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INTERNAL /EXTERNAL: LIVING WITH CHRONIC ILLNESS, PAIN AND HIDDEN DISABILITIES THROUGHOUT THE COVID-19 PANDEMIC YEARS (2019-2022)

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INTERNAL /EXTERNAL: LIVING WITH CHRONIC ILLNESS, PAIN AND HIDDEN
DISABILITIES
THROUGHOUT THE COVID-19 PANDEMIC
YEARS (2019-2022)

By

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A capstone project submitted for Graduation with University Honors

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Abstract
Internal /External

Internal /External is a collection of works embodying research related to the COVID-19 pandemic (2019-2022), that discusses perspectives of living with chronic illness, pain and hidden disabilities related to autoimmune disease. The works are a diaristic perspective regarding challenges of autoimmune disease and social apprehensions related to hidden disabilities, conditions of a body in pain and illness. The inclusion of research and data regarding the socio-economic relationships of labor and illness, healthcare inequalities, exacerbated mental health conditions within people of color suffering from chronic illness. In context of the COVID-19 pandemic this work examines the collective elevated awareness of illness, death and the global experience of divided perspectives in how we see our bodies, agency and their impermanence. This research and body of work hopes to serve as a conduit opening up dialogues related to cultures' influence on health, how illness and pain are experienced and expressed, and how myth and false information affected autoimmune communities during the COVID-19 pandemic. The culminating exhibition *Internal/ External* combines this literary and visual research to create a catalyst for equality by exposing the rhetoric of ableism and assist by bringing together stories of autoimmune disease resilience because solace is found in a shared experience.

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Dedication

“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place”

Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*

This body of work is dedicated to those who suffer, those we lost and those who mourn.

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Disclosure

Please note research began August of 2020 during the COVID-19 SARS-CoV-2 RNA virus and culminated April 2022. Research and ethnographic context is subject to ongoing shifts that change information and facts within the context of this body of work.

Internal /External
Living with Chronic Illness, Pain and Hidden Disabilities
through The COVID-19 pandemic (2019-2022)

Stuck within the confines of home, the home became the body that protected me.

The COVID-19 pandemic shifted life into the indoor space, as a collective safe space surrounding ideas and questions of what the protection and care of a body is. For populations suffering from autoimmune diseases living through the COVID-19 pandemic amplified issues surrounding the management of a body in pain. In this onerous process of living with autoimmune disease there's often many questions but no direct answers on how to find a solution to a management plan unique to your experience of pain. Similarly, no direct answers were provided in the initial COVID-19 outbreak. You had to live with this idea that depending on many variables, if you got sick your body is completely different from someone else's and that those outcomes and experiences may vary. For autoimmune populations the unseen and what is happening to you is a topic which is personal and private. Bringing the private hidden experience into the public in contexts of this body of work is a primary function. It's integral for works to allow a perspective that is unseen and dismissed which presents questions of high consideration. Social norms based on culture create systems that draw a fine line in how illness is discussed if at all. There are many reasons why illness is kept private, however in communities such as chronic illness and mental health there is stigma around sharing difficult experiences which causes harm and risks populations in need of support. This concept of living with chronic illness and laboring through has a long historical context in an ableist economy. Economy over health concerns has been the affluent opinion. Chronic illness never dissipates, it shifts how we experience living through a constant awareness of our bodies impermanence. Didion's reflection that "we are imperfect mortal beings, aware of that mortality even as we push it away, failed by our very complication, so wired that when we mourn our losses we also mourn, for better or for worse, ourselves. As we were. As we are no longer. As we will one day not be at all". Aware of these conditions, living in a body which ultimately will not/does not operate under the social

norms and conditions upheld by hegemony must be dismantled through stories and facts. Internal /External is a body of work related to the intersectionality of living with chronic illness, pain, and hidden disabilities thus imperatively providing equity and solace in the shared experience.

The term “immunocompromised” encompasses many illnesses and includes autoimmune disease. In 2022, globally, “Nearly 4% of the world’s population is affected by one of more than 80 different autoimmune diseases”(NSCF). Having an autoimmune disease entails a broad range of treatment plans to help alleviate symptoms some of them include immunosuppressants. However, due to the manner in which autoimmune disease functions treatments are variable from one person to another. Medications that are prescribed differ from one individual to another, even if you suffer from the same categorized autoimmune disease. Autoimmunity in the body itself suppresses the system thus also attributing risks.



Medicine Cabinet 2021

Wood, Plaster, plexiglass (cabinet) approx 56"x 39" x 28" Wool, tulle, cotton filament (resting mat)
8'x6' Assorted medications, sharps container, COVID- 19 SARS-CoV-2 RNA tests, COVID-19 card

In *Medicine Cabinet 2021*, a ritual space is created, a display of medications personal to my own experience with autoimmune disease. The work is performative, awaiting for the next dose to be taken. Integral to the work is the addition of my personal COVID-19 vaccination card, COVID-19 rapid test and the current medications I take as a direct action bringing attention to my experience, a way to give the audience perspective of what treating illness and pain management

looks like for the autoimmune disease populations. Specific to my experience, but common to others who live in similar circumstances. The multitude of medicines bring awareness that the experience is daunting. In taking very timed medications there is a rhythm which the body has to shift into. Ritual action of taking medication brings a sense of healing to the body even if healing (as in becoming healthy again) is not an option, the act of care to any degree as in relief in pain, or placebo effect may occur in this action of taking care of the body.

Opening up the stigmatization of medications and questions around treatment hesitancy within western medicine. In finding a balance there is trial and error which can be very detrimental to the body. Finding a solution to an ever changing range of symptoms is daunting but there is relief in the context of taking medicines that will in long term extend quality of life. Ideas of what “comfortable pain” is in chronic illness is also a component of the work. Built into the installation, is a resting floor component made from felt, cotton filament and detailed in tulle. Creating a resting place as a gesture of care and medical treatment in itself, allowing the body this opportunity.

Immunosuppressants can help the progression of the illness but cause side effects which include extreme fatigue. Balancing between fatigue syndrome derivative from the source of the illness and fatigue as effects of the medication. The National Institute of Health stated in 2022 looking back at the COVID 19 - virus: Researchers have reported higher rates of severe COVID-19 and death in people with autoimmune disease than in the general population. It is unclear whether this is attributable to the autoimmune disease, the immunosuppressive medications taken to treat it, or both” (NIH, 2022) Initial reports and headlines created fear of this uncertainty as face masks became a social norm in the pandemics initial stage. Quickly, discussions on how this would be an effective way to protect (or not) became the rhetoric, creating social apprehensions and divided opinions. One individual action that could protect populations such as the immunosuppressed became controversial.



(Image 1-2) *Easing Evidence*, 2022 Performance documentation UCR Arts Department c.2021

In my performance *Easing Evidence*, ideas surrounding hidden disabilities, social guising of illness and the materialization of it is presented. The staging and performance reveals this encapsulation of illness and brings this friction within the act of caring for the body. The use of sculptural works created as a manifestation of illness. Felt ribboning tethered to wire form, attached to parts of the body. The sculpture glides from a wheeled base referencing a mechanics creeper that is used to comfortably hold the body while working for long hours at a time. How one works on the body to fix or upkeep it. Performance at a time when opportunities to be with an audience are scarce, I find these direct actions in the performance a form of direct grounding to the reality of illness, a way to make real, tangible the covertness of it all. Isolation from others in this time as variants shifted life back and forth. Encapsulating the variants push and pull from feeling that we are going back to some state of normal only to realize how subjective that is. The experience of quarantine and illness within a home bedroom which becomes a barrier.

There's a duality of dialogues by utilizing the shadows of the sculptures in the performance *Easing Evidence*, revealing a secondary staging reminiscent of a medical room. It brings the shared experience of a doctor's visit. Shadows are activated by the body, chair and

sculpture creating a gatch bed. Calling attention to the care of a body and the specific shared experience and memory of wearing a medical gown or being sick in bed, it stirs up memories of these rooms of illness. Encapsulating the vulnerability of it, being reduced down to a patient in the same medical gown. As a population having worn a medical gown at some point in life is relatable. It holds memories of that care or time in which the body was dependent on others. The performance allowed for personal explorations and ideas behind ritual and healing as well as the intersection of how this connects with others in similar positions of chronic illness.

Obstacles and medical uncertainty in autoimmunity adds to distress living with a condition on the edge of medical knowledge. Author Meghan O'Rourke's *Invisible Kingdom* published in 2022, documents her personal experience in context of her autoimmune disease onset and journey. In her book, her disclosures bring up questions and topics related to the personal experience and uncertainty of the experience itself living with pain: I came to feel (in some unarticulated way) that if I could just tell the right story about what was happening. I could make myself better. If only I could figure out what that story was, like a child fantasy novel who must discover her secret name, I could become myself again. It took years before I realized that illness was not just my own: the silence around suffering was our society's pathology" (O'Rourke). There's a common experience amongst other chronic illness sufferers that initially the challenge is getting through medical gaslighting. How to describe the experience of pain and how to connect with physicians that would in turn assist in a manner unique to specific symptoms. Clarity on what is happening to your body is the objective to be able to have a form of validation. Some of those factors in getting answers are affected by gender.

Gender stigmas surrounding the treatment of male and female bodies continue to dominate the medical systems. Male bodies are also susceptible to chronic/immunological illness however the data is staggering leaning towards women being predominantly affected. In 2021 studies resulted in data that states:

Autoimmune diseases, such as lupus, rheumatoid arthritis, and thyroid disease, tend to affect women more than men,...noted that the rates are striking. She said that 10 women

have autoimmune thyroid disease for every man who does. In the case of lupus, the ratio is nine to one; for rheumatoid arthritis, three to one; and for multiple sclerosis, two to one. (Clouwise)

This leans towards female bodies being predominantly affected however research is sparse when it comes to women with chronic illnesses. In situations regarding pain males have been represented in research predominantly than female bodies. Stories of male complaints of chest pain in ER rooms attribute to a specific heightened response from medical staff than female counterparts. Even though women outweigh the number of heart attacks they often show less experience with pain. The CDC's page on *Women and Heart Disease* has a disclosure related to this gender disparity; the statement reads: "Although heart disease is sometimes thought of as a man's disease, almost as many women as men die each year of heart disease in the United States."(CDC) This statement in 2022 is integral in also looking at other illnesses because chronic illnesses are more complex and less researched, it's important to make note that cardiovascular diseases have longitudinal research but they include statements such as these online regarding gender bias that continue to be present.



Apillada, 2021
2001, Wood, plexiglass, ceramic, adhesive goop, acrylic
paint, photograph on adhesive vinyl print
44"x 28" base (adhesive vinyl print) Height 17"

Thoughts on experience of pain and expression are embodied in *Apillada*, Spanish for stacked. In the Spanish language nouns are gendered female or male with a few exceptions when it comes to endings in “a”(female). The title in Spanish references my cultural background as a Mexican- American and is influenced by my first language, Spanish. Using Spanish captures my experience within the work and activates a connection with other Spanish speaking populations. A particular language captures feelings and culture that are only evoked by that specific language that I find integral. The work relies on a balance of components stacked on one another to create layered sculpture. Using wood, plexiglass, ceramics and adhesive compounds (slime) that bind specific joints, portions of the work to stabilize it. The vinyl print at the base that is not depicted is an important component that stages the work. A vinyl print of photographs taken of the UCR Arts buildings is included as the base which this work lays on when exhibited. The UCR Arts building was designed by Annie Chu, Franklin David Isreal, Steven Shortage Barbera Callas. The building opened to the public on 5/11/ 2001 - this year will mark the 21st year since it was open for student use. The relationship of students in Art And Music programs using this building is important as a place that cultivates and houses the projects and ideas of future generations. I also

think of how the pedagogy of institutions like UCR influence the discussions and topics that are projected on students thus affecting culture. Inclusion of the chipped wall texture of the building connects the negative space within the sculpture to allow for many variables in what you see at a time. The photograph captures some of the distressing in the building which has a peeling surface texture that appears to have been amended and covered up. A cycle of amending it to restore. Peeling over peeling, layers of paint and texture can be seen in the buildings photograph I include as a base. Engagement from the audience is in the form in which the work is displayed. You have to circumvent the sculpture, it requires the audience to look over it and perhaps attempt to see it from floor level, forcing your body to the ground. Interaction with the work in this context further brings ideas of ritual and how we see healing and the shrine.

In 2022 the value of wood continues to skyrocket, including building materials which prompted ideas of value. Materials such as wood have significantly increased due to several factors including what American Society for Health Care Engineering (ASHE) details: that:

...although the quantity of construction projects has increased from the initial downturn at the beginning of the pandemic, the supply chain does not have the labor to keep up with the product demands. Further complicating pricing increases, the AGC reported the price of polyvinyl chloride (PVC), used in electric utility work, has increased over 270% from March 2020 to March 2021. The price increase was a direct result of an extreme winter weather condition in Texas that put a PVC production facility out of commission. (ASHE)

Thinking of this impact in our economic system and how illness disrupted labor and production structures that we rely on. Additionally there's intersectionality in severe weather and climate changes affecting production, labor and access of materials to build. In shifting how we see illness recovery and labor was initially important in the attempt to stop the spread of the COVID-19 virus and variants. Having recovery time and allotment of paid sick time coaxed laborers from coming to work sick. Coming to work sick was a social norm that has since slightly shifted away. There has been a decline since the pandemics measures were lifted. Labor and the means in which we make exchanges socio- economically have to do with ingrained ideas

that we must push bodies through because the structure of laboring demands this forcefulness on the body. There's no option for some minority populations to rest or not come to work if feeling ill.



Knots and Ableism -
2021, wood, latex, paper, oil pastels electrical outlet, found objects
Installation variable size

Knots and Ableism is a sculptural work that dissects the current socio economics related to building materials, urban sprawl, housing as protection during the COVID-19 pandemic and climate change in Southern California. Utilizing plywood, the work is supported by its learning component. Built into the work is an electrical outlet that becomes a conduit and source of connectivity that is redundant. Electronic therapy devices connect to the work and are variable from a library of devices I have collected throughout my personal experience with them. Some are effective while others are problematic in their design and purpose. The purpose for most of these devices is to provide aid. Therapy boxes which are popularly used as sleep and anxiety aids have preset sounds to relax, however I find these settings problematic. Preset sounds of fires evoke memories of wildfires that raged in California, especially the ones which occurred in 2020 which have become a normal occurrence. Important considerations about these devices is that within population increases in anxiety there have been increases in producing technologies which aid in pain relief, anxiety and depression. These increases attempting to relieve stress, anxieties, and depression are positive social changes towards riding stigma about seeking help and a great source if it functions as an aid. However, it's not for everyone and these are objects which

manipulate the body often physically or in a manner that pulls you into a different location and time through audio. I find it problematic that in assisting our disconnect from self or society we seek to further add more tech to the tech we already use. Some of the devices often guarantee a type of result which is variable on the consumers perceptions of these sounds for example fire as relaxation? It's subjective.

There are of course a variety of new technologies and devices that definitely have proven based research that would help. Apps that allow you to connect with sounds from nature or mindfulness apps, neck, foot, back massage tools to also go along with the apps you use. All for the sake of relaxing the body, relieving some of the edge of incessant anxieties. Marketing for these devices is often part of the platforms we use that are causing the stress to begin with, like social media. There is also so much we share online that there are specific marketing tactics used to sell more in consumerist culture fueled by social media. Consideration of how the objects we use to provide aid are often surrogates.



Eso Me Enseño Mamma, (Santa Ana Winds Touch my Skin) 2022
Electric baby cradle, branch, paper, latex, 54"x72"

Santa Ana Winds Touch my Skin (Eso Me Enseño Mamma), is a sound sculpture created with found objects including an electronic baby cradle. The work combines the electronic baby cradle with oak branches and is blanketed with latex paper. The work is a sound sculpture that

functions by the preset rocking component that would rock the cradle; however, I substituted it with oak branches that create a sound as they skim the floor. The stabilizing comes from the pressure of the latexed paper that blankets the work. The work brings up hegemonic motherhood and these ideologies of motherhood within the experience of Mexican-American culture. Ideas of cradles and of the role of caring for another body outside of your own. Within contexts of motherhood I think of biases and female roles vs male roles and find that culturally these toxic ideologies of how babies are cared for is passed on to future generations. Motherhood as a role but also as a social construct that assumes behaviors. In removing the gendered roles and shifting into a culture that thinks about care of others without this pretense of what that looks like. Gender disparities create further bias in health care operations related to women in pain. In addition O'Rourke's chapter *The Woman Problem* she describes how stereotypes affect women who initially express feeling pain. It is more likely to be gaslighted into being told nothing is wrong. This experience is very common in autoimmunity onset, initially to be told it's nothing and making recommendations for psychological help. The idea that it is psychological vs physiological is a common approach when it comes to female bodies in pain. The most invalidating is to believe this experience *is* invalid in your own interpretation of what you are going through because of the relentlessness in being told it's not *real*. This contributes to anxiety and mental health.

The experience of pain as unseen and dismissed is due to historical roots based on gender stereotypes that have led to creating these social conditions. These ideas surrounding female bodies and stigma:

The stereotype of the sickly woman whose disease is strictly pathological still holds today when examples in medical literature of "problem patients" are nearly always women. And so it is a truth universally acknowledged among the chronically ill that a young woman in possession of vague symptoms like fatigue and pain will be in search of a doctor who believes she is actually *sick*. (O'Rourke).

Medical gaslighting exacerbates the situations in which chronic illness and its symptoms are

ignored or dismissed. The term medical gaslighting can be defined as a way to “describe doctors or medical practitioners who blame a patient’s illness or symptoms on psychological factors, or deny a patient’s illness entirely, for example wrongly telling patients that they are not sick”. (medpedia) To be gaslighted for years is common for some chronic illness patients. Living on this edge of medical knowledge is also a contributing factor. Access to care and to the right doctor who will administer a care plan even if there’s no evidence or test to validate the experience of pain.

Accessibility of health care for communities of color that suffer from chronic illnesses were significantly affected by the COVID-19 pandemic. Minorities, which include people of color, had significantly less access to care, testing, vaccines and overall higher rates of COVID-19 reported deaths. Healthcare had been an issue but has increased significantly in relation to the COVID-19 pandemic. For communities of color, minorities, disabled - access to healthcare is difficult which means many people go undiagnosed or receive a diagnosis late once chronic illnesses have progressed. Illnesses such as diabetes can cause irreparable damages to the body. Once you receive care, access and affordability of medications affects prognosis. In addition the cost of living with these types of illnesses affects patient stress and quality of living. If you become unable to work due to disability related reasons it becomes difficult to support yourself and afford the cost of medicines and healthcare.

Measuring pain is subjective and even though we have visual tools like the pain charts that translate it visually there is no way to truly explain what the experience of pain is. It is personal and specific to our experience as human beings. The scale assists in a read of where you are, physically and psychologically. It’s a way that doctors can understand that the pain in context of the experience and it’s distress. However some types of pain cannot be clearly detected. One of those chronic illnesses that is difficult to detect is fibromyalgia. Important in the use of pain scales is that, it is more likely that female patients will be medically gaslighted than male patients. It is more likely women expressing pain will be dismissed. This is due to the underpinnings of society, the result of these gender biased perspectives that are passed on and

influence health care. Ideas surrounding trust in women are a result of what philosopher Miranda Fricker at the City University of New York has called a *credibility deficit*:

they're treated as less reliable sources of information, precisely because stereotypes cast women as untrustworthy and irrational. As a result, society's understanding of things such as workplace harassment, sexual violence and intimate partner violence is profoundly skewed, since we're *less* likely to believe reports from the people *most* likely to be affected. (Fricker)

This issue of credibility carries over onto other perspectives in our society. Gender disparity from expressing that you are experiencing pain to questioning it yourself. Some of these disparities stem empirically grounded and other factors are the social components we have come to establish as norm.

There are three major components surrounding pain which author Elaine Scarry describes as in her book *The Body in Pain*. The first is the difficulty expressing pain, the political and perceptual complications that arise as a result of that difficulty and third the nature of both material and verbal expressibility within the nature of human creation. In our difficulty to express pain Scarry states that "when one hears about another person's physical pain, the events happening within the interior of that person's body may seem to have a remote character of some deep subterranean fact, belonging to an invisible geography that however portentous has no reality because it has yet not manifested itself on the visible surface of the earth". Pains character being private and noncommunicable in ways which will prevent one individual to fully understand its manifestation in another's body. Ideas about empathy and shared feelings come to mind when it comes to other subjective feelings. I find it interesting that we speak of love or hope in manners which we regard as relatable however pain is and can be very lonely. Further, Scarry describes pain in this first *concentric circles* as "unseeable classes of objects such as subterranean plates, Seyfert galaxies and the pains occurring in other peoples bodies flicker the mind them disappear."

The second circle in Scarry *The Body in Pain* is the political and perceptual

complications that arise as a result of that difficulty in expressing pain. In thinking of how pain is political Scarry describes the way we are interconnected in the infliction of pain on another unknowingly. One of the predominant questions regarding pain in this context is “ How is it that one person can be in the presence of another’s pain and not know it... not know it to the point where he himself inflicts it and goes on inflicting it”(Scarry). Our influence in political decisions that harm others provoking pain is often something we remove ourselves from but is present in historical context of war and torture for information. We use pain as a form of control over others bodies. Media rarely reports the precise tactics in which pain is inflicted on others in instances of war, or how information that is gathered through torture and guised in ways that share it was necessary as acts to protect one country over another or one population over another. One body is more important than another, one person’s pain is more visible, or to better describe empathizable than others, when in war.

Additionally intersecting with ideas surrounding pain is Susan Sontag’s book *Illness as a Metaphor and Aids and Its Metaphor* which refers to these ideas that have shaped our views on illness. Illness can be seen many ways in society but in and during the COVID-19 pandemic the way we spoke of illness mattered. Sontag states:

My point is illness is not a metaphor, and that the most truthful way of regarding illness and the healthiest way of being ill is -one most purified of , most resistant to, metaphoric thinking... It is toward an elucidation of those metaphors and liberation from them, that I dedicate this inquiry (Sontag)

Victim blaming and how we speak of people within populations with particular diseases matters. How we portray people in these situations carrying a lot of weight for those with particular illness. During the COVID-19 pandemic stories emerged of populations of people being victim-blamed for contracting it. With this idea of victim blaming the individual making these assumptions feels relief because in their perspective you can blame the victim for making poor choices, and feel they are deserving of their fate. In th US an increase in hate crimes against Asian communities rose” The striking prevalence of Anti-Chinese prejudice led to more Asians

being targets of discrimination, and this brought the level of Anti-Asian hate crimes in the U.S. to the highest it had been in over decade”. (Gorver-Harper- Langton). Placing this anger about the circumstances around this global pandemic where blamed and pushed on people of Asian race leading to acts of violence. Subjecting to violence and causing pain or death to Asian people through bigoted rhetoric and exclusionary policies. Alice Tusi shared her experience as the Covid-19 pandemic began in 2020, “People with Asian-sounding last names not being picked up by Ubers or Lyfts, racist slurs being targeted toward any Asian people who would cough on a subway, and people moving away from any Asians with a face mask on” These types of racist situations surround Asian and Asian Americans continues to be prevalent. In sharing these stories of hate we can shift perspectives, opening up dialogues on how the experience of the COVID-19 pandemic has contributed to this bigotry.

Another aspect of illness, that’s currently being reserached is the is affects and continuing experiences after contracting the COVID-19 virus called long COVID. Suffers of long COVID experience fatigue and symptoms that included brain fog, shortness of breath, headaches, palpitations, muscle pains and other symptoms that are distressing. and dibilitating. The CDC recently stated:

As of July 2021, “long COVID,” also known as post-COVID conditions, can be considered a disability under the Americans with Disabilities Act (ADA)| (HHS.gov, CDC)

This information on the CDC website elaborates that this aids in discrimination of someone who is experiencing disability due to long COVID. There are many questions regarding long COVID that are still being researched. There’s a race to understand it and hope that there will be more research related to infection associated illnesses. This would further assist in understanding immunological responses. The experience of long COVID has affected large populations. Understanding how long COVID symptoms will be present in our society and the understaing of how difficult to navigate. Varied symptoms that range widely making it difficult ot compare one perons COVD response to another, and in long COVID In thinking of this and how to resolve issues around populations with long COVID and ideas around labor, disability when large

number of populations are being affected Our economy will continue to be affected by this wave of ongoing long term affedcts that will persist causing the body pain and disabilities.



Corner Series Installation, 2020
Documentation photos

Experience of pain is subjective based on its own composition and manifestation, but in pain visualization and guided imagery, experiences with pain can shift. Creating a visual manifestation of pain or trauma aids by its expression through sculpture and video installation. In Fall 2020, as the pandemic lingered and events unfolded, I staged a corner of my home, as pain visualization shrines. I titled the project *Corner Series, 2020*. John Hopkins Hospital describes the technique called guided imagery:

By creating images in your mind, you can reduce pain and other symptoms tied to your condition. The more specific the visualization, the more helpful it will likely be. People are taught to imagine sights, sounds, smells, tastes, or other sensations to create a kind of daydream that “removes” them from or gives them control over their present circumstances (John Hopkins)

Found objects including wood string yarn, ribboning cut from felt, balloons latex, and available home materials became sculptural works that for me at the time embodied these feelings of confinement at home. Conceptualizing how to use material bringing out its intrinsic properties without much manipulation. The use of latexed paper became corporeal. Thinking of my home which remained as a form of protection, the corners were integral because they are meeting points with supports, intersections of one space to another. I thought of the duality of this corner inverted as a back turned to its neighbors exposed. Meanwhile the interior of the corners were a point of reference to the events of 2020- 2021- some of the events that triggered the *Corner Series*.

Within stories of violence and death that occurred throughout a continued pandemic *Corner Series* led to video work *Yes, 2020* which includes poetry and staging of the same materials to express or convey the emotional states of events in 2020. Some of the events that provoked the making of this work included the detainment of Mexican families and children 2020 - , the killings of black people by police in America, the injustices around people of color and minority communities. Rhetoric around the justification of these events and tensions within my community in Redlands CA. Rallies and walk outs were scarce compared to major cities like Los Angeles. The events happened while the ongoing pandemic and risks of catching the coronavirus continued. Thoughts of Bell Hooks words: **“True resistance begins with people confronting pain and wanting to do something to change it”** from her book, *Yearning Race Gender and Cultural Politics*.



(YES, 2020, poetry/video work, 2020)

YES

YES

YES

And now... And now... And now... And now...

And now... And now... And now... And now...

We Wait...

When will relief come?

Time Takes it all

Hurry and Save

What's Left

What's Right

HOW COULD YOU?

So many of you!

The sun tans my skin

Grandmother frowns

Stay out of the Sun

Your son is in danger

No relief Now

Maybe soon ... *Do you see me?*

Historically there are lingering concepts that further add to stigmatization of pain behind what is referred to as the “female hysteria accusation”. When looking closely at this issue there is a long historical context of ideas surrounding hysteria and women:

“...It’s no accident that the word “hysteria” originates from the Greek word for “uterus.” There’s still this pervasive belief in the medical community that anytime a woman complains about her health, it’s either related to her hormones or all in her head. Female hysteria was once a common medical diagnosis for women, applied whenever women displayed “inappropriate” emotions such as anxiety, anger and even sexual desire. For centuries, it was believed that the uterus itself was the cause of a woman’s “hysterical” symptoms (Trentacoste, McNally, MD)

This misogyny stems from social norms that have carried on. Creating heightening of how women might perceive pain vs males. This was and *is* a way of control over female bodies their and autonomy.

In the 18th century ideas of what caused anxieties and or responses of hysteria in women and men were based on sound that came from the glass harmonium. Glasssharp or singing glasses were a popular instrument that originally dates back to 14th Century Persia. In the 18th century Benjamin Franklin adapted the instrument into the armonium. The instrument is recognizable by its high pitched sound that became popular and was used by composers like Mozart and Beethoven who composed music with its inclusion. The instrument was quickly considered dangerous after claims that the instrument were rumored to cause “female hysteria”, illness, pain and even death.

The armonica eventually was discontinued in use due to ongoing rumors that arose saying music produced by the machine induced madness in those who heard it. In 1798 Friedrich Rochlitz wrote:

There may be various reasons for the scarcity of armonica players, principally the almost universally shared opinion that playing it is damaging to the health, that it excessively stimulates the nerves, plunges the player into a nagging depression and hence into a

dark and melancholy mood, that it is an apt method for slow self-annihilation... Many (physicians with whom I have discussed this matter) say the sharp penetrating tone runs like a spark through the entire nervous system, forcibly shaking it up and causing nervous disorders He goes on to give some warnings: If you are suffering from any nervous disorder you should not play it...(Archiv für Musikwissenschaft)


In *What is it in a Person Lost*, the video work includes my glass harp sound compositions. The sound composition connects the history of glass harp and arnionom to current contexts in which sound is still used to aid. The video audio intersects with pain visualization therapy methods. In the process, pain visualization therapy is captured in the photo compositions of sculptures made with textiles that appear animated. Photos capture subtle movements of balloons and the latexed forms that are tethered to trees, using rope and wool. The night setting includes shots of the moon as integral to the compositions. The compositions stem from previous work *Corner Series* in which the same materials were used to create momentary shrines. This regeneration of material is important because during the pandemic materials used became a tool for communication. They became shrines and encapsulated feelings one cannot convey such as pain. They lock in time and memories of experiences. The work culminates with a scene staged where I am mourning my former self, mourning ideas about body and abilities lost. In this process there is a reframing to honor my body as is.






Judith Butler Precarious Life states:




When we lose certain people, or when we are dispossessed from a place, or a community, we may simply feel that we are undergoing something temporary, that mourning will be over and some restoration of prior order will be achieved. But maybe when we undergo what we do, something about who we are is revealed... (Butler).


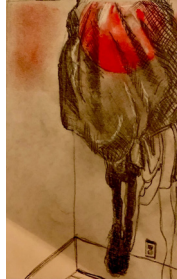




In the collective experience of the COVID-19 pandemic there have been risks and uncertainties that have revealed who we are as a society. Revealing facts and the experiences of the autoimmune communities during this time assists in a social reframing of the conditions which we are living through to achieve a more equitable society. The acceptance of the cycle



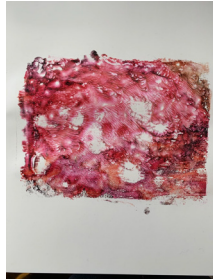


of mourning. I have to accept, mourn, accept, mourn an indefinite amount of times. As Butler explains it shifts into waves of loss for someone I knew best ...myself. I don't feel sorry for the situation but instead realize that "we are not masters of ourselves" (Butler) just simply thinking of these questions and thoughts gives hope because it connects us.

	<p><i>Apillada</i>, 2021 2021 Wood, plexiglass, ceramic, adhesive goop, acrylic paint, photograph on adhesive vinyl print 44" x 28" base (adhesive vinyl print) Height 17"</p>
	<p><i>Medicine Cabinet</i> 2021 Wood, Plaster, plexiglass (cabinet) approx 56" x 39" x 28" Wool, tulle, cotton filament (resting mat) 8' x 6' Assorted medications, sharps container, COVID-19 SARS-CoV-2 RNA tests, COVID-19 card</p>
	<p><i>No Transmission Medium</i> 2021 Wood, chalk pastels, aluminum and copper rods, contact mic, violin bow cables, amplifier speaker 46" x 2 31.5" x 2 4x4s Width</p>
	<p><i>Internal External: What is it in a Person Lost?</i> 2020 Wood, hinges, plaster, acrylic paint, light fixture, bulb 82" x 92" (expanded)</p>
	<p><i>Eso Me Enseño Mamma, (Santa Ana Winds Touch my Skin)</i> 2022 Electric baby cradle, branch, paper,</p>

	<p>Yes, 2020 Video</p>
	<p><i>Buying 2020 2020</i>, Video</p>
	<p><i>Bodies/Slow Happening</i>, 2022 Video</p>
	<p><i>Recess</i>, 2020 2020 Photograph</p>
	<p><i>What is it in a Person Lost?</i>, 2022 Video</p>

	<p><i>Corner Series</i> Installation 2020 Wool, yarn, tulle, balloons, latex, paper, string, felt Documentation photo</p>
	<p><i>Corner Series</i> Installation 2020 Wool, yarn, tulle, balloons, latex, paper, string, felt Documentation photo</p>
	<p><i>Corner Series</i> Installation 2020 Wool, yarn, tulle, balloons, latex paper, string, felt Documentation photo</p>

	<p><i>Corner Series Installation</i> 2020 Wool, yarn, tulle, balloons, latex, paper, string, felt Documentation photo</p>
	<p><i>Corner Series Illustration 1</i> - 2021 Chalk pastel, charcoal on paper (Corner Series) 2.5"x 4"</p>
	<p><i>Corner Series Illustration 2</i> 2021 Chalk pastel, charcoal on paper (Corner Series) 2.5"x 4"</p>
	<p><i>Being Rather than Doing,</i> 2021 Collage on paper, pencil drawing 2021 16.5" x 26"</p>
	<p><i>Assisted Rest</i> 2021 Collage on paper, pencil drawing 2021 18" x 22"</p>
	<p><i>ts Not Rest When the Body is Still, but the Mind is Ruminating</i> 2021 Collage on paper, pencil drawing</p>

	<p><i>Knots and Ableism</i> - 2021, Wood, latex, paper, oil pastels electrical outlet, found objects Installation variable size</p>
	<p><i>Imagery of moments remembered for a lifetime</i> 2020 Canvass, ink, lamp (installation size variable) Canvass extended 60"</p>
	<p><i>Untitled</i> 2020 x 8 Monoprints - (from Imagery of moment remembered for a Lifetime)</p>
	<p><i>Miles of Labor</i> 2022 latex, paper 48"x52"</p>
	<p><i>Corner Rose (Corner Series 2020)</i> 2020 Rose branch, roses and felt 39" (variable)</p>



Resilient Forms,
2020
Medications, burlap, tulle, wood
Installation



Experienced and Expressed
2022
Canvas and acrylic installation0

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