth and aging. Children should not be in constant, debilitating, *arthritic* pain; that is a form of suffering reserved

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[39] Jean E. Jackson, "Stigma, Liminality, and Chronic Pain: Mind-Body Borderlands," *American Ethnologist*, 32, no. 3 (August 2005): 343.
[40] Ibid, 333.
[41] Ibid.
[42] Ibid, 339.

for geriatric patients in nursing homes. Many of my interviewees detailed their complex paths to diagnosis. For example, Adam, a white, middle-aged man, told me,

> I would say [that at] 10 years old, I can remember having pain in my hips. And I would say around 12 to 14 years old, I [had] pain in my heel and in the tendon below my kneecap. And then the doctors just said … that it was just due to playing basketball and being active at that age. They really didn't want to investigate it [and] didn't think much of it.

Jessie told me that when they went to the traumatologist after years of pain since their early teens, he said, "You need to stop reading articles about arthritis and just relax; get a romance novel. That would be good for you." Joy, a Chinese woman in her forties said, "My parents were always like, what's wrong with her, why is she always in pain all the time, you know, she's trying to skip school – are you nervous about your tests?" which delayed her diagnosis. These are striking narratives in which pain was not taken seriously, doubted, and delegitimized by medical professionals and family members because those presenting with the pain transgressed normative understandings of the body.

Bodily Disunity and Curative Logics

Furthermore, conversations of language, liminality, and stigma are seen, not only in the way people with chronic illnesses like AS describe their pain but also within biomedical conceptualizations of illness. As detailed above, narratives of embodied illness *rely* on the objectification of pain in relation to the subject/object conceptualizations of the body.[43] While medical professionals vary in their theorization of pain and chronicity, dualistic and categorical understandings of the body prevail in

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[43] Jackson, "Chronic Pain," 201.

most settings, and the complex relationship between pain and language is at the root of this.[44] Jackson (2005) argues that chronic illnesses (like AS) appear to transgress the "categorical division between mind and body … [thereby] … threaten[ing] the normal routines of biomedical treatment."[45] Biomedical perspectives understand "chronic pain as a process that transforms pain … into the problem itself."[46] Biomedicine increasingly emphasizes the importance of "exercising *control over* medical phenomenon - diseases, illnesses, injuries, bodily malfunctions" and, often, pain is the object thought to lie at the root of such "malfunctions."[47]

Morris (2013) describes past anthropological work by Linda Garro (1994), who claims that chronic pain inhibits the "self and body" from acting "as one" — something Morris phenomenologically dubs more accurately (drawing on Merleau-Ponty) as "disunity" within the body.[48] Themes of disunity show up, not just in narratives of pain as described by those with chronic illness, but also in physicians' descriptions of patients' pain. Melanie Thernstrom, as referenced by Jackson (2005), argues that "clinicians who see pain itself as the culprit speak metaphorically of broken alarm systems, hormones, and surgical mistakes."[49] When I asked Marta, a middle-aged Hispanic woman, how she understood her AS to function, she said her rheumatologist explained, "That your body, you know, your immune system is overactive [and] the way your immune system responds is by … attack[ing] your spine … and this is why there's this damage and pain." Here, her own immune system is positioned as the

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[44] Ibid.
[45] Jackson, "Stigma, Liminality, and Chronic Pain," 332.
[46] Ibid, 343.
[47] Clarke et al., "Biomedicalization," 2.
[48] Morris, "Chronic Pain," 175.
[49] Jackson, "Stigma, Liminality, and Chronic Pain," 335.

"overactive," "attacking" agent on her body as subject, which then causes her to experience pain. Circling back to biomedicine's understanding of the pain as the "problem itself," this narrative of the way AS functions within Marta's body represents the notion that pain is the root problem, brought on by the disunified, malfunctioning body that is attacking itself, further defining pain as a separate entity. It follows that biomedicine rejects the possibility that healing can come from within the very body that is attacking itself.

Within biomedical frames, the "emergent molecular gaze of today"[50] informs doctors' treatment plans for patients, relying on pharmaceutical drugs, with notions of *cure* always in mind and in pursuit.[51] Many forum posts exist in which patients discuss when, if, and how a cure for AS will emerge. Discussions include rhetorics of cure, like, "Biologics can cure multiple kinds of inflammation" and "My doctor seems to be expecting the injectable medications to cure me." In *Brilliant Imperfection* (2017), Eli Clare argues that sexism, racism, classism, xenophobia, fatphobia, transphobia, homophobia, and more are artificial "constraints" projected onto body-minds that create "defects" and "defective" states of being which the medical-industrial complex operates within.[52] Narratives of pain and suffering are inflected by predisposed bias, categorization, and ideas about normative bodies in biomedical frameworks. Clare postulates that the ideology of cure is inextricably linked to notions of "natural" and "unnatural," and is put forth as the bodily ideal — *health* — which all bodies should

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[50] Clarke et al., "Biomedicalization," 4.

[51] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Durham: Duke University Press, 2017), 12.

[52] Ibid, 23.

aspire to. Chronic progressive, degenerative illnesses like AS directly thwart curative logics and goals.

While the liminal and temporal experience of AS varies greatly from person to person, biomedicine has tried to frame it within the normative context of a treatable — *even almost curable* — disease, with the standard prescription of anti-inflammatories like indomethacin and biologic drugs like Humira. During my interview with James, a white man in his late twenties, we discussed the way rheumatologists configure biologics as a critical, necessary form of AS treatment (the key difference between life-long disability and the chance to live a "normal," able-bodied life), much like the way diabetics rely on insulin. However, AS is not like diabetes; progression and prognosis vary greatly from person to person, and one's (immediate) life is not at stake without TNF inhibitors like it might be for diabetics without insulin. While one individual may suffer spinal erosion and subsequent calcification over a few months, another may go years, even decades, without obvious signs of radiographic damage.[53]

In these ways, the biomedical industrial complex ostracizes and is at odds with many of my interviewees and their positionalities. For example, Jessie, who I discussed previously, was told to just "relax" and "read a romance novel," medically informed "direction," undeniably influenced by sexism and racism. Jessie even told me, "the racism and sexism contribute to my unwillingness to go seek medical attention because I expect to be treated unfairly." They explained, "If I could see a functional medicine

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[53] While I discussed the complexities of AS as an invisible illness in the first part of this paper, interesting discourses of the literal (in)visibility of AS emerge on forums and within my interviewees' narratives as they discuss the specific kind of AS that they have. Non-radiographic axial spondyloarthritis is a diagnosis given when doctors suspect their patient to be in early stages of diagnosis, in which tissue/bone/ligament damage is not yet visible on x-rays or MRIs. Radiographic axial spondyloarthritis is the diagnosis given when noticeable changes are observed on x-rays and MRIs.

doctor, you know, a functional MD, then that would be better for me, but allopathic physicians are just all about the meds and not really treating the whole person." Building on this sense of biomedical repudiation, James said,

> Every time I ask the rheumatologists [about alternative treatments], they look at me like I'm a dickhead and they're like, alternative treatments don't work. You need to take this and when that stops working you get on to biologics and that's it. And when you try and talk about other things, they're like, you're just stupid because we've got these treatments that work.

Similarly, Max, a middle-aged white man who has dedicated a significant amount of time and money to trying different supplements to reduce pain and inflammation throughout his body told me, "I don't even bother to tell my rheum what I take. He'd either tell me to stop experimenting or think I'm insane, but what I have done really works. My pain is at a two most days when it used to be a ten all the time." Within these narratives, notions about holism and biomedicine's tendency to treat pain as an isolated object come to the surface. These interviewees appear to transgress normative desires for "good" biomedical care within biomedical frames, and are considered to engage in risky, foolish treatment behaviors with their desires to use holistic treatments. Clear "cleavages" and perspective "gaps" exist between these interviewees and their biomedical doctors.[54]

Towards Bodily Wholeness

The way interviewees articulate and construct interpretations of their bodies informs their interests in alternative treatments. Phenomenological work among chronic pain patients has identified that a "sense of bodily wholeness disintegrates and

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[54] Mol, *The Body Multiple*, 21.

individuals struggle to recreate a sense of bodily continuity in order to restore meaning to life,"[55] relating to the object/subject divisions detailed above. By engaging with holistic healing modalities, most of my interviewees strive *for* "bodily wholeness" and "continuity" in light of otherwise disunified, fragmented experiences of painful bodies. Close explications of interviewees' narratives exemplify AS as phenomenologically constructed.

Most interviewees expressed a deep engagement with and understanding of what "caused" and "triggered" their AS. This baseline knowledge informs the investment in holistic healing modalities. Many interviewees identified leaky gut as the root of their AS. For example, Lydia, a white woman in her late twenties, told me, "[understanding leaky gut] has been so, so key as well in my healing journey and it's still my biggest piece of the puzzle to try and figure out, is the gut health, and I know once I have this under control then my AS will be, you know, much better." Framing leaky gut as "the biggest piece of the puzzle" implies the inherent division and fragmentation of the body, but also its potential "solvability" in efforts to attain bodily wholeness (a *completed* puzzle). With the baseline understanding of the gut as the root cause of AS, Lydia feels empowered to endeavor in a variety of treatments, including intermittent fasting to reduce inflammation and various diets (e.g., Paleo diet and Autoimmune Protocol) to heal her leaky gut and subsequently improve AS pain and symptoms.

Adam, the naturopath, told me about self-directed research that led him to learn about the "gut-joint" connection; "I came across the gut-joint connection, that what

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[55] Becker, "Phenomenology of Health and Illness," 129.

happens in your gut can affect your whole body, and especially your joints and even your brain." By linking the functions of the gut to the joints and brain, he extends notions of mind-body connectivity and rejects Cartesian dualism. He continues, stating, "And, I'm like, *whoa*, this is what's going on with me. It's been my digestive health my whole life. That's been the problem, this is where the chronic inflammation is starting." It is the very realization and acknowledgment of *how* this inner turbulence creates the bodily experience of pain (and AS) that motivates his use of holistic treatments. Adam further explained that after learning about the way gluten "can damage the cells of our intestinal lining and how that can trigger inflammation," he "immediately cut out anything with gluten." He said,

> It's like, *oh wow*, I just cut one thing out and all of a sudden, I have a dramatic change overnight, and then, not only that, my inflammation [and] pain went down big time too, just from cutting out gluten, so that motivated me. I'm like, okay, I've got to look deeper into nutrition and the effect that it has on digestive health, but also inflammation and pain. So, I just kept researching, whether it was green vegetables, anti-inflammatory omega-three fatty acids, just by drinking enough water, how anti-inflammatory pure water can be. I just started doing those basic things; the nutrition, water. And boy … the inflammation was reduced, my pain was reduced. And I'm like, *wow.*

The immediate reduction in pain and inflammation confirmed his understanding of the gut as the root cause of AS. The notion that his actions — the food he eats, the amount of water he drinks — can directly impact his inflammation and subsequent levels of pain proves immensely and fundamentally life-altering for him. He even quit his job as a middle school teacher and became a naturopath to impart this passion for functional medicine to people with autoimmune diseases. He told me, "the foundation of my practice and my approach as a naturopathic physician is to be looking for the underlying root cause of symptoms.” With an emphasis on an internal “root cause,” acknowledging and understanding the connectivity between mind, body, and even the gut become critical. With this mindset, the ability to naturally heal the body is within the realm of possibility, contrasting the biomedical approach.

To further unpack the factors that motivate interviewees’ use of holistic treatments, I want to highlight Jessie’s narrative. Jessie explained to me that they had an eating disorder in their teens and twenties, which they believe developed as a way to “compensate for what [they] felt were shortcomings” — namely, their Blackness and their weight. They said that they saw themself “as a total failure for not maintaining a size two, which is not what [they] should be in the first place.” This led them to “binge” all of the inflammatory food that they had not had for years. Holding back tears, their voice strained, Jessie told me, “I was just so ashamed of myself and I’m like, well, I've destroyed myself … I literally created a situation internally between chronic stress and gut dysbiosis and introducing all of these inflammatory foods, it was just like, here we go.” Here, a palpable sense of self-blame surfaces. They also expressed the feeling that they “could have kept [AS] dormant for longer,” indicative of their perceived culpability. While various forms of trauma informed the development of their eating disorder, which, in turn, may have contributed to gut dysbiosis and the onset of AS, their narrative suggests that they have taken full responsibility for the disease. Through healing their relationship with food and their view of their body, Jessie attempts to use holistic treatments to fix their gut and mitigate AS symptoms.

Jessie also described an understanding that the onset of AS is linked to their personality. They explained, “Chinese medicine [says] people with Ankylosing

Spondylitis also have problems with rigidity and perfectionism. That was me from the age of ten. If it wasn't perfect, it was a failure." I could not find concrete evidence that Chinese medicine conceptualizes people with AS as rigid perfectionists. Regardless, Jessie's emphasis on their personality as a primary AS trigger is analogous to Susan Sontag's (1978) discussion of the perceived blameworthiness of cancer patients due to their personality traits (e.g., "forlorn, self-hating, emotionally inert creature[s]").[56] Sontag argues that "psychological theories of illness are powerful means of placing the blame on the ill. Patients who are instructed that they have, unwittingly, caused their disease are also being made to feel that they have deserved it."[57] She also explains that "widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility for both falling ill and getting well."[58] The notion that Jessie *caused* their AS via their eating disorder and perfectionist tendencies informs the implicit notion that they are also responsible for healing themself naturally (e.g., "I will always prefer supporting myself in the ways I can.") Jessie also mentioned their interest in a book entitled *When the Body Says No* (2003), which they told me "breaks down the emotional, mind-body component underlying [the] disease [that each chapter is about]." Jessie's interest in the psychological underpinnings of AS transforms into a weighty sense of responsibility that drives a desire to use holistic treatments.

Lydia also conceptualized an intrinsic, deep-rooted relationship between the psyche and bodily experiences of pain. As Jackson (1994) argues, the "experience of

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[56] Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), 53.

[57] Ibid, 57.

[58] Ibid.

pain is simultaneously sensation and emotion."[59] Lydia's description of the mind-body relationship echoes this; "your thoughts impact your actions and your feelings. It's related, it's a circle, and so the way you think about [AS] will impact your actions, that will impact your feelings and pain, and on and on." A circle is a compelling way to conceptualize the mind-body relationship; one that is a continuous, infinite feedback loop. Lydia also told me, "I believe there is this mental part of it, so you can make [the pain] worse the way you think … Because you have a flare, you're stressed, and then you think negatively about it, it's going to make your flare worse." Lydia clarified that AS is not psychosomatic, but her interest in the mind-body relationship informs the way she understands her pain and uses positive psychology and mindfulness to lessen its intensity.

Furthermore, by engaging with often self-directed, iterative approaches to holistic treatments, interviewees attain a uniquely intimate connection to their bodies and pain. Joy, who has AS and is also an integrative medical cannabis doctor, explained the complex process of determining the best course of AS management, including how much CBD and THC works for her body, coupled with hot yoga, foam rolling, and diet. While in medical school, she methodically journaled the way different CBD and THC tinctures made her body feel (e.g., "tingly," "sleepy"). When discussing her desire to be a medical cannabis physician, she told me, "this is my specialty because I scratched my own itch, right, this is *my pain,* and I had to figure out how to get to *the heart of it,* so [AS patients] find me." Joy continued, "I think patients with AS are the strongest patients that I know. And mostly in tune with their body, more than the average patient, because

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[59] Jackson, "Chronic Pain," 201.

the pain and the discomfort are always there, and believe me, I still have a lot of pain and discomfort.” As Joy explains, chronic “pain and discomfort” bring her patients *toward* greater bodily connectivity. By her account, the chronicity of pain and discomfort strengthens them, contrasting understandings of chronic pain sufferers as intrinsically fragmented in their bodily experiences. Within her narrative, a level of acceptance of pain and discomfort emerges.

While biomedicine chases cure and the eradication of pain, my interviewees, in their engagement with holistic modes of healing, narrate pain as a kind of extension of their bodies, bringing them towards bodily unity. For example, Jessie referred to their pain as a “constant companion,” and Max uses his pain to guide his treatment “experimentation.” He explained, “The pain indicates how my treatments are working. [My pain levels] led me to what I'm using now, the Semax for ADHD [which also helps with pain], the carnivore diet, and CBG [cannabigerol] … Now, [my pain] fluctuate[s] between a point five to a two, daily." He described the highly complex, laborious process (which he likened to spending six years working on a novel and shutting “everybody else out”) by which he has managed to decrease his AS pain and symptoms, stating, “I’m really good at making connections [about how different treatments impact my body].” As seen within these narratives, the process of lessening pain through holistic treatments is accessed through an intimate, deep-seated, and ever-shifting understanding of one’s body. Within these narratives, pain is not framed as a “culprit” in the same way that biomedicine views it. Rather, pain is a constant point of reference and something to make peace with throughout the healing process.

Ultimately, phenomenological frameworks allow entry into a nuanced discussion of AS interviewees' narratives of chronic illness and chronic pain. The complexity of expressing pain in language unearths the fragmented views of painful bodies that inform biomedical approaches to pain. Biomedical doctors push for the prescription of NSAIDs and biologics to stop the progression of AS in pursuit of cure. However, as a chronic, degenerative disease, AS foils curative end-goals. In light of phenomenological constructions of the body, my interviewees have chosen to circumvent these normative treatments and forge their own paths toward bodily unity and continuity. Their interpretations of their bodies and pain tend to center on the "root cause" of autoimmunity and desires to attend to the intrinsic relationship between body and mind. In light of this, motivations to engage with holistic approaches to healing come to the fore. Interviewees' perceptions of their bodies inform the implicit understanding that what they put *into* their bodies, how they *move* their bodies, and how they *conceptualize* their pain can holistically impact their AS, bringing them towards a restored sense of bodily wholeness.

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