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Chronic Livelihoods:

The Social, Political, and Economic Impacts of SARS-CoV-2 on the Chronically Ill

by

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LIST OF ABBREVIATIONS

| | |
|--------|--|
| SEP | Socio-Economic Position |
| CDC | Centers for Disease Control and Prevention |
| PCC(s) | Post-COVID Condition(s) |
| RA | Residents' Assistant |

Abstract

Chronic Livelihoods:

The Social, Political, and Economic Impacts of SARS-CoV-2 on the Chronically Ill

Thesis Abstract--Idaho State University (2023)

The threat the COVID-19 pandemic presents to chronically-ill individuals is multiplex: economic precarity, bodily risk, and biopolitical violence endanger wellbeing. Using multi-modal data gathered from a series of semi-structured interviews, this research explores the various modes of livelihood labor enacted by the chronically-ill in the intermountain US during the COVID-19 pandemic. Results demonstrate increased socio-economic pressures due to the fiscal expenses of chronic illness management and the pandemic's impact on the economy. However, chronic labor extended well beyond the market: increased vulnerability engendered social labor through 'mental contact-tracing' and the hyper-regulation of social and clinical landscapes. More, chronically-ill participants were forced to politicize their own livelihoods in response to the institutional disregard for chronic illness within pandemic policy. Imagining chronic labor beyond the body allows for a richer understanding of the chronic experience, for which centralized research is needed. Moreover, the liminality that exists as we transition into the 'post-pandemic' provides an opportunity to reflect on disproportionate risk. While many have progressed past the pandemic into socioeconomic renewal, biological, socio-political, and economic inequity continue to threaten the lives of vulnerable populations.

Keywords: Chronic Illness, COVID-19 Pandemic, Livelihoods, Labor, Pandemic Politics, Chronic Illness Work

Chapter One: Introduction

Reaching a global ‘critical moment’ (Han, 2012) in late 2019, the COVID-19 pandemic emerged, acting as an incendiary event that severely exacerbated pre-existing socioeconomic inequity. It quickly became evident that government preparedness failed to account for the multidimensionality of the pandemic: specifically, the economic, social, and health inequalities that compounded the virus’ effect, amplifying the adverse experiences of marginalized populations. While some nations implemented immediate lockdown policies that sacrificed economic prosperity in order to protect population health (Ecks, 2020b), many western states favored a neoliberal approach initially, prioritizing a free market (Han, 2012). However, with rising mortality rates, the United States and United Kingdom governments were forced into a belated lockdown (Ecks, 2020b; Tooze 2020; Tooze, 2021). The delay was costly. Inflation and job precarity threatened livelihoods across social, cultural, and economic divides, while infirmity and death threatened chronic lives. Restricted access to care (Manderson & Wahlberg, 2020), increased risk and exposure (Sabatello et al., 2020; Manderson & Wahlberg, 2020; Fonesca & Fleischer, 2021; Topriceanu et al., 2021; Ecks, 2020a), and pre-existing socioeconomic precarity (Booker et al., 2020; Witteveen, 2020) compounded the pandemic’s effect on marginalized communities’ lives. The chronically ill experienced overlapping forms of COVID risk through bodily, socio-economic, and political vulnerabilities.

1.1 How were ‘chronic livelihoods’ affected by COVID?

Chronic illness management takes a toll: bodily, fiscally, and socio-emotionally. By exacerbating pre-existing inequities and introducing new vulnerabilities, the COVID-19 pandemic threatened chronic livelihoods. Just *how* chronic livelihoods were affected by COVID received little attention within academic and political spheres. In pursuing this line of inquiry, I

aim to holistically characterize the chronic experience of the pandemic within the intermountain US, and elucidate the mechanisms with which chronically ill individuals protected their livelihoods amidst the pandemic. The bidirectionality between chronic livelihoods and health characterizes the chronic experience of COVID-19; health is economically and politically determined, and livelihoods embodied. It is within this intersectional domain that chronic individuals experience the pandemic.

1.2 What barriers to health did the chronically ill face amidst the pandemic in the Intermountain West?

For the chronically ill, ‘making a living’ includes pursuing endless medical and pharmaceutical care. The COVID pandemic overwhelmed clinics and hospitals, upset supply chains, and created scarcity. The mechanisms and extent of limited care access is an integral question in understanding livelihood impacts among the chronically ill. In asking “What barriers to health did the chronically ill face amidst the pandemic in the Intermountain West?” I interrogate the structural inequities that create vulnerabilities within chronically ill communities.

Chapter Two: Literature Review

2.1 Pandemic Vulnerability: exposure, risk, and recovery

While the impact of COVID-19 has been immense, it has not been uniform. COVID-19's multisystemic pathway of infection is much more likely to cause protracted symptoms or fatality in hosts with pre-existing chronic health conditions (Ecks, 2020; Manderson & Wahlberg, 2020). Pre-existing health conditions are compounded by the socioeconomic and political context they are situated within (Manderson et al., 2016b). The pandemic operates within this intersection of vulnerabilities, creating multiple forms of risk for these communities. Such risk comes in the form of increased infection, mortality rates, and ever-increasing long-term health effects. One of the strongest predictors for COVID-19 mortality is the existence of chronic illness prior to viral contraction; subsequently, socioeconomic disadvantage is highly correlated to co- or multimorbidity (Ecks, 2020b). In this way, the pandemic has demonstrated Weber's concept of *Lebenschancen*; quality and access to care is dictated by one's "economically determined social class" (Grøn & Meinert, 2017, p.169). The working and living environments of low socioeconomic status, as well as restricted access to adequate healthcare reduce positive health outcomes. Economic poverty both precedes and follows health poverty: a process that increases the risk posed by COVID-19 immensely.

Similarly, the pandemic's effect on the U.S. economy led to large numbers of COVID-19 cases and deaths. Individuals with lower socioeconomic position (SEP) are less likely to have the means that are required to cease working in public facing places of employment and to quarantine when exposed or ill with COVID. Moreover, lower SEP is associated with jobs that increase exposure (Garimella et al., 2021). In this way, the (in)ability to follow CDC regulations becomes class-determined; the "public health practices around masking, washing hands and

physical distancing, while necessary to reduce the risk of contracting the virus, have little resonance with the living and working conditions” in which populations with pre-existing vulnerabilities live (Garimella et al., 2021, p. 201). Pandemic health status thus becomes a result of interactions amongst SEP and vulnerability.

Not only is there the risk of a COVID infection, but each infection actually increases the risk of long COVID, as the scientific community is just beginning to understand the complexities of this process (CDC, 2022b; Jayadevan & Sashidharan, 2021; Higgins et al., 2020). As researchers across various sub-disciplines within medicine work to demystify SARS-CoV-2, long-term effects of COVID-19 are appearing with increasing pace. Post-Covid Conditions (PCC) (CDC, 2022b) include viral “persistence, sequelae, and other medical complications” that can affect a wide array of bodily systems (Lopez-Leon et al., 2021, p. 1). Individuals that had contracted COVID-19 were more likely to experience neurological symptoms, such as headaches, anxiety and depression, seizures, or tremors (Xu et al., 2022; Steenhuisen, 2022). Patients that experienced more severe symptoms of COVID-19 show abnormal CT scans of their lungs, even after a year of ‘recovery’ (Kanne et al., 2022). The extent of long-term effects is largely unknown; the distribution of long COVID on different populations, especially those with pre-existing vulnerabilities is even more so unexplained (CDC, 2022b). It is now known, however, that sequelae and chronic symptomology is associated with both comorbidities and reinfection (Ecks, 2020; Manderson & Wahlberg, 2020; Bowe et al., 2022). The chronicity of COVID-19 is thus proving to be the result of the dynamics between “social organization, economy, and politics,” wherein these institutions “interact with pathogens and biology to determine the epidemiology and chronicity of a disease” (Manderson et al., 2016b, p. 138). In

order to maximize prevention and treatment methods, the various mechanisms that shape differential experiences of COVID-19, acute and long, must be determined.

The disproportionate impact of the pandemic upon vulnerable communities is well established (Ecks 2020b; Manderson et al., 2021; Sabatello, 2020; Manderson & Wahlberg, 2020; Coetzee & Kagee 2020). The asymmetrical patterns of communicability and fatality demonstrate the varied experience that COVID-19 creates among different demographics. Individuals suffering from chronic infirmities experience compounded social, economic, and health effects as a result of the emergence of the SARS-CoV-2 virus. Increased risk of contraction and mortality, restrictions to essential medical care, and intensified self-isolation asymmetrically endanger chronically ill communities. How this affects chronic livelihoods and subsequently, overall wellbeing, remains largely undocumented. For this reason, this study will describe the lived experience of COVID among chronically-ill individuals in the US Intermountain West.

2.2 Chronic Livelihoods and Pandemic Repercussions

‘Livelihoods’ is used herein simply to refer to the various ways in which individuals and households make a living (Miller, 2019). Livelihood health determines wellness far beyond economic security, for the economy is socially-embedded (Granovetter, 1985). Rather, as Ethan Miller eloquently articulates it, an economy is “neither a force nor domain, but rather a relational space of sustenance, a normative aspiration built around the specificity of people and place. It is a composition of habitat, the enactment of livelihoods” (2019, p. 150). The COVID-19 pandemic affected many livelihoods across the globe, but the United States’ economy was hit critically, the impact of which was felt most severely by populations with pre-existing vulnerabilities (Fonesca & Fleischer, 2021; Booker et al., 2020). The jumbled political response-which will be discussed

in more depth later- to the coronavirus pandemic resulted in a severe economic recession, rivaling that of 2008, though the pathways of economic decline took decidedly different forms:

“The coronavirus pandemic ushered in quarantines, mask mandates, product shortages, business closures, and businesses scrambling to figure out new ways to keep their doors open” (Roman et al., 2022, p. 1).

While the Great Recession ultimately began within the fiscal system, the pandemic recession occurred as a result of the policy response to the pandemic’s biological threat (Canfranc, 2020). In 2020, the World Health Organization (WHO), International Labour Organization (ILO), Food and Agriculture Organization (FAO), and International Fund for Agricultural Development (IFAD) released a joint statement, addressing the economic impacts of the COVID-19 pandemic on livelihoods. Said statement determined that an estimated half of the global workforce was put at-risk for losing their livelihoods as a result of the pandemic (2020). However, the presented figures underrepresent the economic crisis experienced by many populations.

Livelihoods have been impacted by the pandemic spanning across all socioeconomic boundaries; yet, those with pre-existing socioeconomic precarity bear the brunt of the economic recession. The ways in which livelihoods are adversely affected are as diverse as the modes of livelihoods themselves. Lockdown measures prevented many workers from their means to live (Garimella et al., 2021), with workers in the informal labor market and those with job precarity being especially vulnerable to losing their livelihoods (Fonesca & Fleischer, 2021; Garimella et al., 2021). Further, livelihoods are adversely affected by the pandemic through economic pressures enacted for hygiene procedures and prevention measures; The economic burden of masks, alternate transportation, sanitization products, inflated commodities, and supply

deficiency fell to the public (Krauss et al., 2022). Yet, how and to what extent the pandemic recession affected chronic livelihoods remains relatively unknown.

Amidst the economic recession that is adversely affecting general livelihoods, individuals with the pre-existing economic precarity that accompanies chronic condition-management experience multiple threats to their livelihoods. Pre-pandemic figures establish that individuals with chronic illness are more likely to experience poverty than their healthy counterparts (Jan et al., 2012; Booker et al., 2020; Manderson et al., 2016b). Specifically, chronic illness is associated with a significant reduction in weekly working hours (Booker et al., 2020) and increased capital spent on medical treatments. In general, exploratory research, one interviewee discussed the ramifications of having a chronic condition upon their working capacity:

CY (Author): Were there any days where you had to stay home because of your chronic illness?

SL: Absolutely. I actually take quite a bit of sick days for my chronic illness. Sometimes getting to work is just not possible.

Factoring in the pandemic, with precarious job security and threat of exposure, exacerbates the stress these communities experience. SL continued, discussing the stress their combined paid time off (PTO) and sick leave induced amidst COVID ‘scars’: “what will happen if I run out of time?”

The pandemic “triggered unprecedented changes affecting healthcare (which shifted to prioritize COVID-19 patients) and socioeconomic dynamics (caused by restricted movement, changes to work patterns and remuneration, and unstable housing)” (Topriceanu et al., 2021, pp. 6–7). In this way, the coronavirus pandemic exacerbated the economic pressures on chronic communities by limiting supply: With the inundation of healthcare facilities with emergency

cases of COVID, outpatient appointments, procedures, and surgeries were postponed indefinitely, or patients avoided visiting healthcare facilities for fear of infection (Manderson & Wahlberg, 2020). Quantitative analyses revealed that the chronically ill were two times as likely to have canceled or postponed healthcare appointments whilst also being twice as likely to need a higher level of care, with multimorbidity increasing adverse effects (Topriceanu et al., 2021). Ayo Wahlberg summarizes the single-mindedness of healthcare during the early stages of the pandemic: “What we are seeing is a globally unprecedented redirection of priorities and resources towards the containment and treatment of one condition, at a time where more people than ever before... are living with and dying from a multitude of conditions” (Medical Anthropology, 2020, 0:00:15–0:00:29). As such, this study aims to describe the context of how economic policies and pre-existing biosocial vulnerabilities coalesced to shape chronic experiences among a group of chronically ill individuals in the United States’ intermountain west region.

Microeconomic studies, and subsequent policy, often isolate an economy from its socio-political and cultural context. However, economic anthropology, and subsequently this study, present the economy as entirely socialized. Individual social status and social interrelationships are inseparably entwined with economy (Gibson-Graham et al., 2013; Granovetter, 1985; Miller, 2019). This concept of social ‘embeddedness’ (Granovetter, 1985) acknowledges the impact of economy on sociality, and vice versa. Individuals act in response to various social, cultural, and political stimuli, not just economic incentives (Peterson & Isenhour, 2014). Neoliberal policy and capitalist means of production reshape individuals’ and communities’ social relationships (Granovetter, 1985), chronically ill individuals more so than most. These individuals already occupy non-standard socioeconomic niches; a part of living with chronic illness is “restructuring

social and economic activities and relationships” (Manderson et al., 2016b, p.145). Following capitalistic dispossession, individuals are ‘desocialized’ (Besky, 2013) from their existing social networks.

2.3 Pandemic Biopolitics

Just as illness and SEP interact to synergistically produce health outcomes, so too do illness and sociopolitics (Fonesca & Fleischer, 2021). Broadening Singer’s (1996; 2009b; 2013) term ‘ecosyndemic,’ to include large-scale economic policy and its interconnected health outcomes provides a new lens with which to view the pandemic: COVID risk and infection interacted with the United States’ political response, manifesting in particular forms of ill health. While the pandemic has become the characterizing cultural event of the early 2020s, the temblor felt by the global population was years coming. Rather than observe the pandemic crisis as a singular catastrophe, we should approach “2020 as a comprehensive crisis of the neoliberal era – with regard to its environmental, social, economic and political underpinnings” (Tooze, 2021). The COVID-19 pandemic as experienced by chronically ill communities was the product of synergistic interactions among ecological, political, economic, and biological domains (Singer, 1996; 2009b; Singer et al., 2021). The United States’ response to the pandemic was the result of policy negotiation amongst biopolitics (Foucault, 2001), necropolitics (Mbembe, 2019), and neoliberalism (Navarro, 2020; Tooze, 2021; Ecks, 2020a). These policies increased vulnerability exponentially.

The coronavirus economic recession was primarily caused by the United States’ response to it. The populations affected most severely were those with pre-existing vulnerability, like the elderly and chronically-ill. Compared to the HIV/AIDS pandemic wherein men-loving-men (MLM) populations suffered disproportionately, or the 20th century Spanish Flu pandemic,

wherein the disproportionate mortality rate amongst the labor force caused economic collapse, the COVID-19 economy is resulted from the early triumph of capitalism over biopolitics, followed by a left turn into radical biopolitics after the health system was overrun (Ecks, 2020a). The neoliberal status quo was disrupted by the extreme stress placed on the healthcare system, with the U.S. government turning to radicalized biopolitics in order to preserve population health (Ecks, 2020a). The negative impact radical biopolitics has on economy led to a fast return to neoliberalism (Ecks, 2020a). However, in Ecks' great battle of neoliberalism versus biopolitics, the violence inherent in biopolitics is left unaddressed (2020a). Biopolitics governs life through the protection of the social body by enacting a biosocial hierarchy, through which the governing body 'lets live or lets die' individual bodies, based on their socioeconomic value (Foucault, 2001; Rouse, 2021). The United States Government's deferred biopolitics compounded the bio-economic vulnerability of marginalized communities. This type of pandemic biopolitics does not serve the population as a whole, but rather engenders a hierarchy of who deserves to live (Foucault, 2001; Rouse, 2021). In this way, biopolitics in the time of COVID converges with necropolitics (Mbembe, 2019; Fonesca & Fleischer, 2021). Necropolitics was conceptualized to address more contemporary forms of control over life, death, and the in-betweens (Mbembe, 2019) that traditional biopolitics (Foucault, 2001) fails to. The ways in which chronic illness and COVID-19 intersect, including Post-COVID Conditions and Long COVID, influenced by State policy, are examples of this.

Not only did the United States' neoliberal policy coincide with biopolitical policy in targeting pre-existing socioeconomic vulnerabilities; neoliberal policy created pandemic vulnerability at the state-level, as economic globalization and the privatization of healthcare hobbled transmission-reduction responses. Globalization, and its spread of neoliberal and

economic austerity policies, reduced the response capacity of its governments (Navarro, 2020). Unregulated globalization increases international mobility-of both labor forces and commodities, thereby increasing communicability, while significant cuts in social services increase popular vulnerability to contraction, communicability, mortality, and economic crisis (Navarro, 1989; 2020). The fluctuating policy the United States enacted in response to COVID-19 demonstrates the varying logics that dominated politician and population opinion during the pandemic. Such logic is influenced by “tempo,” and allows “for the incorporation of new information that is constantly being added, embodied, and acted upon in concert” (Cartwright, 1998, pp. 252-253). In this way, the flow of time, with its associated sociopolitical, biological, and economic movement, informed U.S. pandemic policy. The industrialized and privatized healthcare system in the United States was unprepared for the preliminary influx of COVID-19 patients (Geyman, 2021; Navarro, 2020). From the outset of the pandemic through early 2020, the Trump administration employed a ‘negationist’ stance (Fonesca & Fleischer, 2021; Abutaleb et al., 2020) in order to preserve the free market economy in the U.S. The public were told that “the productive workforce would acquire immunity” (Tooze, 2020) by retaining socioeconomic normalcy. However, when the human and economic consequences of the pandemic’s death toll could no longer be negated without increasing risk, the U.S turned to radical biopolitics, which resulted in a brief, yet severe economic recession. This recession, while short-lived, acted upon pre-existing economic vulnerabilities. Mid and upper-class populations experienced mild economic stresses while livelihoods with pre-pandemic precarity were threatened more severely (Booker et al., 2020; Fonesca & Fleischer, 2021).

Chapter Three: Methods and Theory

3.1 Methodology

Subjectivity, often problematized scientific disciplines, is actually *necessary* in anthropocentric pursuits, as the human experience is, by its very nature, subjective. This is not to say that subjective accounts are necessarily “more accurate reflections of underlying bodily reality” than that of other scientific accounts, but rather human subjectivity should be “thought of as phenomena having potential epidemiological significance, especially when similar subjective accounts come up repeatedly in any given group of people” (Lock & Nguyen, 2018, p. 92). Thus, a phenomenological study is necessary in order to become versed in the lived experiences of the socially vulnerable, and to accurately evaluate how best to ameliorate the adversity the pandemic has created for these individuals. A core goal of this study was the thick description (Geertz, 2008) of the lived experiences of chronically ill individuals. As an underrepresented and underserved population, it was imperative that participants retain agency over their narratives. As such, methods were established with phenomenology in mind.

3.11 Positionality Statement

In the spirit of research reflexivity, I acknowledge the role of my own experiences within both the design and carry out of this study. Therefore, I present the below results as one of many possible interpretations for these individuals’ experiences, based on my perspective as a young adult with chronic illness. The lived reality created by these interacting identities allowed me to engage meaningfully with my participants. Other overlapping identities of privilege—whiteness, economic security; and disadvantage—non-heteronormativity, femininity—shape epistemological paradigm and authorship as well. The shared membership with my participants is not viewed as a framework vulnerability, as the myth of scientific objectivity characterizes

researcher involvement, but rather as a step towards prioritizing emic perspectives in anthropocentric research.

3.12 Population Sampling

The sample for this study was defined by the existence of one or more chronic illnesses, an age within the range of eighteen to twenty-nine years, and residence within the US intermountain west. Fulfillment of these demographic requirements were established solely through self-report. Study collaborators were recruited through a combination of networking and targeted advertisement. Contacts at on-campus resources, such as ISU's Counseling Center and ISU Disability Services, as well as local medical facilities that could inform their clients of the research opportunity were sent study and PI contact information.

3.13 Semi-structured Interviewing

As the first in a series of interviews, collaborators participated in a brief, semi-structured interview over Zoom. Interview one focused on gathering oral data from interviewees regarding their overall experiences during the pandemic, with an emphasis on economic security and health outcomes. During this interview, a general interview guide was used in order to elicit interviewee narratives. The interview guide addressed interviewees' livelihoods through proxies regarding occupation and workplace COVID hygiene regulations, ability to maintain housing, ability to attain necessary medications/medical equipment, and access to needed care. Ethnographic interviewer's notes were taken during each interview, and audio recordings were transcribed using Otter.ai programming. After transcriptions were completed, audio recordings were deleted to ensure collaborators' anonymity and privacy. The resulting anonymized transcripts were coded qualitatively using the Hyper Research program, implementing an integrated inductive-deductive technique (Blair, 2015; Fereday & Muir-Cochrane, 2006). Codes were generated from

interviews as well as from the author's theoretical approach. Intercoder reliability (Schensul et al., 1999) was ensured, as all data was coded by the Primary Investigator, the author.

3.14 Ethno-timelines

Following the completion of the semi-structured interview, interviewees co-created interview two: the ethnographic timeline. Interview two included the researcher-participant partnership constructing an 'ethnographic timeline.' Prior to meeting for interview two, participants were sent instructions for media discovery (Appendix A). Participants, following these instructions, curated a file of multi-modal media that was either created or consumed during the pandemic, defined for this study's purposes as between the years 2020 and 2022. During the second meet, the collaborators' media files were presented using screenshare programming, discussed, using photo elicitation methodology (Wentworth, 2017), and then placed in chronological order along a template timeline. Using interviewees' verbal descriptions, media files, and ethnographic observation, the 'ethno-timeline' was constructed to demonstrate chronically-ill individuals' temporal experience of the pandemic.

Each timeline was constructed using the online software, *Sutori*. Images, primarily in the form of social media screenshots, memes, and cellphone photographs, were ordered chronologically and assigned brief descriptions. Videos were significantly less common, but TikTok videos and other consumed media were arranged in the same method as still images. Other forms of media were arranged on a case-by-case criteria. For example, [*Ethnotimeline 004: "Vel"*](#) displays a Spotify link to artist Orville Peck's song, "Roses are Falling" adjacent to a screenshot image of my collaborator's Spotify Wrapped (an annual summarization of users' type and quantity of music streamed), wherein the aforementioned track is listed as "#1" in "Your Top Songs" (004). This particular artist is significant to this individual's experience of the pandemic:

not only was listening to his music comforting during quarantine, and the associated socio-emotional turmoil, my participant and their partner were forced to skip attending a concert due to contracting COVID (004). Each piece of media is matted on a white background, while the socio-politically significant landmarks identified by the author are layered in red. Broad markers for culturally-significant emergences of COVID variants are displayed on a green background. This allows for the visual-schematic juxtaposition of institutional versus individual experiences of the COVID-19 pandemic.

3.15 Limitations

Two notable limitations affected this study. First, due to limited time and resources, the sample size of this study reduces its impact. Results, while providing rich, ethnographic data, are not accurately extrapolated to broad populations. Second, the demographics collected from participants demonstrated a lack in ethno-racial diversity; While gender and sexuality were diversely represented, participants were primarily white. In this manner, further research with non-white chronic individuals in the Intermountain West-and beyond- is needed.

3.2 Theoretical Approach

The analytical framework employed in this study is a patchwork paradigm, drawing on the theoretical corpora of critical medical anthropology, environmental anthropology, economic anthropology, and the intersections that lie therein. At the core of analysis is the co-constitutive role biological and social processes maintain in (re)producing the lived realities of the chronically ill. The interactions between social and biological forces code individuals' and communities' lived experiences of illness, economics, politics, and the intersections therein. This interactionist framework is necessary for the understanding of how chronic livelihoods were affected by the pandemic.

3.21 ‘Syndemics’ and ‘Local Biologies’

Critical medical anthropology’s ‘syndemics’ model (Singer, 1996; 2009b; 2013; Singer et al., 2021) provides a basis for understanding the relationships between health, disease, and social environment. Epidemics can only be fully understood when the “synergistic nature of health and social problems facing the poor and underserved” are examined in tandem (Singer & Snipes, 1992, p. 225). Approaching socioeconomic inequity and disease as separate epidemics hinders amelioration of both, for contemporary public health is pervaded by “complex health problems resulting from the interactions between epidemic diseases... and harmful endemic social conditions” (Weaver et al., 2016, p. 435). The socioeconomic aspects of social vulnerability cannot be removed from the biomedical; “the black-boxing of the biological, human body and its marked separation from historical, social, and political events is inappropriate” (Lock & Nguyen, 2018, p. 92). Further, the varied patterns of COVID’s effects must be observed and analyzed within their own context. In this way, framing the social and epidemiological concerns of SARS-CoV-2 infection as part of local biologies allows researchers to examine both aspects of the biosociality of the virus (Lock & Nguyen, 2018). And SARS-CoV-2 *is* a social disease. Applying a syndemics framework to the pandemic relates COVID-19 as “complex multi-system clinical syndrome” to social conditions, such as poverty, and multimorbidity (Ecks, 2020, p. 493). Such a diversified etiological approach is needed, wherein biochemistry is implicated in sociocultural structures and vice versa. This study expands Singer’s (2009b; 2013) ‘ecosyndemics’ model from the ecological to include the economic; The author examines the synergistic role of the pandemic and economy on chronic lives and livelihoods.

Pandemic experiences, with all the pathogenic, economic, and political aspects, are a biosocial product, for “biological and social processes are inseparably entangled,” and as such,

our “individualized embodied experience of these processes are inevitably contingent” on the environmental, linguistic, social, and political contexts within which they exist (Lock & Nguyen, 2018, pp. 90-91). Thus, the sociocultural processes that delineate socioeconomic class intersect with the biological processes that constitute wellbeing; “Social organization, economy, and politics...interact with pathogens and biology to determine the epidemiology and chronicity of a disease” (Manderson et al., 2016b, p. 138). It is in this way that ‘local biologies’ (Lock & Nguyen, 2018) are conceptualized within the bounds of this study. Chronic illness intersects with COVID pathology; contraction of COVID intersects with livelihood vulnerability. This study frames the chronic experience of COVID-19 as a product of social, biological, and economic environment. Essentially, ‘local biologies’ (Nguyen & Lock, 2018) situates ‘syndemics’ (1996; 2009b; Singer et al., 2021) within specific contexts for the purpose of maintaining the different experiences of the pandemic at the individual and institutional levels. In this way, this study’s use of Singer’s ‘syndemics’ (1996; 2009b; Singer et al., 2021) models, in combination with Nguyen and Lock’s ‘local biologies’ (2018) informs the author’s analysis on chronic livelihoods by allowing multi-level, biosocial interpretation.

3.22 ‘Penetrations’ and Social Reproduction

‘Syndemics’ (Singer, 1996; 2009b; Singer et al., 2021) addresses lived reality as a product of the interaction between biological and social forces. Within the scope of this study, the former focuses on the pathogenic properties of chronic illness and COVID while the latter centers labor economics. In tandem, the two interactionist theoretical perspectives provide an analytical framework suitable for an inherently biosocial issue. Social reproduction theories attempt to explain the maintenance of the modes of production, and its workforce (Marx, 1867; Cashbaugh, 2021; Vidal et al., 2018). The focus of this study, in regards to social reproduction, is

on the reproduction of labor power within the US pandemic economy. The increasing neoliberalization of the US has created what Fraser calls the ‘social-reproductive contradiction’ (Fraser, 2017). The forms of subsistence required in order to access labor power are being deprioritized, which impacts the reproduction of labor power in the working-class populations (Marx, 1867; Fraser, 2017; Cashbaugh, 2021). The pandemic threatened social reproduction. After an initial crisis for US neoliberalism caused by “the problem of ‘unexploitability’ – the inability to exploit the labour-power of a significant share of the population – it has not been a crisis for all and has not undermined the core working principles of neoliberalism” (Mezzadri, 2022). The US’ neoliberalization of healthcare, a necessary form of subsistence upon which labor power is founded, created structural vulnerabilities that led to the loss of labor power through the mass infirmity, mortality, and quarantining of vulnerable individuals (Marx, 1867; Cashbaugh, 2021; Navarro, 2020). Traditional social reproduction theories fail to fully address ‘pandemic neoliberalism,’ the intensification of neoliberal logics that resulted from the pandemic (Mezzadri, 2022); “It is not a case that the pandemic, whose deadly effects were amplified by neoliberalism, generated a hike in the incomes of the super-rich; a fall in income for labouring classes; and a deepening of economic, social and existential inequalities,” but that the pandemic exacerbated these symptoms of neoliberalism (Mezzadri, 2022). Pre-existing neoliberal logics worsened the pathogenic properties of COVID while the pandemic deepened neoliberalism in the US (Mezzadri, 2022). The worsening socioeconomic inequity the US is currently experiencing originates with capitalist logics, not the pandemic. However, the pandemic’s effect on the socio-economy necessitates new ways of thinking about economic inequity. Through disembedding workers from social networks (Granovetter, 1985), dispossessing labor power (Cashbaugh,

2021), and deprioritizing subsistence (Marx, 1867; Cashbaugh, 2021), the pandemic deepened neoliberal logics.

Upon this shifting stage, a class struggle takes place. The chronically ill grapple with the policymakers within governing bodies such as the CDC, local, state, and federal governments, as well as their employers. The conflict between the chronically ill and policymakers leads to social ‘penetrations’ (Willis, 1981) wherein the state’s devaluation of chronic lives are revealed to the chronically ill. In this way, ‘penetrations’ serve the chronically ill both to unmask the “conditions of existence” as chronic laborers as well as to act as a form of resistance (Willis, 1981, p. 3). However, “the tragedy and the contradiction is that these forms of ‘penetration’ are limited, distorted and turned back on themselves, often unintentionally, by complex processes ranging from both general ideological processes” (Willis, 1981, p. 3). I utilize this conceptualization of ‘penetrations’ to two ends: first, in order to demonstrate how neoliberal logics pervaded pandemic policy and culture, which led to the chronically ill’s implementation of pandemic counterculture. Second, to explain how chronic ‘penetrations’ exposed institutional biopolitical (Foucault, 2001) and necropolitical (Mbembe, 2019) logics and protected chronic livelihoods from pandemic risks; yet, ‘penetration’ simultaneously re-embedded chronic livelihoods within the neoliberal capitalist enterprise that predicated the exploitation of their labor-power to begin with. In doing so, I address the processes through which chronic labor was ‘subjectively understood’ and ‘applied objectively’ (Willis, 1981, p. 2).

Willis argues that penetrations are limited by one’s own submersion in their culture, thereby unable to evolve into radical class consciousness (1981). Moreover, these limitations engender freedom by affirming the working-class identity and empowerment through rebellion, eliminating the need and possibility for change (Willis, 1981). However, in this study, I employ a

model of ‘penetrations’ that does not limit ‘penetrations’ to failed revolution and the maintenance of the status quo. This neo-traditional model refocuses dialectical materialism; conditions of life are produced through the contradictions in class relations and labor (Marx, 1867). Chronic realities during the pandemic are determined by ‘penetrations’ and their interactions with both chronically ill and policymaking entities. Therefore, ‘penetrations’ are not simply coping mechanisms enacted in order to avoid class consciousness, but radical acts of micro-revolution through which the chronically ill transform their labor-power. This model is further supported by the expansion of ‘penetrations’ into the digital domain. Social media provides working class populations with powerful tools for unionization, resource dissemination, and outreach. This can reduce the power employers and others with ownership over the means lever over their employees in order to reproduce the capitalist structure. So, in this way, digital ‘penetrations’ do hold significant potential for radical class consciousness (Marx, 1867; Willis, 1981). It is from this conceptualization of labor, political power, and class that the ethnotimeline methodology arises. Digital, multi-modal data regarding enactments of chronic labor-power, visual representations of ‘penetration,’ and chronic perceptions of ‘pandemic neoliberalism’ (Mezzadri, 2022) are integrated in order to portray the lived experience of pandemic living with chronic illness. Participants’ consumption and recirculation of political messages on social media is one example of digital ‘penetration’ (Appendix B).

Chapter Four: Results

4.1 Bodily Impacts

The COVID-19 pandemic affected chronic livelihoods in many, interrelated ways. Social, economic, and political vulnerabilities intersected to create new, compounded forms of risk for chronically ill individuals. This section discusses the bodily impacts that chronically-ill individuals experienced during the pandemic, and their effect on overall chronic experiences.

4.11 Symptom Overlap

The biological pathways through which pre-existing illness and the SARS-CoV-2 virus interact remain predominately unidentified. However, the experience of comorbid COVID and chronic illness demonstrates a clear intersection. Many of my collaborators, with various pre-existing conditions, detailed exacerbated symptomology. This symptom overlap is experienced entirely different between individuals, however. For James, the overlap meant increased discomfort and pain whilst recovering from COVID. James discussed with me how his ADHD, in isolation, increases his sensitivity to stimuli. So, when his contraction of COVID flooded his body with pain and fatigue, it was a compounded experience:

“Experiencing pain and being overstimulated the entire time, was exhausting. Like, my, just tolerance was extremely low. And so it was, it exacerbated things for sure” (007).

For James, the overlap between his chronic illness and COVID compounded to create a heightened pain experience; However, another one of my participants, Cora, experienced symptom overlap in an entirely different manner. Cora deals with chronic muscular pain due to her pre-existing illness. As such, her tolerance to this type of pain is increased. So, when Cora contracted COVID, the pain was consolidated rather than compounded:

“Because I deal with so much general chronic muscle pain because of my channelopathy [diagnosis], I think I was more used to that part of it than my- the rest of my family. So, I experienced that. But it wasn't more than I was used to. Neither was the fatigue” (006).

The difference between James’ and Cora’s experiences with COVID symptomology is resultant of the different social, economic, and biological environments within which COVID was contracted (Lock & Nguyen, 2018). Beyond the different diagnoses-Cora’s channelopathy and James’ ADHD-the different social environment each individual finds themselves in engenders different health outcomes and illness experience (Singer, 1996; 2009b; Singer et al., 2021). The specific interactions that occur between pre-existing pathologies and COVID cannot be predicted and often, is obfuscated by chronic symptomology.

“COVID especially ramps up people's symptoms” (003). Margo’s experiences during the pandemic proved doubly insightful, as an individual with chronic illness who also worked as a healthcare provider during the pandemic. Margo showed me the other side of the curtain, so to say; symptom overlap affects not just the quality of health in chronic patients, but also their care. Caring in the time of COVID was complicated as overlapping symptoms exacerbated and obscured chronic symptoms. Margo remembers the confusion and fear that the overlap between neurological degenerative symptoms and COVID symptoms caused in Parkinson’s patients under her care, as well as their providers. She told me how the loss of smell and taste were associated with both COVID and Parkinson’s, as well as increased tremors. Patients and providers feared a rapid increase in the course of Parkinson’s, but it turned out that many cases were in fact caused by the contraction of COVID (003). The clinical hierarchization of illness acuteness contributed to this type of diagnostic confusion. The prioritization of COVID and

COVID symptomology that resulted from ‘pandemic neoliberalism’ (Mezzadri, 2022) created a clinical-cognitive bias that adversely impacted chronic care.

4.12 Extended Recovery Period

Additionally, contraction of COVID with pre-existing comorbidities extended the length of recovery. While the author recognizes that the guidelines produced by the CDC (2022a) regarding the timeline of COVID recovery was based upon a standardized body and evolving scientific literature, those with chronic illness consistently demonstrated recovery periods that extended far beyond public health and employers’ expectations. Each individual I spoke to reported an extended recovery or persistent symptoms after contracting COVID. CDC guidelines regarding quarantining indicate that recovery can occur within a span as short as five days (CDC, 2022a). However, COVID illness narratives with my collaborators proved these guidelines to be overly conservative, with many individuals remaining ill and testing positive for several weeks (coding notes). This exacerbated the disembedding of chronic workers during the pandemic (Granovetter, 1985). James discussed how his employers at the time of his contraction expected him to be able to return to work within a few days, yet James continued to feel ill and test positive for fifteen days after his original diagnosis (007). Margo told me about the appearance of PCCs in her patients, how “COVID can create more lasting problems,” compounding chronicity both by generating new pathogenic processes and exacerbating pre-existing ones (003). COVID sequelae stress chronic bodies by acting upon pre-existing chronicities, which can lead to biological, economic, and political ramifications for these individuals. In our discussion, Clem also felt as though he was experiencing PCCs or Long COVID:

“I’d say lung capacity definitely feels permanently altered, or long term altered. Myself that made the people I’ve talked to seem to feel that way” (002).

To date, the full suite of PCCs remains unrecognized by researchers and clinicians.

Margo, Cora, and James' illness narratives exemplify the chronic COVID experience as a product of 'local biologies' (Lock & Nguyen, 2018); while each experienced the convergence of chronic illness and covid symptomology, the difference in environments, internal and external, engendered diverse pathologic experiences (Lock & Nguyen, 2018). These localized, bodily experiences were compounded by embodied socio-political interactions as well (Singer, 1996; 2009b; Singer et al., 2021).

4.13 Access to Care

Ability to access care is essential for those with chronic illness. Regular correspondence with clinics, counselors, pharmacies, insurance provers and their intermediaries are commonplace among the chronically ill. However, the pandemic introduced a hierarchy of need based on acuteness into the care domain. Care is an essential aspect of the social reproduction of labor-power (Cashbaugh, 2021; Fraser, 2016). However, the great contradiction of capitalist society is that the social reproduction processes that allow capital accumulation are undermined by unfettered accumulation (Fraser, 2016; Marx; 1867). The pandemic deepened this disjunct through hyper-neoliberalization of healthcare (Navarro, 2020; Mezzadri, 2022). A host of barriers resulted, obfuscating chronic care. In attempts to slow transmission and preserve supply, healthcare centers implemented restrictive policies. These new 'hoops' made getting care increasingly difficult for my study participants. James explained how his local clinics and healthcare centers had extremely restricted accessibility. Location, patient status, and facility funding all played a role in accessibility; James described many clinics keeping their client lists closed to new patients during the pandemic to prevent transmission (007). Clem, James' partner

and another one of my collaborators, elaborates on the extensive process of trying to get care during the pandemic:

“You had to pursue a bunch of phone calls and phone numbers to figure out what office you would be allowed to go seek care, which is not always like, guaranteed that you could find a way there, get there effectively, when you feel like shit” (002).

Early on in the pandemic, Vel experienced a health scare outwardly unrelated to their chronic illness, which led to them having to go see a provider amidst high infection rates. The influx of COVID patients at the time worried Vel, who feared going in could end up being worse for their health, were they to contract COVID:

“I had to go to the emergency room because it's a sign of stroke. The left side of my face stopped moving the muscles weren't moving. And so, I was really frustrated because I was trying to call my- I was trying to call any doctor, I was trying to be like, ‘can I just do it over telecom?’ Because at the time, you know, ever it was brand new and I was really freaked out about having to go to the emergency room during the pandemic because I didn't want to be exposed, but I had to go. They were like, ‘No, you can't do it. You can't not go’” (004).

As COVID cases rose, at- and over-capacity hospitals and clinics were forced to prioritize emergency cases over chronic cases, which led to many chronic patients being transferred to telehealth modes of care. The wave of COVID cases that flooded healthcare facilities during 2020-2021 was due, in part, to negationist policy. The Trump administration's prioritization of neoliberal policy, translated through low compliance in masking and distancing, resulted in high transmission rates for which healthcare centers were unprepared (Ecks, 2020a; Navarro, 2020). Early unpreparedness resulted in the inundation of medical facilities, which subsequently de-

prioritized chronic and non-emergency health events (004; Manderson & Wahlberg, 2020). More, the pandemic's deepening of neoliberal logics in the US fueled hierarchal care delivery (Mezzadri, 2022). While Vel would have preferred virtual care due to COVID risk, many individuals felt as though it was not as effective for them. Cora explained to me how virtual care is suitable for some of her care needs, but not all:

"I had to do everything virtual. So that meant for my counseling, my other doctor's appointments, everything. For the counseling, I did not like that so much. But for like the doctors and stuff, I actually did kind of prefer it for some because I always find waiting in the waiting rooms very stressful" (006).

James reflected Cora's sentiments on virtual care, telling me how he has never actually met his provider in-person:

"I never met with this person in person ever. All of them were moved online. So, we may wish we're in person. But, yeah, I never ended up seeing people in person, everything's online" (007).

Effective care for chronic illness is built on longstanding provider-patient relationships (Fox & Chesla, 2008). In cases like James, the pandemic prevented individuals from receiving quality care for their chronic conditions. The pandemic affected James' care in many ways: not only was he deprived of an effective patient-provider relationship, but also his ability to obtain his prescription medication was impaired. When I prompted James to tell me about any problems he may have encountered in obtaining the supplies he needed to manage his chronic illness, I was wholly unprepared for his response.

Author: Did you notice that there were, you know, like, shipment delays or just any other kind of problems with getting the treatment you needed?

James: Yeah, there, especially during the pandemic, began the national Adderall shortage. So, because of what type of controlled substance it is, only a certain amount can be made and delivered to each pharmacy. However, the pharmacies can take on as many people as they want, who need that prescription, but if they run out, they're not allowed to bill anymore. And so, people go without their prescriptions being filled because it's over-prescribed...and I ended up not being able to get refilled because of the shortage. And then because I ended up having to go off of my meds cold turkey, and I just never went back on them” (007).

Unable to get the medication his providers had deemed necessary for the management of his illness, James simply went without: This is a clear example of negotiation between the political-economic regulation of pharmaceuticals, physiological necessity, and socioeconomic ability, driven by neoliberal logics.

4.2 Economic Impacts

This section highlights the primarily economic pathways through which chronic livelihoods were endangered during the pandemic, including mechanisms both enacted and experienced by the chronically-ill.

4.21 Livelihood Threats

“And so actually, I ended up losing both my jobs right at the beginning of the pandemic,” James began (007). Fortunately, James was sitting in the office that his current, stable job provided while he spoke to me about the hardships the pandemic caused for him financially. Paying for sessions with providers and clinic visits on top of medication costs were a heavy financial burden:

“It ended up being like, \$300, \$350 a month in medications, visits and checks and things, and so the fact that I have rent, and these payments and the responsibilities of being an adult, and having to pay for that, it got really hard and really stressful” (007).

At his next job, he was still living paycheck to paycheck when he contracted COVID. His employer’s policy regarding sick leave was not accommodating:

“So the expectation, if you got COVID was that you just wouldn't be scheduled. And therefore, just wouldn't be paid” (007).

Since James was testing positive for fifteen days, he missed almost an entire month’s worth of pay (007). In order to exchange labor-power for capital, James needed subsistence, in the form of care (Fraser, 2017; Cashbaugh, 2021). However, ‘pandemic neoliberalism’ deprioritized chronic care, leaving James unable to maintain his livelihood, leading to new debt (Mezzadri, 2022).

When I asked how his work life compares now, he replied:

“Yeah, I would even say it's not over. I mean, I still am like, financially recovering from debt taken on in the pandemic, which is hard” (007).

The long-term financial ramifications of the pandemic present a serious hazard for chronic livelihoods. The conditions that created pre-pandemic economic precarity remain, and the increased debt taken on during the pandemic heightens vulnerability to future crises.

Grey suffered similar financial struggles after being put on furlough. In March of 2021, they had been furloughed indefinitely (001). Grey had to apply for unemployment and the CARES Act, which luckily allowed them to maintain housing and medical treatment (001). The ‘what ifs’ did weigh on Grey, who told me “Without those, I would have been in a very tight situation” (001). Grey’s employer held similar leave policy to James’ wherein employees carried the majority of the fiscal loss associated with COVID contraction. COVID time up to two weeks

was allotted, but required quarantines due to possible contact was taken out of this time. Grey recalls the stress this policy created:

“So, it definitely was a little scary for some people to have to take those days when it wasn't their fault. And they weren't actually positive. And knowing in the future, if they did get it, they would have less days for recovery” (001).

More, policies like that of Grey and James’ employers do not account for the extended recovery period that many individuals with chronic illness experience.

Clem made the transition from undergraduate to graduate student during the pandemic. He was working as an RA during his senior year to offset the costs of school and housing when the pandemic first hit. His position, and therefore housing, was terminated. Scrambling to find housing at the time “was almost impossible” (002). Clem told me he and the other RAs “had to fight [University Housing] for a couple extra weeks to transition into summer accommodations” (002). Clem still needed a job, despite the rampant insecurity that accompanied the high infection rates in 2021:

“Yeah, I mean, in-person work from 2020 to 2021 was the high infectious rates. However, I still needed a job. So, I worked as a summer intern at a museum for a summer children's program. So that's working with like, 50 kids every single day, for like, 10 hours a day” (002).

The pandemic introduced economic pressures that required a balance of livelihood risk versus reward. With economic precarity, Clem was forced to work in a high-risk position. Economic necessity out-weighed safety, and Clem was forced to work with increased stress due to his vulnerability to the virus.

4.22 Environmental Risk Management

The lack of uniform and enforced regulation of pandemic hygiene resulted in a disproportionate socio-economic responsibility and labor being bore by the chronically ill. Due to their increased vulnerability, chronically ill individuals had to compensate lax institutional policy with heightened risk management mechanisms in occupational and clinical environments. In this way, the ‘chronic homework,’ the labor carried out by the chronically ill outside of the medical domain to manage their illness, was increased (Mattingly et al., 2011; Manderson et al., 2016a) At the time of our interviews, the majority of my participants worked in non-public facing occupations; however, many discussed a transition from higher risk, public-facing jobs during the course of the pandemic (004;002;007).

Grey worked as a lab technician during most of the pandemic. We talked extensively about how they managed the risk of being an essential worker; Grey was required to be in-person for their work, and due to economic pressures, could not afford to not work. Their stress increased tremendously.

“Because you're going to work, and then you're going home, and it's kind of this and you don't do anything else, you can't do anything else, but you're still have to go to work”
(001).

This tradeoff between medical and economic security was common among my participants. For Vel, personal security was a priority. When job hunting in the midst of the pandemic, they opted to apply only for work from home (WFH) positions; “I was not applying anywhere that required in-office” (004). This opportunity cost extended beyond occupational environments to clinical ones. During one of our meetings, Grey told me about the de-prioritization of non-emergency appointments during peak infection periods, explaining:

“Some of my doctors set up virtual visits, which were very helpful due to a lot of clinics wouldn't even let you come in. If you didn't, if you weren't physically ill. So, it was a little scary to know that, you know, if I needed to go in if I needed questions, it could be longer process. And I definitely put off doctor's appointments, dental appointments, things like that. Due to COVID restrictions and just COVID scares” (001).

Even after infection rates decreased and local regulations began to relax masking mandates, social distancing, and quarantines, clinics did not feel safe for Grey:

“During the last little portion, this last year, I think, both CDC and federal regulations been almost completely abolished, has made it easier to get care, however, definitely still doesn't feel, you still feel at risk going into these clinics and knowing that infection rates are still skyrocketing, but the most you see is masks being required in certain areas. And even now, I've seen nurses and doctors who aren't wearing masks. So, it definitely doesn't give you the warm fuzzies to go in and get the care you need” (001).

Environmental risk management demonstrates a ‘penetration’ of chronic laborers’ social conditions (Willis, 1981). In delaying care and avoiding employment in high-exposure settings, the chronically ill recognize the cultural devaluation of their lives while also enacting resistance to this message. However, these mechanisms can actually reify status quo labor relations by reducing chronic labor-power through restricted care as well as through economic precarity (Willis, 1981; Fraser, 2016). These forms of risk management are an extremely taxing enactment of chronic livelihood labor that further disproportionate impacts on the chronically ill.

4.3 Socio-political Impacts

The COVID-19 pandemic became highly politicized in the United States. Mask mandates, quarantines, and vaccine compliance became politically-charged. Pandemic practices became political practices.

“It was very political. You could look on a map and you could see where people were getting vaccines and it was very much politically based. So there was a big blue circle...where people were getting vaccinated, and everywhere else out of that people who are not getting vaccinated. Right. And as far as values go, I think people who have people in their life with chronic illness did value it more. But I think unfortunately, it became construed with political values, which is so fucking stupid” (004).

Pandemic practices became political practices. Below, I review some of the ways those with chronic illness were impacted by these socio-politics.

4.31 Hyper-regulation of Socio-medical Landscapes

Adjacent to risk management, a common political mechanism for protecting livelihoods among my collaborators was the extreme regulation of the landscapes they occupied. The social and medical environments, in particular, were hyper-regulated in order to mediate risk. Grey described to me a division amongst their working community, between those who were playing it safe and those who denied the pandemic’s threat. Grey limited their social activities outside work to a group they trusted, that valued their safety:

“Yeah, I mean, everyone that I spent time with outside of work, was very responsible, and making personal sacrifices as well as just trying to be as safe as they possibly could for themselves on their families” (001).

Grey regulated their social environment by excluding certain individuals and including others, on the basis of individuals’ and their own social groups’ socio-political practices.

In order to protect their livelihood, Vel conducted a similarly exclusionary sociality during the pandemic. Vel described to me a specific manifestation of social hyper-regulation: mental contact tracing:

“I have been doing contact tracing mentally, in my head, the entire pandemic. Like, who's hanging out with who, like, before I would hang out with any of my friends. I'd be like, hey, what have you done the last couple of weeks. And I felt like an asshole for because a lot of people were just ready to be like over it. But I was pretty uptight about who was in my bubble and who was in their bubble” (004).

Vel's 'mental contact tracing' is not as odd or uncommon as it may sound. As readers, many of you will have received or know someone who received a call from the local public health center: a contact tracer investigating potential routes of transmission. Chronically ill individuals were conducting similar investigations inside their minds. In the face of increased vulnerability and limited institutional regulation of shared landscapes, the chronically ill individuals must take on an increased socio-political workload in order to protect their livelihoods and health (Mattingly et al., 2011; Manderson et al., 2016a). Mental contact tracing and restrictive sociality in this way demonstrate pandemic counterculture (Willis, 1981). Popular politics and culture characterized pandemic hygiene as anti-American; masking stifled freedom, quarantining destroyed the market, and so on. In this way, pandemic safety practices became a form of cultural resistance for chronic individuals. Masking, distancing and WFH served as 'penetrations' to protect chronic livelihoods while also contending popular pandemic culture's depreciation of chronic lives (Willis, 1981).

My participants enacted similar hyper-regulatory mechanisms within clinical landscapes. Chronic illness management often include non-pharmaceutical treatments, which are often

delivered by intermediaries through the mail system. When the pandemic hit, supply chains were disrupted. Which resulted in delays, and as James' discussed, even companies' inability to fulfill prescriptions. Cora talked about experiencing delays in receiving her treatments. Cora responded to these dangerous delays by ordering her supplies a week earlier than necessary in order to receive her treatments when she needed them (006). Navigating the labyrinth of insurance networks, healthcare providers, and pharmacy fulfillment is nebulous on the best days; with the stress the pandemic placed on the US' delivery industry, the medical supply system began to fail. Vel receives the bulk of their supplies through mail couriers. Vel and I discussed the pandemic's effect on mail delivery, which proved enlightening for me. Vel's response to their medical supplies' delay was to stockpile:

Vel: I had been doing, yeah, like mail delivery before the pandemic. And I also am in a fortunate position where I had a stock pile of supplies beforehand. So even in times where like if it would be a week or so late, it didn't really affect me. Fortunately, yeah.

CY: Okay, and your stock pile, was that something that you consciously did or was that like, a reassurance for the pandemic, or it just kind of happened that way?

Vel: It was intentional (004)

Vel continued, describing to me how they had to over-request the quantity of their supplies from their provider in order to create an emergency supply (004). In doing so, Vel avoids relying on the various supply and delivery intermediaries to provide their necessary treatment. Comparatively, Cora's preemptive ordering compensates for delayed delivery. Both these mechanisms protect Cora and Vel from the threats posed by 'pandemic neoliberalism' (Mezzadri, 2022), by circumventing treatment scarcity.

Grey, Vel and Cora protected their livelihoods by enacting regulatory mechanisms within their socio-medical landscapes. Even with these precautions, my collaborators contracted COVID. When I asked Cora about how she felt regarding her community's pandemic safety practices, she was reticent to outwardly admonish, but emphasized her personal choices.

Author: Do you know if your community had masking mandates for most of the pandemic?

Cora: Yes, they did.

Author: And do you feel like they were followed by the majority of your community?

Cora: For a little while, and then they started not being followed so much after maybe a year.

Author: Okay. And you know, like, how did that make you feel, you know, having chronic illnesses. Do you feel safe with that or not so much?

Cora: I still try to mask up whenever I can. And I don't really go out so much anymore, so I'm not really as safe as I probably could be. But I do my best to just minimize as much chance as I can (006).

In this way, Cora focused on variables she could control: her own behavior, the environments she entered. Contracting the virus, even with all the hyper-regulatory mechanisms they had enacted, was upsetting for Vel:

I was pretty upset because I work from home. I was- I'm probably one of the more careful people that I know, in my community, and I got it because my partner has to go to work (004).

Cora's micro-level approach focuses on individual responsibility while Vel's macro approach assigns culpability at the institutional-level. Despite the hyper-regulation of their environments,

my participants were unable to control their entire communities' pandemic practices, indicating structural vulnerability.

4.32 Politicized Livelihoods

Hyper-regulation of socio-medical landscapes was enacted in order to protect individual livelihoods; however, livelihoods were enacted themselves. 'Pandemic neoliberalism' (Mezzadri, 2022) became a domain wherein processes of precarization occurred under capitalism, and capital and state structured access to livelihoods (Menon & Sundar, 2019). Bodies then became political centers of negotiation between institutions, individuals, and pathology. The institutional neglect for chronically ill individuals led to the politicization of chronic livelihoods.

"A lot of people [were] floating around survival of the fittest mentality that only emphasize the word that the only the elderly and immunocompromised would be at risk, as if that is not an issue or concern for the broader community" (002).

All of my collaborators felt as though information disseminated by the CDC, their local public health, and employers were deficient; messages circulated lacked significant coverage of the chronically ill as a population, while trivializing marginalized populations' disproportionate risk, spreading the message that **only the vulnerable are being killed by COVID, and that is okay** (coding notes).

"I remember the big controversy of when there was a statistic being spouted that it was like people with comorbidities are four times as likely to contract, to have COVID complications. So, you don't need to worry about it was the public health message; it was like don't be scared of COVID, only people who are already ill are going to die....super fucked up. But there really wasn't information that was like, this is how it's going to impact this illness specifically, and there wasn't really much else done that was like, oh,

because our community has people with comorbid conditions, or it has people who are elderly, like we should be more careful. It was definitely more geared towards people who were 'healthy'” (004).

Vel responded to the inattention of chronic lives by becoming a committed media activist. They used their social media audience to increase awareness of the chronic experience of COVID-19, posting images and infographics. Further, Vel turned the chronic body into a political body: by continuing to mask and practice COVID hygiene beyond the general population, they prompted discussion and sent a political message to their community regarding the lives of the chronically ill (004). Here, Vel demonstrates an extension of ‘penetration’ (Willis, 1981) beyond the current model; Vel is engaging with resistance and recognition of chronic neglect; however, Vel is not reaffirming their own exploitation. Diverging from Willis (1981), Vel’s efforts do have potential to turn into radical class consciousness. Rather, Vel, and their audience, embody class consciousness through their circulation of political materials. More, Vel is enacting a sort of social reproduction through caring for the chronic community, digitally.

Clem discussed how all the unknowns adding up contributed to pandemic fear:

“I guess heightened fear of what COVID looks like in chronically ill body is unknown, understudied. Fear of the unknown, you don't know if it's gonna affect you more drastically, if you're going to be out of work for longer? Or if you're just going to be hospitalized, or what?” (002).

Fear of SARS-CoV-2 affected individuals across demographic divides however, was amplified within populations with comorbidities. The pathways through which COVID pathogenically interacted with pre-existing susceptibilities were uncharted, which veiled the biological threat and its associated socioeconomic ramifications. Chronically ill individuals, in this way, were

forced to reconcile increased threats with reduced data. While the lack of scientific knowledge cannot easily be remedied, public health, employers and federal organizations can provide more chronically-centered informational materials.

James, when I asked how he felt about his at-the-time employer's pandemic policies, presented his perspective on why vulnerable groups like the chronically ill were disregarded by institutional policy:

"I also think that came with what position of power they were in, because people making policy and regulation for COVID protocol and responsibilities weren't necessarily people who had to follow those themselves. And so the people enforcing that really didn't have an understanding... We understood things and acted differently" (007).

Higher-ups created company policy regarding the pandemic: paid or unpaid leave, on-campus masking mandates, WFH opportunities. However, these individuals' experiences of the pandemic were mitigated by differential resource access and proximity-in short: power. Individuals, like James, who were working in sub-managerial positions experienced pandemic risk more viscerally. The policy implemented by managers and owners and its associated efficacy and security, became embodied by workers. Such imbalances in power between populations with wildly different pandemic experiences spurred the politicization of chronic livelihoods. Chronic labor-power, within livelihoods, were enacted in response to political inattention (Marx, 1867; coding notes).

While discussing his experience of COVID, Clem posed an interesting point on the politics of pandemic vulnerability; While Clem by ADA standards has a chronic illness and disability, the CDC had not categorized his illness as vulnerable to COVID-19.

“I had a longer recovery period than most. But I mean, it's hard to say whether that's just due to the strain I had, or a lot of other factors; it's hard to say if it's due to being chronically ill. My illness is not technically under an immune compromised subset by the CDC” (002)

By stipulating what type of illnesses are vulnerable to COVID-19, the CDC further politicizes the chronic body. Despite experiencing protracted symptomology, Clem’s access to vaccines and care were limited because he was not vulnerable enough, or in the right manner, according to institutional regulation. The chronic body becomes a political site through the interactions between and amongst institutions, environment, and the “body itself,” as it is “politically inscribed and is shaped by practices of containment and control” (Brown & Gershon, 2017, p. 1). US pandemic policy enacted body politics, “subjecting the body to systemic regimes – such as government regulation,” maintaining hierarchal survival amidst COVID (Brown & Gershon, 2017, p. 1). In this way, the pandemic engendered embodied political responses. The protective mechanisms implemented by chronically ill individuals, like hyper-regulation, are subversive forms of resistance against US body politics.

The rate of success or failure of these ‘penetrations,’ hyper-regulation, environmental risk management, politicized livelihoods, cannot readily be determined. The complex nature of ‘penetrations’ (Willis, 1981) as forms of resistance, recognition, and conformity, as well as the novelty the pandemic introduced into social reproduction, complicates qualifying outcomes. Vel’s hyper-regulation succeeded in revealing their social conditions, yet failed to protect them from contracting COVID (004); Grey’s avoidance of care during COVID successfully protected their health from infection, but limits social reproduction of labor-power (001), which will ultimately affect their livelihood negatively within the capitalist society (Fraser, 2016;

Cashbaugh, 2021). As such, the role of ‘pandemic neoliberalism’ (Mezzadri, 2022) in shaping chronic experiences is undeniable: care, labor and livelihoods, and politics were all influenced by neoliberal logics and the ‘social-reproductive contradiction’ (Fraser, 2017). The inherent contradictions and interactions within capitalism generate realities; the conditions of life are produced through the contradictions in class relations and labor (Marx, 1867), while chronic realities during the pandemic are determined by ‘penetrations’ and their interactions with both chronically ill and policymaking entities (Cashbaugh, 2021). The processes within ‘penetrations’-interactions between resistance, identity affirmation, and class consciousness-produce chronic social conditions (Willis, 1981; Marx, 1867; Cashbaugh, 2021). Moreover, these social conditions interact with biological processes-interactions between pathogenesis, chronicity, and multimorbidity- to produce the lived experiences of the chronically ill (Singer, 1996; 2009b; Singer et al., 2021).

Chapter Five: Conclusions and Future Research

The threats, obstacles, and infirmity experienced by my collaborators during the pandemic were entirely idiosyncratic: Each individuals' bodily experience of illness from the SARS-CoV-2 virus was the result of localized interactions among pathology, biology, and social environment (Lock & Nguyen, 2018), which were compounded by the phenomenological products of interactionism among localized institutions, policy, and labor (Tsing, 2011; Marx, 1867). While each experience remains unique, barriers to health shared among participants demonstrate structural deficiencies, that if left unaddressed present infrastructural vulnerabilities for the future. For, "it is neglected people who have neglected diseases, and this social problem cannot easily be addressed by vertical biomedical interventions. Indeed, top-down delivery mechanisms are as likely to reinforce power relations as to undermine them" (Manderson et al., 2016b, p.141). The pathogenic and political products of COVID and chronic illness, as long as they remain neglected, pose a threat to the livelihoods of marginalized populations, and therefore to broader social integrity.

To that end, more critical and engaged research on the pandemic experiences of marginalized populations is needed. As previously stated, the economic impact, and its subsequential impact on overall chronic lives, are largely undocumented by researchers. Within the fields medicine, public health, and anthropology, the focus of pandemic-era studies has been focused on comorbidity and increased risk of contraction. However, researchers and health practitioners alike need to look "beyond individual infections to consider how they may be capacitated by the presence of other diseases and conditions and sustained by social inequity and the unjust exercise of power, which channels and sustains damaging disease clusters in

disadvantaged populations” (Fonesca & Fleischer, 2021, p. 243). Subjectivity, often scorned in ‘hard’ scientific disciplines, is necessary in anthropocentric pursuits, as the human experience is, by its very nature, subjective. It is not to say that subjective accounts are necessarily “more accurate reflections of underlying bodily reality” than that of other scientific accounts, but rather human subjectivity should be “thought of as phenomena having potential epidemiological significance, especially when similar subjective accounts come up repeatedly in any given group of people” (Lock & Nguyen, 2018, p. 92). Thus, a phenomenological study is necessary in order to become versed in the lived experiences of the socially vulnerable, and to accurately evaluate how best to ameliorate the adversity the pandemic has created for these individuals. To that end, the publication of the resulting data from this study should serve to inform advocates, academics, and local Idaho policy. Health policy research indicates that “evidence-informed health policy will be most successful if policymakers understand research methods and interpretation, researchers share their findings in accessible ways and funders adequately support research programs addressing key policy issues” (Pomeroy & Sanfilippo, 2015, p. 179). While chronic livelihoods were adversely affected by the pandemic, they were not the only casualty of pandemic socio-politics: BIPOC, women, and queer populations also experienced reduced health and social outcomes. These populations experienced a paucity of attention in both the academic and public spheres which translated into negative wellbeing impacts (Fonesca & Fleischer, 2021; coding notes). Moving forward, US pandemic policy needs to address disproportionate vulnerability and risk by drawing on phenomenological studies that center underserved populations.

In ameliorating inequitable risk, disseminating accurate and available data, with targeted population material at local, state, and federal levels is essential. The Idaho Communivax

project, working on qualitatively understanding local Hispanic vaccine hesitancy, found “that undocumented workers were concerned about going to a government-sponsored public health office to get vaccinated,” due to fear “that they would have to show proof that they were in the United States legally” (Cartwright et al., 2021). In response, the team collaborated with Southeastern Idaho Public Health in creating informational artefacts “that expressly stated that no documentation of any kind would be required for a person to receive a vaccination through their office” (Cartwright et al., 2021). This is a small-scale demonstration of targeted information dissemination, which was needed direly for the chronically ill community during the height of the pandemic.

Finally, the structural violence enacted by ignorant policy implementation necessitates that we question our social, economic, and political priorities. The impacts of COVID-19 upon chronically ill populations demonstrates a tiered chronology of violence. First, the virus itself threatened vulnerable populations through pathogenic means; increased risk of contraction, severity, and mortality rates posed bodily risks (Ecks, 2020; Manderson & Wahlberg, 2020). Next, pandemic politics created structural vulnerabilities within the US healthcare system, which longitudinally affected chronically ill individuals disproportionately; initial neoliberal priorities increased transmission while biopolitical rhetoric trivialized chronic mortality (Navarro, 2020; Abutaleb et al., 2020; Tooze, 2021; coding notes) all culminating in reduced health outcomes for vulnerable populations (coding notes). Now, as the majority of the US enters the ‘post-pandemic,’ the chronically ill are left behind to struggle with financial debt taken on as a result of the pandemic; to enact socio-political labor in compensation for institutional neglect; to recover slowly from extended symptomology (coding notes). Chronic lives in the time of COVID are produced by the interactions amongst a web of risk and response enacted by various

agents: SARS-CoV-2, US federal, state, and local governing bodies, employers, providers, and patients. Risk and negative response mechanisms can and must be mitigated, through critical research and informed policymaking.

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Appendix A

Timeline Media Discovery Instructions

1. Scroll through your phone or other device, and find photos, videos, sounds, text messages, other screenshots, memes, etc. that you took or saved during the pandemic. Try to find several from various time points- beginning of pandemic (2020), middle (2021-22) and end (2022-23).
 - a. If you contracted COVID, what pictures do you have of that time?
 - b. You may have lots for some time periods and very little from others-THIS IS OKAY!
2. Email a file folder titled TIME_00# (the number integer will be provided to you) to chyyoder@isu.edu.

Appendix B



Instagram post by user @florencepugh.makes.me.sweat with ACAB graphic, stating: “A NEW WORLD IS COMING/THERE IS NO ROOM FOR COPS THERE.” Participant 004 shared this, demonstrating recognition on the role policing plays in maintaining capitalistic status quo