

COVID'S CHRONICITIES

FROM URGENCY TO STASIS
IN A PANDEMIC ERA

EDITED BY
LENORE MANDERSON & NANCY J. BURKE

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Covid's Chronicities

CULTURE AND HEALTH

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A. David Napier and Anna-Maria Volkmann

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Covid's Chronicities

From urgency to stasis in a pandemic era

Edited by Lenore Manderson and
Nancy J. Burke

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List of acronyms and abbreviations

ALICE	Asset Limited, Income Constrained, Employed
ARV	Antiretroviral therapy
CBO	Community-based organizations
CDC	Center for Disease Control and Prevention
CMP-IHQ	Community Monitoring Platform for Indigenous Health Quality
COFS	The COVID-19 Farmworker Study
CONFENIAE	Confederation of Indigenous Nationalities of the Ecuadorian Amazon
COVID-19	Corona disease 2019, contagious disease caused by the coronavirus SARS-CoV-2.
CSC	Community Score Cards
DSEI	Special Indigenous health district
DTHF	Desmond Tutu Health Foundation
DTTC	Desmond Tutu TB Clinic
FOIRN	Federação das Organizações Indígenas do Rio Negro
FSIRN	Rio Negro Indigenous Health Forum
FUNAI	Fundação Nacional dos Povos Indígenas [National Indigenous People Foundation]
H1N1	Influenza virus, formerly known as swine flu
H5N1	Influenza A virus subtype of the influenza A virus causing influenza primarily in birds ('bird flu' or 'avian flu')
HHS	U.S. Department of Health and Human Services
HRCSL	Human Rights Commission of Sri Lanka
HRSA	Health Resources and Services Administration (USA)
ICHW	Indigenous Community Health Worker
ITCM	Inter-Tribal Council of Michigan
JPCA	Japanese Primary Care Association
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer (or Questioning).
LTTE	Liberation Tigers of Tamil Eelam
NFWM	National Farm Worker Ministry
NGO	Non-governmental organization

NOCPC	National Operation Center for the Prevention of COVID-19
PCR	Polymerase chain reaction test used to diagnose people carrying the SARS-CoV-2 virus that causes COVID-19.
PPE	Personal protective equipment
PTA	Prevention of Terrorism Act
RCT	Randomized controlled trial
RMG	Risk Mitigation Guidance
SARS	Severe acute respiratory syndrome caused by the virus SARS-CoV-1
SARS-CoV-2	Severe acute respiratory syndrome coronavirus 2, the strain of coronavirus that causes COVID-19.
Super spreader events	Events such as large social gatherings, in which an infectious disease is spread much more than usual
UFWA	United Farmworkers of America Union
USAID	United States Agency for International Development
WHO	World Health Organization

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Introduction: care, chronic neglect and intentional forgetting

Nancy J. Burke and Lenore Manderson

As we write this introduction, it is over four years since the first cases of the unidentified illness that came to be named officially as COVID-19. Now, as the pandemic moves into a non-emergent stage, we live with a slower pace of transmission and, in a subdued register, we reclaim prior forms of social life. This shift from urgency to endemicity partly relates to the success of rapid testing and the development and delivery of vaccines. Now, states have diverted funds allocated to responding to COVID-19's emergencies back into programs neglected at the height of the pandemic. With this easing back to normal, people report checking the news less obsessively, allowing their attention to turn from case tracking and mask and test chasing to other matters – some banal, and others terrifying in their impact and implications. Globally, we struggle to address the longer-term effects of the early months of the pandemic and non-pharmaceutical interventions, the continuing confusion about long COVID, the economic disruptions and the social and political fallout of lockdown. We have had a little time to reflect on how, globally and among nations, we have navigated the pandemic and assessed the public health and fiscal interventions to forestall its worst economic impacts. And we have begun to account for how COVID-19 impacted other physical and mental health states. This is a continuing story.

The epidemiological picture of the pandemic, everywhere, is still somewhat blurry. Countries varied in their capacity to detect cases and maintain and report administrative data, and people varied in their willingness to seek care in the face of counter directives to stay at home and avoid social interactions, such as queuing, that would increase transmission. And plenty of infections were asymptomatic or sub-clinical. While some things are only now becoming clear – the insidious effects

of infection on people in the longer term, for example – the social impact of the pandemic was predictable. We anticipated that those living with chronic poverty, those already experiencing poor health and those who were politically marginalized and socially excluded, would be hit hardest (Manderson and Levine 2020; Manderson and Wahlberg 2020), and so they were. Given the chronicities of inequality and poverty, therefore, for many people the pandemic was just another disruption – not the result of a ‘sudden tear within the fabric of everyday normality’ but, rather, another crisis emerging within ‘slow processes of deterioration, erosion, and negative change – of multiple traumas and friction’ (Vigh 2008, 9).

In this volume, we focus to a large extent on the experiences of people who are politically, socially and economically marginalized or ignored: those for whom crisis, as Vigh described, is ‘endemic, rather than episodic’, defying delineation ‘as an aberrant moment of chaos or a period of decisive change’ (2008, 5). Understanding how COVID-19 spread, what it exposed and what it effected has allowed us to scrutinize other social structures, states of urgency and crisis and patterns of sociality. As the pandemic made clear, structural vulnerability threatens both lives and livelihoods. Pandemics, environmental disasters, wars and other crises and emergencies all expose such vulnerability and amplify its effects. This includes people who, lacking national identity papers, are deemed simply to not exist, and so systematically lack entitlement or access to state support, programs or, in the case of emergency measures during the pandemic, financial and material aid. But the pandemic also invoked contradictions, as it still does: it led to people ‘unraveling’ at both personal and community levels, regardless of their economic status, and to the unexpected stigmatization of people who were previously embedded in communities. And, predictably, it compounded the difficulties for those living in states of chronic precarity.

As is being documented now by anthropologists, historians and other social scientists, social and political structures and their technologies of power provided countries variously with ways to respond to the pandemic and steer people through points of crisis. The public health system in many countries increased its capacity to reduce and manage cases, often through new and stronger collaborations with community organizations, and occasionally with businesses, as a result of the uneven access to resources, skilled professionals and trusted medications which hampered state responses (Manderson and Wahlberg 2020; Dinleyici et al. 2021; Myers and Liu 2022 and Heinemann and Rubenstein; Burke, Saroya and Thao, this volume). We witnessed a new round of government failings, including through heavy-handed approaches to risk

(see chapters by Akello and Jayakodi), slow and inconsistent response (Burke, Saroya and Thao, this volume) and neglect of other health conditions and infections (Manderson and Wahlberg 2020; Yates-Doerr, García Meza and García Maldonado, this volume). Hence in contrast to accounts on pandemic responses and government failings that we documented in our previous book, *Viral Loads* (Manderson, Burke and Wahlberg 2021, in which see chapters by Gamlin, Gibbon and Calestani; Bharadwaj; Pop; Alyanak; Onoma; Garimella et al.; Rashid et al.), here we explore how states, multilateral agencies, national governments, non-governmental organizations (NGOs) and communities also took anticipatory and remedial action. With this, we have gained a sense of how local communities, networks of friends and civil society were able to respond to unfolding emergencies in supplementing formal responses, and in the face of state ineptitude.

We have observed in this and prior work (Manderson, Burke and Wahlberg 2021) how the pandemic unfolded over time: the ways it allowed for the flourishing of persistent inequities, challenged scientific projections, forced state and national governments to engage in ‘hammer and dance’ responses (Pueyo 2020) and unfurled in waves of varying size and lengths (see Teruyama et al., this volume). The long engagement with uncertainty that we all experienced has posed ‘a problem of projection and action’ (Petryna 2018, 571) for scientists and policymakers, and has unsettled senses of home, place and security in different ways at various times across the globe. The persistence, variability and stasis of precarity characterized what Fassin has described as the expanded pandemic moment, the present ‘undoubtedly dilated’ (2021, 168). The pandemic has shown how surety falters ‘in the face of runaway change’ (Petryna 2018, 572).

The pandemic also posed a challenge to memory, as exhibited within the various chapters of this book. Teruyama and colleagues describe how they needed to provide a timeline for the doctors they interviewed, to remind them of what happened in which year. One participant referred to his own Facebook posts during their interview as a cue to remember the sequence of events. The young people interviewed in Lisa Hardy’s contribution shared memories ‘interwoven with awareness of injustice and structural violence; characterized by the illusion of fixed continuity in the face of constant change’. They expressed ‘painful confusion’ about how old they were then and how old they are now. These difficulties remembering the recent past conflicted with the emphasis on the present depicted in Danya Fast’s contribution. The young people she followed ‘inhabit a different kind of temporality’ in which local COVID-19 responses appeared as ‘just one more assault

that threatens to engender or deepen painful affective senses of isolation, loss, stagnation and boredom'. The capriciousness of memory, for some, enabled a convenient forgetting. As Broch and Hensler note, '(t)he public seemed to forget and marginalize the experiences of those most severely impacted by the pandemic'. Burke, Saroya and Thao argue that this form of 'willed forgetfulness', through which people return to pre-pandemic priorities despite the lessons learned about marginalization and inequity, is a privilege of the powerful that enables cruelty.

Learning from the pandemic

Understanding how COVID-19 spread, what it exposed and what it effected, allows us also to scrutinize other social structures, vulnerabilities, states of urgency and crisis, and patterns of sociality. What we learned from the pandemic translates directly to other global concerns. At time of writing these include the ethics of response to newly onset and protracted wars, new outbreaks of violence, persistent humanitarian crises and the impacts of climate change and extreme weather events. The seeming endlessness and continued spikes of infection and hospitalization, notwithstanding the different epidemiological and clinical patterns linked to differences in viral strain and drifts, have pushed state actors and publics to question the desirability of interventions and their sustainability. People have tired of restrictions, as they struggle to address both new problems emerging from the pandemic and old problems that were magnified as side-effects of the economic fallout. Chronic illness, chronic poverty, unemployment and statelessness and lack of entitlement to care, basic services, shelter and access to food and nourishment were largely ignored while states and people focused on the pandemic. But these chronic problems remain challenges, globally. In this volume, we explore the material and social conjunctions of chronic conditions – the syndemicity of everyday life – and the difficulties that states, communities and households face in addressing these in different contexts.

Our use of the term chronicity draws attention to enduring problems which interfere with appropriate, timely and effective responses in a crisis such as a pandemic. The response of states to soften the impact of loss of work and livelihoods, in countries where social welfare systems stretched to top up grants and to reach others known to be socially excluded, was a case in point. Government agencies found housing for people so as to enforce their physical isolation, an irony when people

without shelter are largely treated as invisible and experience chronic social exclusion (see Pawson et al. 2021, for Australia; Rottnek and Laxton 2021, for the United States). In Australia, for example, people who were ‘sleeping rough’ prior to the pandemic were accommodated in hotels, often finding themselves housed securely for the first time in years. In one example in South Africa, a municipal government, university and civil society actors collaborated to provide food and shelter while also managing drug dependence and introducing harm reduction strategies, after years of political resistance to this (Marks and Moodley 2022). In Canada too, as Danya Fast describes (this volume), state entities and non-governmental organizations (NGOs) worked together to limit risk of infection by COVID-19 while addressing housing needs, drug dependency and overdose risk. Likewise, generally with civil society advocacy, governments found loopholes and changed legislation to support people without formal identity documents by allowing them to stay without visas on a temporary basis, and receive financial support (EMN/OECD 2021). Governments identified resources and funding streams to support multilingual communication campaigns for languages often neglected in standard public health outreach. At the same time, while chronic social disadvantages were in some places to some extent addressed early in the pandemic, corporate concerns took advantage of this subjectivity by recruiting people into clinical trials, for small amounts of money as ‘compensation’ that were critical for everyday living (see Manderson and Levine, this volume).

In medical terms, ‘chronic’ marks the long-term persistence of a disease. It is a temporal concept, used to distinguish those illnesses or social challenges that are entrenched and seemingly intransigent from those that are acute, short term, and in some respects more malleable. In 1993, Sue Estroff argued that chronicity referred to the ‘persistence in time of limitations and suffering’ (250). Following on this work, Manderson and Smith-Morris (2010) called upon the broad and deep work of medical anthropologists documenting the health impacts of structural violence to trouble static binary understandings of chronicity, and to encourage conceptual engagement across medical anthropology and epidemiology. As they argued, ‘unexamined use of the dichotomy’ distinguishing chronic from acute diseases contributes ‘to the invisibility of suffering – specifically the lifelong suffering of persons with severe, curable diseases who cannot access good care’ (2010, 11). The chronicity of structural violence, marginalization and exclusion that underlines this differential access, they argued, maintains and produces ‘fluidity and flux’ in disease patterns across the globe (2010, 1). In essence, their

conceptual intervention eased the way for broader engagement with a syndemic approach to understanding disease burden.

The call to attend to the contexts in which diseases occur and persist, intrinsic to this redefining of chronicity, pushed researchers and providers alike to recognize the intersections of biological and biographical life (Fassin 2018, 2021). Much of the initial response to the pandemic, as we detailed in *Viral Loads*, was focused on protecting biological life. Lockdowns, social distancing and quarantining all undermined social and psychological wellbeing, but were designed to ‘slow the spread’ and ‘flatten the curve’ in a time of urgency. The concept of chronicity with which authors engage in the current volume calls attention to the biographical life that was lost or injured in these efforts – we turn to the social effects of the pandemic on individuals, families and communities as they engaged with social institutions that, at times, failed to protect them. As Fassin points out, ‘these injured lives are even more ignored than the missing ones. There are no statistics kept about them’ (2021, 170). In this volume, Yates-Doerr and colleagues argue that chronicity has a normalizing effect, making chronic conditions ‘imperceptible’ and therefore not countable; Heinemann and Rubinstein write that chronicity ‘draws our attention to the *temporal connective tissues* that link individual experience, identity and life course to those of communities, regions and nations in a thoroughly globalized world’, and Jayakodi in her contribution mobilizes the ‘insight that chronicity needs to be understood beyond the linear understanding of time’ as central to her understanding of the ‘chronicity of militarism’.

These distinctions underlie our use of ‘COVID-19’ and ‘Covid’ throughout this book. COVID-19 refers to the biological – the disease that emerged in 2019 and its prevention and treatment, while ‘Covid’ refers to the biographical – that is, the social – experience of the pandemic. So, Lisa Hardy’s contribution, for example, details the ways young people’s lives were transformed – their identities shifted and molded – by their experience of the pandemic. They are, in their own words, ‘children of Covid’. In this sense ‘Covid’ refers to the biographical life that was injured and changed by the experience of living during the time of the pandemic. We use a similar distinction in the use of ‘long COVID’ and ‘long Covid’. Claudia Merli, for example, explores the many ways the medical condition of long COVID has been depicted in Japan and Sweden, using ‘long COVID’ to refer to the persistent viral condition and ‘long Covid’ to refer to the long, dragged-out existential dimensions of the pandemic.

The counter to ‘chronic’ in diagnostic terms is ‘acute’; in social terms it may be ‘crisis’. Our invocation of ‘chronicity’ in this volume’s title

points to the endemic social conditions in which the pandemic occurred and which at times were amplified or newly produced. The word ‘chronicity’ points also to the temporal transitions (not always linear) that marked the social experience of the pandemic. The persistence of the sense of urgency and crisis – the pandemic along with coterminous environmental, social and political upheavals – requires a rethinking of crisis as momentary fragmentation to ‘condition’ (Vigh 2008, 9). In this context, we show that the COVID-19 pandemic revealed not only inequity and pre-existing structural violence, but also the chronicity of crisis as a condition of daily living: a pervasive critical state in which ‘disorder becomes the expected order of things’ (Vigh 2008, 10). Kristina Schwenkel described this as ‘the routine, fractal “always-almost-falling-apart” world’ (2015). In such states, the ability to predict, to engage in future thinking, becomes truncated. As Visacovsky argued,

Crisis situations must be understood as special cases of the experiences of time ... a discontinuity or rupture has occurred and time is perceived as ‘stagnant’, ‘stopped’, ‘frozen’. The order and the course of events assumed as ‘normal’ are altered, but not replaced by new ones. Everything seems to happen at the present time and future cannot be immediately imagined. (2017, 12–13)

The temporal effects of this crisis condition – differently experienced by marginalized and poor individuals, compared to others – inform many of the contributions to this book, and much of the writing that has emerged in the social sciences around the COVID-19 pandemic. Reflections on how time was stretched (Glade and Young 2021), moved in waves (Teruyama, Horiguchi and Kimura, this volume), and compressed in spaces (Broch and Hensler; Fast, both this volume) identify the shifts made possible when the ‘world stopped’ and highlight the privileged nature of this ‘stop’ in places where the pandemic obscured other epidemics that were contemporaneous with it. For example, in Yemen, COVID-19 was but one of many threats to people’s lives. It overlapped with what has been described as the world’s largest food security emergency, and with the largest and fastest-growing cholera epidemic since the World Health Organization (WHO) began recording cholera cases in 1949 (Peutz 2021). In January 2018, for example, more than 8 million Yemenis were on the brink of starvation and, by December 2019, at the very beginning of the COVID-19 pandemic, Yemen had reported nearly 2.2 million cases of cholera and 3,750 deaths (Peutz 2021). For Yemenis suffering these multiple epidemics, COVID-19 offered a

merciful, quick death, preferable – Peutz suggests – to the ‘slow deaths – from hunger, trauma, untreated illness, displacement, the absence of any viable future and the daily annihilation of the soul – that can inflict an even greater anguish’ (2021, 311).

This confluence of epidemics, most forgotten or ignored as the world tracked the movement, waves and variants of COVID-19, occurred in contexts of neglect, in spaces where global actors define ‘who matters and who does not, who is disposable and who is not’ (Mbembe 2019, 80). Judith Butler (2022; see also Wade 2020) argues that this neglect is a form of insidious violence issued through political, economic and legal institutions. Speaking of farmworkers like those addressed by the COVID-19 Farmworker Study Collective (this volume), Butler draws attention to the precarious housing, lack of access to medical care, and exposure to illness and death in the context of the pandemic (Butler in Wade 2020). As Butler argues, ‘these populations are considered as on their way to death anyway, not worth safeguarding, and a metric is implicitly or explicitly adopted that determines whose life is valuable and whose is not’ (Butler, in Wade 2020). This assessment of worth extends to the calculation of ‘grievability,’ the assessment of whose lives are worth grieving, while others’ lives are simply tallied as abstract numbers (Butler 2004, 2020). The ‘death dealing’ that resulted from unequal policies that jeopardize lives in favor of economic recovery is a piece of COVID-19’s afterlife that remains to be chronicled (Butler 2020, 2022). In this volume, contributors address the chronicity of structures and infrastructures through which the institutional violence of failure to communicate information about the disease and to test adequately occurred. They address, also, the refusal of some to accept this neglect and so respond through civil and communal action.

The afterlife of the pandemic

History helps us understand this new pandemic and anticipate its afterlife. The great influenza pandemic, best known by its misnomer, the Spanish flu, is dated from March 1918, when the first case was identified in Kansas, United States. By 1920, when it was generally considered to be over, almost one third of the world’s population had been infected, over four successive waves that had resulted in the deaths of between 17 million to 100 million people. In the United States, the influenza pandemic is estimated as having caused 675,000 deaths: around 5 per cent of the population. In South

Africa, around 6 per cent (350,000) of the population died in a period of six weeks in September and October 1918 (Phillips 2018; de Kadt et al. 2021). The images of the great influenza pandemic's management and effects – carts laden with corpses, overcrowded cemeteries and mass graves – are those that characterize both earlier and later epidemics, from the plagues of Europe in the fourteenth and seventeenth centuries, for instance, to Ebola in West Africa in 2014–16.

A number of lessons emerge from this. The incidence and case fatality due to the great influenza pandemic were not evenly distributed, and the summaries of illness and death are in metrics that hide geographic variation. In South Africa, case fatality of the first wave of infection, in Natal Province, was only around two to three per cent; the second wave, arguably a more lethal strain of the virus, spread by returning soldiers in the Cape Province, resulted in the estimated deaths of at least nine per cent or more of the population (Fourie and Jayes 2021). Death rates expressed as a mean, however, hide the skewing of deaths, particularly among poorer people with least access to effective care. Closer analysis shows that the distribution and lethality of influenza tracked economic and social inequalities. Age, access to information and the capacity to reduce risk of infection, related to residence and occupation, also influenced outcome (de Kadt et al. 2021, 183; Fourie and Jayes, 2021). People living in crowded areas were more likely to be exposed to the virus and so experience severe infection and die, although the primary factor resulting in death was poor access to health services. Fourie and Jayes emphasize that 'the Spanish flu not only exposed the healthcare sector's racial inequalities but exacerbated them' (2021, 16).

Despite the conventional chronology of this pandemic, influenza did not stop in or around April 1920. It had measurable long-term economic and demographic impacts (for South Africa, see de Kadt et al. 2021), and it continued to spread, morph and resurge in new epidemics. Morens, Taubenberger and Fauci write of a 'pandemic era' dating from 1918, and they refer to the complexity and persistence of the 'progenitor virus', its 'descendants' and 'lineages', characterized by 'an ever-growing family tree' (2009, 225). The influenza 'shift pandemics' of 1957 and 1968 and the pandemic-like events of 1947, 1951, 1997, 2003 and 2009 (Morens, Taubenberger and Fauci 2009, 226) were all caused by direct descendants of the viruses of the 1918 pandemic.

Viruses do not just disappear, therefore; they continue to circulate, cross species, transmogrify and re-emerge in different populations and settings. Morens and colleagues (2009) had optimistically suggested that, despite this, the severity of pandemics and epidemics appeared to

be decreasing, likely because of both evolutionary measures in the virus and improvements in health and medical care. But this is tempered: race and its coordinates – poverty, discrimination, unavailable and poor quality health services, the unaffordability of timely medical care – overdetermine who are infected, how severely and with what outcome. COVID-19 proved this point.

Biological anthropologists Jessica Dimka and colleagues (2022) identify in their comparison of the 1918 and 2009 influenzas and COVID-19 that sex, gender, race, ethnicity, Indigeneity, pre-existing poor health and disability all create interweaving profiles of vulnerability to severe infection and death. They are not alone in emphasizing inequality as the most sensitive and obvious predictor of the impact of infection; disparities in infection incidence and outcome among populations and communities derive primarily from social conditions, particularly via the intersections of socially ascribed race and poverty (Sparke and Anguelov 2012; Kondo et al. 2022). Epidemiological work in California, for example, draws attention to sharp disparities in death rates by race, ethnicity and occupation in the first months of the COVID-19 pandemic; difference in increases in mortality spanned from 16 per cent to 59 per cent for white and Latino food and agricultural workers, respectively (Chen et al. 2020).

Shaping the future

How will the pandemic shape the future? We reflect on the conversations that have opened up, not always optimistically. After each crisis – wars, environmental disasters and pandemics – countries have been enjoined to take steps to ensure preparedness. Across Africa, countries met in 2009 during the H1N1 pandemic to define and agree on the requisites for the pandemic preparedness capacity of all national governments, with the participants having the intention of working with and across sectors of government to ensure this was the case (Sambala and Manderson 2017). The same discussions for pandemic preparedness re-emerged with Ebola and, to a lesser extent, with Zika. They have re-emerged now, as we ride the long tail of COVID-19. These attempts to project and plan are designed to bring an unknown future into the present ‘as an object of knowledge and intervention’ (Petryna 2018, 573). The mutability of options is made clear when historicized, as is the challenge of making ever-changing knowledge ‘actionable and not obsolete’ (Petryna 2018, 573).

COVID-19’s physical after-effects, in the form of long COVID or some kind of post-COVID-19 syndrome, complicate management

and patient care, including for pre-existing and new comorbidities (Manderson and Wahlberg 2020). This raises questions of how social and economic precarities impair recovery from the physical and mental effects of the pandemic, and the mental effects of its prevention. Claudia Merli takes up the question of long Covid in this volume, as we address further below; the majority of authors address other effects.

The early chapters in this volume deal particularly with how the pandemic undermined a sense of personal (and community and national) security. While many populations have long lived with insecurity (or have never lived with security), Covid disturbed everyone. As we indicated above, measures to contain infection and save lives tipped social relations, household economies and access to services. In the earliest directives, people were urged to stay at home and limit social engagement. Contributors take up questions of the transformation of spaces, and from this, the redefinition of risk in homes, workplaces and shelters. Social relationships, including within civil society and between civil society and state actors, were transformed in consequence, although sometimes the pandemic simply reinforced pre-existing relationships of fear and distrust.

As a number of authors illustrate, the capacity to adhere was shaped by having a home and having a safe home. This precondition was largely taken for granted, even as there were rising reports in different country settings of increased intimate partner violence in crowded, stressed living conditions. At the same time, confinement to home has had continuing effects on young people, as Lisa Hardy describes in this book and as widely reported. The fallout is reminiscent of *hikikomori* (a form of severe social withdrawal) as documented among young people in Japan (Rubinstein and Sakakibara 2020) or *uppgivenhetssyndrom* (resignation syndrome) among refugees in Sweden (Aviv 2017). It has taken only a few years for many young people especially to lose confidence in a world beyond the confines of their homes, and to infect others with a flatness of affect, if not melancholy. This mood persists, and we find it reflected in the moods we gather from the contributing chapters; it's a mood that is reinforced, concurrently with continued infections, as we witness with growing despair the multiple sites of war and civil violence, the impending crises of environmental disasters associated with climate change, the persistence of race-based violence, and crises in government and democratic systems across the world. We have shared with our colleagues despair with the re-emergence of extreme right-wing politics, flares in anti-Semitism, anti-Asian violence and Islamophobia, the revocation of sexual, reproductive and human rights and the limits to action. Here we refer not to

‘resilience’ to minimize the trauma of Covid for some, but the capacity to think and act laterally. Many have been gripped by inertia.

A number of chapters address the changing workplace, and the ways in which agricultural fields, food production facilities and clinical spaces during the pandemic became risky settings in which safety was fleeting, assured neither by corporations nor leaders. Farmworkers continued to labor in extreme heat with minimal if any personal protective equipment (PPE), and meat packing employees stood shoulder-to-shoulder as production sped up to meet fears of reduced production capacity and viral spread. Fields and buildings became ‘topographies of cruelty’ (Mbembe 2019, 92), spaces in which individual rights were ignored or trampled. They also became sites in which care emerged or continued through pre-existing networks and processes, as illustrated by the COVID-19 Farmworker Study Collective and their co-authors, Vargas, Tapia and Smith-Morris, and Batista, Ramos and Achatz. Moral actors ensured risks were communicated in community languages, that culturally appropriate care options were available, and that workers understood changing policies and the rights to sick leave and quarantine support they afforded. These chapters trace the reactive and anticipatory actions in which communities and individuals engaged to blunt the violence of state and corporate structures.

Vaccines

The introduction of first-generation vaccines seemed to hold promise to control the pandemic, but we also learned, quickly, that viruses shift and drift more quickly than vaccines can be tweaked. In this volume, we include contributions to understand how vaccines were tested and introduced, with what social and political effects, and with what levels of uptake and resistance, but this is an ongoing task (Jansen and Auerbach 2023). Vaccines always featured in discussions of preparedness and control from early in the first year of the pandemic. Their availability and acceptability have, like COVID-19 itself, traced demographic intersections, socioeconomic status and belief systems, including of the intentions of the state itself. This was true for earlier vaccines, as evident with the variable uptake of the H1N1 vaccine in the United States (Galarce et al. 2011; Jung et al. 2013) and in Ghana and Malawi (Sambala and Manderson 2017). For despite conventional public health understandings of the power of adequate vaccine cover to contain the spread and effects of H1N1, people from poor ethnic

minority groups were often suspicious of the vaccine's safety and administration, and in any case found it unavailable at local health centers.

In this volume, Manderson and Levine describe the intricacies of efficacy testing of the Johnson & Johnson COVID-19 vaccine in a South African clinical trial. Evoking the legacy of colonial medicine, they resist a simplified reading of clinical trial participation among those who may choose to participate to gain access to medical care. Heinemann and Rubinstein highlight the role pharmacies play in rural settings with inadequate medical services. Writing of North Dakota, a state with high mortality rates and low COVID-19 vaccination rates, they describe the importance of trust and long-term relationships in contexts of uncertainty and political turmoil. Grace Akello describes the mismatch between local understandings and experiences of COVID-19 and international efforts to promote vaccination that resulted in harassment and at times 'over'-vaccination in Uganda. These contributions highlight the complexity of COVID-19 vaccine development, testing and global distribution – its prioritization in health systems and international aid organizations. Meanwhile, throughout the world, HIV, tuberculosis, malaria and other 'neglected' diseases continued to be transmitted and to cause serious illness, deaths and lifelong disabilities, particularly among people living in the poorest conditions in poor countries. For these infections, no simple preventive medication or vaccine has yet been developed. While smallpox has been virtually eradicated and its terrible effects eliminated, other viruses and bacteria (measles, mumps, polio, diphtheria), controllable through immunization, have rebounded as health systems pivoted to focus on diagnosing and managing COVID-19, and as parents declined to present children for immunization when they were otherwise urged to remain isolated and at home.

Overview

In their article in the *New England Medical Journal*, published some 15 years ago, Morens, Taubenberger and Fauci speculated,

... although we must be prepared to deal with the possibility of a new and clinically severe influenza pandemic caused by an entirely new virus, we must also understand in greater depth, and continue to explore, the determinants and dynamics of the pandemic era in which we live. (2009, 229)

This remains as true for COVID-19 now as it was for H1N1, when this was first written.

Covid's Chronicities documents the enduring impact of the pandemic on people's health, lives and livelihoods, and the chronic structural, social and health challenges that predate but were complicated and amplified by COVID-19. We also illustrate the contradictions that characterized the pandemic – its continued exceptionalism in parallel with a diffusing of urgency as other prevailing problems more immediately challenge peoples and governments.

The spread of chapters in this volume is global, but we could not be encyclopedic either in geography or theme. Everywhere the pandemic unfolded in different ways. Authors draw on ethnographic research and experience from Japan, Sri Lanka, Uganda, Vietnam, Sweden, Norway, Canada, Brazil, Ecuador, Guatemala and South Africa, as well as from various immigrant, First Nations and rural populations in the United States. In some cases, however, we failed to include contributions which we had thought important. In particular, we wanted a chapter which reflected on experiences of the pandemic in China, both because COVID-19 had its origins there, and because the harsh and determined imposition of lockdown that was reported to so effectively limit infections and deaths. But the medical anthropologists and other social scientists whom we approached lacked time to contribute, and our colleagues in China were wary of collaboration and so declined or withdrew. Other chapters, which might have geographically rounded this book, fell through, their authors overwhelmed by new workplace demands, new modes of engagement, new obligations, and sometimes by the weight of long COVID on their own health. On the other hand, many of our themes are broad and common enough – marginalization and inclusion, the persistent weathering (Geronimus et al. 2006) of pre-existing inequalities and chronic structural violence, and the side-steps around new impositions. The range of meanings of chronicity in relation to and other than applied to Covid is vast, and in this volume we take on the task of thinking this through with ethnographic contributions from varied contexts.

The pandemic transformed how people lived in many ways, and it animates our understanding of the unequal distribution of access, exposure and freedom of movement. From homes to clinics, and classrooms to worksites, individually and institutionally, in relation to movement, stasis, confinement and constraint, there have been dramatic changes. Some of these are quotidian – a warning on a doctor's clinic to wear a face mask as a new round of infection takes hold, a wary glance at the sound of a sneeze or the attention to hand washing. Others are deeply

troubling – consider the growing reports of school refusal (see Hardy, this volume); the slow accumulation of knowledge on the complexity of people’s experiences of long COVID and post-COVID-19 syndromes; the malaise that appears to saturate social life. Time intersects with place in many cases, providing a sense of shrinkage and expansion, loss and compression. When attempting to envision the future, the time after the current wave or crisis, contributors document the collapse of time, the inability to remember what happened when, in what year. While for individuals this comes across as sometimes melancholic confusion, for institutions and states we get a sense of intentional forgetting.

Chapters

Writing of Norway and Sweden ([Chapter 2](#)), Tuva B. Broch and Ida Hensler reflect on how the pandemic forced humans to relate to each other and their surroundings in changed ways, both empathic and aggressive. Repetitive lockdowns – ‘house arrest’ for whole populations – made visceral the possible cruelty of homes. The authors interrogate how feelings of home and homeliness were transformed in and by both public and private spheres. In Norway, the pandemic altered once peaceful nature paths to crowded thoroughfares, while formerly packed city streets were left abandoned and bare. In Sweden, people had the choice to stay at home or not; the gestures of individual choice encouraged seclusion only for those with a choice. As ‘safe’ symbols like the home and homeliness crumbled, unfamiliarity became a threat both separating and binding people together. And, as the authors themselves reflect, these are stories of the state and viral suppression in settings where the vast majority of people were – relative to the world’s majority – privileged, with food and shelter.

The clinic was another site of action and enclosure throughout the pandemic. Junko Teruyama, Sachiko Horiguchi, Shuhei Kimura and the Covid Primary Care Collaboration, in [Chapter 3](#), base their research on interviews with primary care doctors working at the frontlines of the COVID-19 response in Japan. Perceptions of time and chronicity in doctors’ narratives changed over the course of the two and a half years of their study. Doctors first perceived the pandemic as a transient ‘incident’ which they anticipated would be short-lived, but they then experienced multiple ‘waves’ of infections, with each wave infecting greater numbers of people. Their sense of time oscillated, as they sought for ways to anticipate future outbreaks and to allocate resources in preparation. Over time, these authors argue, doctors began to form longer-term

visions about the duration and trajectories of the pandemic and its unfolding social consequences.

The changing nature of the pandemic in these doctors' understandings impacted local experiences and public health initiatives widely. Jennifer Ilo Van Nuil and Ha Nguyen Thanh (Chapter 4) illustrate this in Vietnam, drawing on interviews conducted across the country, initially from November 2020 to March 2021 and then again from April to July 2022 with different participants. The pandemic was generally considered exceptional in its early months, with few cases and few deaths; community members highlight how experiences and attitudes changed, along with shifts in infection rates, government responses and community attitudes. As Van Nuil and Thanh illustrate, longstanding structural inequalities, changes in epidemiology and varied public health responses all impacted people's everyday experiences.

Worldwide, children's lives were transformed as schools closed, instruction ceased and computer screens (where possible) replaced classrooms. Lisa J. Hardy (Chapter 5) brings us to the United States, and to the period post Covid, identifying continuing challenges which have global resonance. When schools and other social activities closed down, young people were faced with learning to live under lockdown. Political forces dictated where and when they could leave their homes and caregivers; their teachers became immediate and constant authorities on safety and rules and the limitations of geographic and social interactions. As Hardy illustrates, young people often struggled to make sense of shifts of power, and shifts in personal relationships, space and wellbeing. For some, this has proven particularly difficult. COVID-19 regulations have shaped how young people who lived through lockdown see the world, and how they try to imagine a future that is definable and solid.

In Chapter 6, Danya Fast writes also of young people – mostly Indigenous young people, living in Vancouver with long histories of drug dependence and insecure housing, struggling with the risks of overdose and continual cycles of intervention. These issues were complicated by COVID-19. As the pandemic and its imposed constraints unfolded in Vancouver, homeless camps were emptied and young people were moved into repurposed commercial hotels and community centers and subjected to enforced isolation, securitization and surveillance. Building on her book *The Best Place* (2023), Fast illustrates how interventions responded to the declared public health emergency which occurred in parallel with potentially life-saving interventions related to drug use. The conjunction of the two largely left those subject to them with a sense of ambivalence, if not despair.

Mitigating income loss for people without papers was a major challenge in numerous countries, worldwide. This is given visceral form in [Chapter 7](#). Nefissa Naguib writes of Cairo, of her friend and interlocutor, Laila, and the impossible Catch-22 in which Laila was trapped as she tried to gain an ID number, which she needed in the absence of a birth certificate. Without an ID number and without a card, Laila was ineligible for medical care in a public hospital, public housing or processing for a property title or inheritance, and could not obtain formal employment, education and banking services. She was ineligible for a smart card to buy basic food stuffs at government-subsidized prices. At each point – including each visit to the government offices – Laila was forced to wait, suffer disregard from the men on the counters, jump through tortuous hoops and experience the endlessness of the task. Nefissa Naguib's account of the mechanisms through which people come to have no rights highlights how the societal effect of Covid was just another assault on the bodies of poor people, who remained invisible to state apparatus.

This assault has historically taken the form of under- and malnutrition for many. In the last decade – marked by the United Nations as the 'Decade of Action on Nutrition' – global health workers have organized development aid around the anthropometrics of chronic malnutrition, frequently treating height-for-age as synonymous with long-term hunger. In their discussion of Covid and nutrition in a Mam-Maya community in Guatemala ([Chapter 8](#)), Emily Yates-Doerr, Rosario García Meza and Maria García Maldonado examine how this metric-focused orientation to hunger shaped political responses to food security during the pandemic. Policymakers claim their concern with the chronicity of hunger and undernutrition among Indigenous citizens. But reliance on body measurements has kept the political focus on short-term, magic bullet treatments such as food supplements and nutritional education outreach to mothers, while ignoring the structural conditions of hunger and the failure of the state to nourish people during the crisis of pandemic. Hunger remains. The failure of policies directed at chronic malnutrition to alleviate hunger has implications for how we can understand and respond to Covid's chronicities today. Yates-Doerr and colleagues consider ways other than anthropometry that policymakers might use to evaluate and act upon hunger.

Farmworkers in the United States were designated 'essential workers' early in the pandemic and were identified as key to stave off food shortages. The COVID-19 Farmworker Study Collective (COFS) conducted a study with over a thousand farmworkers across three states

to document pandemic harms. In [Chapter 9](#), the COFS Collective, with Tomás A. Madrigal, Jennifer Martinez-Medina and Dvera I. Saxton, illustrate the long-term systemic hazards and injustices which dominate and shape Covid's added impacts. Local 'chronicities of care' derive from long histories of cooperative labor, collective decision making, and relationship-based support networks which help people deal with structural assaults. How people live and work, and are exploited, in these food and agricultural industries is not exceptional, but the model that Indigenous and undocumented farmworkers have embraced offers the possibility of empowerment and change.

Likewise, in [Chapter 10](#), Indira Azucena Vargas Guatatuca, Andrés Tapia and Carolyn Smith-Morris describe agency and community care in an affirming counter-narrative to that of vulnerability, marginalization and exploitation. Indigenous peoples in Ecuador were especially vulnerable to the COVID-19 pandemic because they were already poorly served by national and regional government prevention and treatment programs. But people drew on their own knowledge and used their own strategies to understand and respond to the pandemic, in the same way that local populations circumvented state control during other deadly epidemics and pandemics (for example, Parker et al. [2019](#)). This chapter focuses on one community of Kichwa-speaking people who comprise the Union Base community of Puyo, Pastaza, Ecuador, of which the first author is a member. Here, people took up the task to educate community members on COVID-19 prevention and care, including the creation of an accessible resource listing medicinal plants that had the potential to prevent infection and aid care for people who were sick.

Ethnographic and cinematic films have provided a partial view of people living in the upper reaches of the Amazon River, primarily in Brazil but extending into Venezuela and Colombia. The Yanomami are best known among anthropologists, but large numbers of Indigenous peoples live in the Upper Rio Negro, Brazilian Amazon. As Carolina Batista, Danilo Paiva Ramos and Rafaela Achatz describe for Indigenous peoples in Brazil ([Chapter 11](#)), Hupd'äh, Yuhupdëh, Daw and Nadëb peoples are multiply vulnerable to exploitative labor, the appropriation of their land and deforestation of their forests, economic exploitation and extreme poverty and multiple potentially fatal vector-borne diseases and other health and social problems, including interpersonal violence, alcohol misuse and suicide. The COVID-19 pandemic was one new assault that highlighted both the value of communal approaches to healing and the challenges to engagement with regional health care resources.

Heather Howard-Bobiwash, Danielle Gartner and Madeline Nash ([Chapter 12](#)) turn to postpartum mental health among Indigenous women in Michigan, who are at elevated risk for postpartum depression and anxiety. Asking how COVID-19 shifted women's mental health concerns, they identify the supports available to Indigenous people perinatally during the pandemic. As they illustrate, Indigenous community service providers persevered in delivering care, comfort and creative solutions to birthing people and their families. Through research conducted in collaboration with the Inter-Tribal Council of Michigan, and drawing on consultations with health and wellbeing providers, the authors illustrate the perniciousness of settler colonialism as it intersected with the pandemic. Disproportionate rates of chronic disease, trauma, child apprehension, suboptimal nutrition, substance misuse and violence lie behind the increased incidence of infection and the fear of infection during and after pregnancy, with catastrophic consequences for women's physical, mental and social wellbeing. The authors argue the imperative to decolonize health services to ensure better health outcomes.

Indigenous resources elaborated in Howard-Bobiwash and colleague's contribution point to the need for community and civil response in the absence of state care. Nancy J. Burke, Premjot Saroya and Chia Thao take us to San Joaquin Valley ([Chapter 13](#)), the site of a major COVID-19 outbreak that resulted in the deaths of nine workers, many of whom were Punjabi immigrants. Despite this, the site, the Foster Farm's chicken processing plant, closed only temporarily; it was deemed a 'necessary' industry as the United States faced possible meat shortages. Among Hmong immigrants living in the same region, funerals for those lost to the virus became 'super spreader' events and community-based organization staff worked with families to identify alternatives to these large gatherings to ensure the safe passage of the dead. The authors explore community and organizational responses to the uneven effects of the pandemic in these two immigrant groups in Central Valley, a region known as the 'breadbasket' of the country and home to the highest rates of food insecurity, asthma, hypertension and poverty in the state of California. Here, community-based organizations played an essential role in ensuring immigrant access to information, vaccination, testing and care.

As we have illustrated, the pandemic concentrated resources and attention. Everywhere, countries and communities drew on existing resources, including the infrastructures of prior pandemics (notably, HIV) to organize populations, initiate supply chains and access data, systems and personnel. Levine and Manderson ([2023](#), [2024](#)) describe

this as including the co-option and diversion of scientists to attend to the pandemic, including an impressive resource of epidemiologists willing to provide media coverage, interpret trends in infections and deaths, advise and support shifts in policies of protection, and participate in the global scientific work of vaccine development and delivery. In [Chapter 14](#), Lenore Manderson and Susan Levine describe the conduct of a vaccine trial which proceeded with speed through the appropriation of established laboratory infrastructure, human resources and the goodwill of the local community. Population recruitment and retention are central to any vaccine trial, and a core component of infrastructure is an accessible population. The scientists involved in the ENSEMBLE study had worked in a deeply impoverished study area for several decades. But familiarity does not imply equitable partnerships. As the authors illustrate, the provision of technologies, cell phones, cash compensation and regular health care all influenced people's willingness to participate.

Laura L. Heinemann and Ellen B. Rubinstein ([Chapter 15](#)) illustrate the crucial role of community pharmacies in the rural US state of North Dakota, characterized by some of the highest COVID-19 mortality rates globally and some of the lowest COVID-19 vaccination rates nationally. The authors examine how rural community pharmacies contributed to statewide efforts to increase vaccination rates and address vaccine hesitancy, in a context where pharmacists were at times the only formally-trained health care professionals. Their work underscores the centrality of relational approaches to health in contexts deeply impacted by the chronicity of systemic precarity.

Grace Akello, writing also on the politics of vaccination in [Chapter 16](#), examines the role of frontline health workers, district administrators and local populations in Uganda, where people's experience of coronavirus infection was almost always mild. State efforts to impose isolation and enforce vaccine uptake were incommensurate with local experience of the disease. Conventionally National Medical Stores deliver vaccines to districts and designated health centers in villages, and from these points, people willingly access the vaccines for conditions such as measles, polio and diphtheria. During COVID-19, the state introduced the campaign mode for COVID-19 vaccinations, so enforcing compliance. The phrase 'but we want cassava not COVID-19 vaccine' reflects people's resistance to the state.

[Chapter 17](#) turns to the use by the Sri Lankan state of the rhetoric of war to justify and legitimize its use of military forces in everyday life to enforce adherence to regulations to contain the pandemic. But the

militarization of infection control was concentrated among marginalized groups, particularly in the north and east of the country, which had for decades been the primary setting of civil war. The militarization of everyday life in Sri Lanka, Jayakodi argues, sustains violent dominance and hierarchies, reinforces structural violence and marginalizes particular communities. Utilizing government policy documents, government media briefings, social media posts and news reports on COVID-19 as examples, Jayakodi explores how government policy and socio-historical and economic factors enabled a chronic state of militarism that permeated public, institutional and personal spaces.

Claudia Merli ([Chapter 18](#)) returns us to the unevenness of the pandemic, and the ways in which this has had implication for people living in Japan and Sweden. In both countries, public health authorities defined the disease in terms of infectivity and chronicity. ‘Long COVID’ now affects at least 65 million individuals worldwide and is increasing (Davis et al. [2023](#)). The lingering symptoms of infections over time, spanning a few weeks to several months, have led to an emergent discourse of long COVID. In both Japan and Sweden media coverage of long COVID and patient activism reflects demands for recognition. In Japan this has led to state-supported studies and activism for patient care. In Sweden, where the term post-COVID-19 is used for the same condition, patients struggle for recognition of their suffering.

What is missing?

While Claudia Merli introduces some of the challenges related to long COVID, we recognize that there is much still unknown about what this entails. The biological mechanisms are still unfolding; clinical research is underway to track changes over time and variations in manifestations, as well as potential treatments (Altman et al. [2023](#)). The multiple meanings of long Covid are also unfolding, in relation not only to its physiological toll but also the social fatigue with lockdown, mask wearing, social distancing and long-term personal and interpersonal fallouts. As the young people in Lisa Hardy’s contribution highlight, identities will never be the same, they are ‘children of Covid’. We recognize that we have only begun to touch on this expansive concept here.

We are also mindful of the continuities and disjunctures with the stratified livability we identified in *Viral Loads*. This collection focused on the earliest months of this unfolding global crisis, as infections and mortality rates escalated. Then, we brought together diverse political

and economic settings to document the ways in which this pandemic, like any pandemic, exploited and amplified social, structural and economic vulnerabilities. In this respect, we highlighted how pandemics are fueled by pre-existing inequalities.

These include Danya Fast's depiction of the unanticipated effects of a progressive harm reduction strategy in Vancouver; the uneven spread of both the virus and vaccines, and their uneven acceptance as depicted in Grace Akello's contribution; the deepening understandings of extended militarized responses (Jayakodi, this volume); robust local responses based in the absence of state attention (Burke, Saroya and Thao; Vargas and colleagues; COVID-19 Farmworker Study Collective et al.) and Indigenous ways of knowing (Howard-Bobiwash et al.). The piling on of crisis upon crisis as depicted by Batista, Ramos and Achatz, and the intersections between pre-existing epidemics and COVID-19 (for example, Yates-Doerr, García Meza and García Maldonado) point to the chronicity of precarity, uncertainty and structural violence, and the unexceptional nature of the pandemic in many, perhaps all, parts of the world.

Conclusion

The COVID-19 pandemic continues to be treated as exceptional, despite the persistence and repercussions of HIV that suggest this to be a fallacy: other pandemics and disasters have continued to devastate people who are structurally vulnerable and socially excluded. The exceptionalism lies in the massification of response and ongoing fallout. State responses forced our attention to the inconsistencies and amplifications of pre-pandemic stratifications and inequities, and the lack of capacity of states to address these in the process of managing the pandemic. The sharp economic and social effects in both the short and long term are not unique, except in scale – nearly 700 million cases and 7 million deaths as we write, in February 2024 – and the extent that it was mediatized. Reflections on what the pandemic has revealed have proliferated, especially the glaring limits of biosecurity and the universal nature of every individual's 'right to breathe' (Mbembe 2021). The hegemonic invisibility of the differential valuation of lives based in class, caste, geography, ethnicity and race is no longer; the shroud has been removed from our eyes again and again. The challenge, even so, is to force remembrance, and to 'reclaim the lungs of our world with a view to forging new ground' (Mbembe 2021, S62).

The pandemic is not over. It has evolved from a crisis to a state of being. As we write, it is hard to ignore reports of new variants, new spikes, the need for new vaccines and more, even as we – everywhere across the globe – contend with ongoing wars, floods, wildfires and increasing heat, stemming from climate change and its cascading effects – mass displacement, hunger and fear. History provides us with prior examples (as examples, H1N1; the ‘Spanish flu’), placing COVID-19 within a pandemic era in which emergency response strategies and tactics are refined after each catastrophe. The COVID-19 vaccine is now regarded as like a flu vaccine, to be administered yearly or even more often. Yet, identities have been forever changed, and ‘papering over the cracks simply won’t do’. The future requires a ‘radical imagination’ (Mbembe 2021, S60).

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Fraying and patched homes: home and homeliness during the pandemic

Tuva B. Broch and Ida Hensler

Time passes slowly and quickly simultaneously in Tuva's home in Oslo, Norway. Neighboring windows are decorated with colorful rainbows and flowers, accompanied by children's handwritten letters stating 'Det blir bra igjen' ('It'll be fine in the end'). Tuva's youngest hates his art homework assignment – he does not have the patience to cut and fold paper birds. Instead, his nose is squeezed against the glass windowpane, trying to spot a familiar face or little friend in the streets outside. He pounds on the window as he spots Sara. She has a new box of chalk-sticks that keep her busy drawing rainbows and flowers on the pavement. He knows he is not allowed to meet anyone, not even outside the apartment door. Not yet: they do not know enough about this pandemic and its virus that has found their bodies as a new potential home. There are too many people defined by health authorities as 'at risk' around them – people they depend on for their daily life. Tuva's daughter is independent to a point that sometimes worries her. Her digital school hours start at 8 a.m. and the amount of work she is given keeps her going until 4 p.m., working consistently, without long breaks. She is patient, this 12-year-old, keeping with the regulations without much complaint. She only leaves the apartment to run, mostly alone, maybe in an attempt to keep the abnormal normal. Her youngest child is too young to be out alone.

Feelings of entrapment dominate the weeks of lockdown. Reading the newspapers feeds into despair and constant astonishment. Who is enjoying this forced detention? Who has time to leave the home to enjoy nature walks with their kids, while home-schooling and working from home themselves? Who are these superhumans praising a new *slow life* in the corners within Norway's elongated borders? Time has changed in Tuva's single-parent home as well. The days seem endless, and yet time

goes too fast as the workload piles up. Home as a free space, safe space, family space – a space to long for – has started to crumble. The many rainbows in the many windows signal a hope of breaking free, out of the solid walls of home.

Later on, in a parallel existence in Stockholm, Sweden, another day is passing in Ida's home with a new-born baby girl. It is quiet as Ida looks outside, holding her child and thinking about how long she has been separated from her friends. During the pregnancy she was at risk, but now her new-born is. She wonders, is it business as usual for other families? She is not forced to isolate. The societal recommendations are just that, suggestions for everyone's sake. When she tries to venture outside of their self-selected confinement, it seems, perhaps to her overcautious mind, that there is always someone coughing, sniveling or sneezing. People are not as strict as during the outbreak, and it feels like the perseverance to be cautious is severely depleted. Plans she looked forward to are canceled upon hearing that another guest has a light cold. Away from home is riddled with risk, not just of contracting COVID-19, but also other childhood diseases that have spread like wildfire (winter flu, respiratory syncytial virus) as society gradually opens up. She wants to be a good mother and protect her daughter, even if it means feeling lonely. She tells herself it is just a few more months. Home is safe; Ida and her partner make sure it is. They spend time outside in places that are accessible without using public transportation. A few friends occasionally visit, wearing facemasks to come indoors or keen to enjoy coffee outside in the freezing cold. Ida is joyous at getting to know her baby while her partner works from home. She is grateful that her partner can be close to both of them, and that his home office has a door that can be closed during the weekend. He uses his breaks at work to make conversation, relieve her and bond with their baby. After careful consideration, they decide to celebrate Christmas with family, if everyone feels completely healthy. They plan for an alternative celebration in case this does not work out.

In their separate countries and cities, Tuva and Ida follow daily press conferences and share an eerie feeling, scared of the unknown. They wonder if they, as others, underestimate the impact this disease will have on our lives. They isolate, one following regulations in Norway, one following the recommendations in Sweden, both for felt protection. At first, it is pleasant to be relieved from commuting, to spend more time with the intimate, nuclear family and make time for leisure. Then the dining tables start seconding as desks for online workspaces, full of equipment. Workloads pile up, and the apartments start to feel cramped.

It is hard to shut off work when work computers are visible from every angle and the buffer between 9 to 5 is non-existent.

In the beginning and in the midst of these experiences, a new project dependent on participant observations was about to start. But in March 2020, Norway went into lockdown due to the COVID-19 pandemic. So the fieldwork, planned among young women in Oslo, was forced to begin with online conversations using Zoom or Messenger, both communication services which allow video calls. These meetings continued until June; Tuva praised her luck in already knowing the now young women: they had first met in 2013 through an outdoor education program and spent time together over a period of two years. Their first online conversations circled around their shared memories, but also the present lockdown. The seven¹ young adults were united in their agreement that digital socialization satisfied their need to meet up with friends and family. To them, to hang out and talk online from home was equal to physical meetings. Tuva did not share their experiences but tried to understand them, as she partook in digital game and movie nights. After a good month, she asked them if they did not miss sitting side by side with their friends. The answer was ‘nope’. Embla, who likes gaming and is a bit withdrawn, said that quarantine was the best thing that ever happened to her. She didn’t like being outside with others anyway. Finally, she could live the life she always wanted, at home, preferably in front of a screen, gaming, drawing or chatting. But by the end of the fieldwork, in December 2021, all of the young women had changed their perspectives on home and digital sociality.

The pandemic and social relationships

The COVID-19 pandemic forced humans to relate to each other and their surroundings in altered ways, both empathic and aggressive. Repetitive lockdowns – ‘house arrest’ for whole populations – and diverse living conditions made visceral what Douglas (1991) would refer to as the possible cruelty of homes. The trust in public institutions in Sweden and Norway might make individuals rely on the state to take care of the problems of their fellow people and society at large (Bendixsen, Bringslid and Vike 2017; Vike, Lidén and Lien 2001). Yet, the two countries approached mitigation of the pandemic with similarities and differences. In Sweden, the recommended but voluntary compliance to societal restrictions (Kavaliunas et al. 2020) largely left the responsibility

and choice of whether or not to comply, and to stay at home, to the individual; in Norway, people faced enforced restrictions and consequent changes in everyday life (Ursin, Skjesol and Tritter 2020) facilitated through Norwegians' spirit of the *dugnadsånd* ('community spirit') that implied individuals were working towards a common goal: to fight the pandemic (see Gross 2023; Sørhaug and Borgan 2024). Both voluntary and enforced restrictions made autonomy salient in Norway and Sweden. Associations to home may change when decisions regarding mobility (as in the encompassing house) are forced. The concept of home with a symbolic meaning of togetherness, coziness and safety was challenged during the pandemic.

But in both settings, feelings toward the house as a home were diverse and occasionally paradoxical: a place safe from external threats, enabling recovery and the convenience of everyday life; a place of incarceration, boredom and isolation. Feelings of home and homeliness might have transformed in and been transformed by both public and private spheres. We do not account for all pandemic-related consequences related to physical housing conditions. Rather, we shed light on how feelings and understandings of a symbolic, benevolent home were challenged by external, enforced or voluntary restrictions of autonomy, evidence of societal inequality and occupancy of spaces within and outside one's home. As 'safe' symbols like the house as a home and homeliness fray under the intrusion of contrasting experiences within oneself and of others, the home must be patched either by harboring multiple paradoxical connotations, or by building up walls to separate the inside from the external threat.

To illustrate such transformations, we merged anthropological fieldwork conducted with Norwegian young adults from March 2020 through December 2021, empirical research during the pandemic and personal experiences from Norway and Sweden. We shed light on how feelings and understandings of home changed with enforcement and autonomy, as meta-narratives of the home were challenged. We traced the individual experiences and public descriptions related to home and homeliness during the COVID-19 pandemic, to illuminate how a home can be expressed simultaneously as a free and cozy space and a prison from which one wants to escape.

Before we tackle the symbolic home, we introduce the house as a place of multiple and vastly different homes, and as an important symbol and metaphor. Broch (2020a, 2020b) builds on Gullestad (2002), describing home in Norway as grounded in the idea of family, marriage and heritage. Thus, the house as a home becomes a symbol of care and

compassion, tied to safety, predictability and warmth. In this sense, the home can be understood as a mental structure, with the house as the core symbol (Broch 2020b; Douglas 1991).

A house on fire!

In 2018, as children and youth left their homes to sit down behind their desk at school to learn, a Swedish 16-year-old girl, Greta Thunberg, sat down outside the Swedish parliament building every Friday morning with a banner, to teach world leaders about climate change. A year later, she expressed the symbolic power of a house. At the World Economic Forum in Davos, she urged the world to save our common home as she proclaimed 'I want you to panic! ... I want you to act as if our house is on fire. Because it is' (Thunberg 2019).

It is no coincidence that Thunberg referenced our shared planet with a house. The house was early on tied to the term home; the household was one of the home's main components, thus a great point of departure for social analyses (Barth 1959; Evans-Pritchard 1940; Van Gennep 1909). Anthropologist Marianne Gullestad (1979, 1984) describes the house as the core symbol of home(liness) in Norway and distinguishes the house as the tangible entity that can accommodate a multitude of people. However, the meaning of home depends on individual experiences and meanings (Broch 2020b). Home becomes a realization of people's ideas of it (Douglas 1991, 290), and it is not always place-bound, nor behind or within the walls of a house (Douglas 1991; Jackson 2000). The house as home separates itself from other place-bound buildings like hotels, because it constitutes structures that add to its both aesthetic and moral dimensions (Douglas 1991). This makes the home a collective good, which implies morals and structures that maneuver actions and interactions. A home harbors implied social norms set by its owners and society. A home needs to be maintained, constantly at work both in relation to hierarchies within the home and to keep the house representable to those who are let in, or even imagined peeking in, over its threshold.

These social norms, as well as the home's physical constraints, are what Douglas (1991) terms the tyranny of the home. Douglas emphasizes that it is expected that many young people seek to break free from its scrutiny and control. Likewise, Mallet (2004) highlights the home as a setting where place and time are controlled and structured. These descriptions, and experiences of people who experience oppression,

violence and distress tied to their homes, stand in stark contrast to dominant narratives about the home as a safe haven.

In the quote above, Thunberg critiqued the inaction of world leaders and argued for engagement on a personal level in a time of crisis. Thunberg personalized the crisis by evoking the metaphor of the house instead of the more common symbol of earth as a shared home. Home as symbol is abstract; a materialized house can burn to the ground. Metaphorically, Thunberg illustrates one shared enormous house consisting of many different homes. She focuses an affective magnifying glass on the globe and the crisis, putting a whole world with all its living creatures and landscapes under the one roof. We are all caught in the fire.

Crises like climate change and pandemics are magnifiers of inequalities, injustices and structural problems (Gross 2019, 2023) that affect individuals to a dissimilar extent. The objective health impact of the COVID-19 pandemic was ‘magnified’ by intertwined pre-existing inequality and societal structures (Bambra, Lynch and Smith 2021, 7; Levine and Manderson 2021). Thus, crises can uncover existing, naturalized structures and enhance their symbolic magnitude. As we elaborate below, the house as a home is one such structure that was frayed and challenged during the COVID-19 pandemic. From here on, we use the term house in the symbolic sense, in line with Thunberg, representing a home in all its forms.

Fraying homes

In November 2020, some 3,325 people lacked a permanent place to live in Norway and 2 per cent of homeless people had no shelter (Husbanken 2023). A pre-pandemic report estimated that 33,269 people in Sweden (3.3 per cent) were homeless (Knutagård et al. 2020). In contrast, 81.8 per cent in Norway (Statistics Norway 2023b) and 64.6 per cent in Sweden (Statistics Sweden 2023) of people who inhabit a dwelling own, or own the right to occupy, their home (Statistics Sweden 2023) or rent their home (Norway: 18.2 per cent, Sweden: 34.9 per cent; Statistics Norway 2023b; Statistics Sweden 2023). In Europe, the proportion of ownership ranges from 25–46 per cent (Statistics Norway 2019). Overcrowding has been estimated to 9.7 per cent in Norway and 19.1 per cent in Sweden (Statistics Norway 2023b; Statistics Sweden 2023).

Our privileged outlook from Sweden and Norway stood in stark contrast to other societal settings’ ethical challenges during lockdowns

and housing conditions (Team and Manderson 2020). However, we attempt to illustrate that a key symbol, the private, secure and cosy home, may still fray, even under privileged circumstances and if only for a moment. We argue that the symbolic home's invisible borders were invaded during the pandemic by, for example, formal restrictions implemented by the state, lockdowns, social control and media coverage of people suffering in relation to homes. During the pandemic, we read concerning headlines in Sweden and Norway:

Sweden: 'Slutfestat – nu kan de privata tillställningarna ge vite [The party is over – now private events can be fined]'. (Westin 2021)

'Hemlösa hårt drabbade i pandemin [Homeless severely affected during the pandemic]'. (Selåker Hangasmaa 2020)

'Misshandel i nära relation ser ut att ha ökat under pandemin [Domestic violence appears to have increased during the pandemic]'. (Gustavsson 2021)

Norway: 'Festen er over, det er pandemi igjen. Regjeringen spisser tiltakene – mot deg [The party is over, the pandemic is back. The government is intensifying the measures – against you]'. (Lund 2020)

'Bekymret over tomme krisesenter: – Aldri vært så stille som nå [Worried about empty shelters: – Never been so quiet as now]'. (Øverbø and Lie 2020)

'Grov vold i hjemmene under pandemien: – Barn ned i 5-årsalderen har selv ringt oss [Severe domestic violence during the pandemic: – Children as young as 5 have called us themselves]'. (Sæther 2022)

These examples illustrate that the house as a home and its symbolic significance are connected to the exterior surroundings, and the contrast between the house and the physical and social surroundings maintain its symbolic meaning. Broch (2020a, 10) argues that the house as home 'is separated from the streets, from the city and from work. Compared to the private home, nature is outside, wild and chaotic. Compared to the city nature is home, calm and harmonious'. She further claims that home as a metaphor may create sharp divides that result in invisible fences or mental borders for what is inside and outside, distinguishing private and public (Gullestad 1984), pure and impure (Douglas 1991), belonging and alienation. As Lakoff and Johnson (2003) argue in *Metaphors We Live*

By, metaphors are not just rhetorical or for show. They are fundamental tools of thought that connect lived experiences and abstract concepts and institutions to shape our understanding of the world.

During the pandemic, informed by recommendations aiming to limit disease transmission, disease contraction and death (World Health Organization 2020), states across the globe enforced policies that entered people's homes (Steiner and Veel 2021) and confined people to their homes and neighborhoods (Bambra, Lynch and Smith 2021). The state regulated and altered norms regarding who and how many we could invite in over our private threshold. Public policies affected private matters concerning how, where and with whom we lived our lives. As pointed out by Steiner and Veel (2021, 83), the home needs to be understood as a 'societal institution, a form of spatial and social organization that is highly public'.

Confinement is a strategy that exercises control, regardless of the intention. Authorities can intend to reduce harm by lockdowns, attempt to control disruptive prisoners by separation, similar to how parents discipline disobedient children with house arrest. Voices from the outside (rules and regulations) that were always present in homes were magnified and became audible and noisy. The private became public, too, as public spaces like the workplace relocated and broadcasted people's homes to the outside. Citizens and authorities debated and disagreed on matters of autonomy, control, intentions and consequences (Gestblom, Claesson and Thomsen 2022; Wikman et al. 2021).

Team and Manderson (2020) point out that new societal regulations during the COVID-19 pandemic paid little attention to people without homes or shelter: 'Instead the regulations thrived on the structural vulnerabilities that worldwide shape access to quality and secure housing' (671). There was also emerging global evidence that people with different racial, ethnic, educational backgrounds and social, economic and geographical conditions were disparately affected by the COVID-19 pandemic in terms of disease and economic repercussions (Bambra, Lynch and Smith 2021; Gross 2023). Within the first year, the voices of those marginalized, such as immigrants, contract laborers, single-parents' households, pensioners in caring homes, people of color, people with disabilities and with fixed income (see Team and Manderson 2020, 672) came forth across the globe. The homes of people with unstable employment and insecure accommodation were threatened by financial instability and stress (Joelsson and Ekman Ladru 2022). Living conditions in Scandinavia are very good. Still, crowded housing conditions in low-income areas and migration

background were related to the spread of COVID-19 and high mortality rates in Scandinavia (Ismail, Warsame and Wilhelmsson 2022; Indseth et al. 2020; Joelsson and Ekman Ladru 2022; Kjøllesdal et al. 2022), an indication of the magnified consequences of socioeconomic inequalities during the pandemic.

Bartoszek and Woll (2023) visualized how during the pandemic a renovation project of a municipal housing complex in Oslo was experienced as a double lockdown. Low-income tenants described how chaos, dust, noise and workers stepping in and out penetrated their home. The residents were deprived of daylight for months, as windows were covered for protection. They became confined in compressing homes, without a second home as refuge. The renovation meant to increase residents' standard of living and quality of life evoked prominent feelings of loss of privacy and security and of lacking control over their own home.

In addition to people's own life experiences, the voices of those who previously, and now even more desperately, needed shelter from their home were broadcast. For example, representatives from Norwegian shelters for victims of domestic violence observed cases where perpetrators took advantage of restrictions in society, and expressed concern that requests for assistance were declined during the pandemic (Bergman, Bjørnholt and Helseth 2022). Representatives of women's shelters in Sweden speculated that people subjected to abuse could be at greater risk of violence during social distancing measures (Petersson and Hansson 2022). The international evidence on changes in domestic violence during the pandemic was inconclusive, but suggested that psychological, emotional, sexual and unspecified domestic violence may have increased (Thiel et al. 2022), and reports of domestic violence increased after the enforcement of lockdowns or sheltering in place (Piquero et al. 2021).

Similarly, people expressed concern about the risk of alcohol and substance abuse during the pandemic. International findings, mostly from the beginning of the pandemic, regarding whether alcohol and substance abuse increased were mixed. A greater proportion of people reported drinking during the pandemic, while people with pre-existing high-risk drinking habits or alcohol-use disorder maintained or increased their alcohol consumption (Kilian et al. 2022). Fewer social functions, increased parental supervision and obstacles for procuring substances could explain alternative findings for decreased alcohol consumption (Kilian et al. 2021, 2022; Layman et al. 2022).

In summary, the hardships experienced during the COVID-19 pandemic magnified or exacerbated underlying inequalities and frayed

the idea of safety as a general quality of all ‘sound’ homes. These examples underscore tension in the idea of the home as simultaneously a sanctuary and a site of caring duties and labor, and a place of abuse and violence. The home changes meaning when it is the isolated setting of the perpetual presence of an abusive spouse, or of threatened or actual violence, or a place where boredom and cravings are triggered.

However, not only headlines and marginalized voices challenged understandings of home. People like ourselves, from the viewpoint of and gratitude for our safe homes, could also feel trapped. A constant, lurking ‘uncertainty as to when, how, and in what form the pandemic will next manifest itself’ (Steiner and Veel 2021, 2) kept many at home to ensure their safety. Restless people longed to be away from home. The increased use of outdoor spaces (Hansen et al. 2023; Ulset et al. 2023; Venter et al. 2020, 2021) manifested the longing to get away from home, to venture into the outdoors.

When the safe home becomes a deserted island

In our personal experience, as described in the introduction, the conditions of the outside challenged the experience of home when sheltering was either forced or felt like the only viable option to avoid an external threat. The metaphor of home as safety, care and companionship was frayed by parallel and incongruent experiences of stress, loneliness and monotony. Nevertheless, it is simplistic to talk about a general psychological response to the pandemic. Trajectories can vary across different subgroups and populations. The perception of loneliness, an emotional state which can occur both in the presence and absence of others, was heterogeneous during the pandemic (Patulny and Bower 2022). As young Norwegian adults argued (Broch 2022), the digital could ultimately not replace physical meetings; rather, it became a supplement – a band-aid – in a forced situation.

Paradoxically, people in Sweden expressed satisfaction with their homes, but also anticipation and positive feelings toward excursions, outings and visits to their other homes away from home, such as summer houses (Eklund et al. 2022). In Norway and Sweden respectively (Statistics Norway 2023a; Statistics Sweden 2020), there are around 448,805 and 607,000 vacation homes. However, access to these is a luxury and not a given (Statistics Sweden 2021). In Norway 50 per cent of the population state that they have access to a cabin (Larsen and Sti 2020). Those who could, fled to their ‘homes away from home’ to

enjoy nature more freely than in the cities, to run away from the virus and stay safe while digitally connected to work, friends and family (Bratrud and Lien 2021). However, local residents living in cabin areas felt threatened by the perceived invasion of potential virus bearers; small rural areas with limited medical capacity could not handle a breakout among cabin inhabitants in addition to their permanent population. At one point it became illegal to travel to one's cabin (Bratrud and Lien 2021). In light of what was going on in society and the world, many people expressed gratitude for what they had, excitement about leaving home and frustration when the autonomy to leave or use their homes was restricted.

In Sweden, social interaction and relationships was one of the main aspects of daily life that made people feel well during the pandemic (Eklund et al. 2022). The Norwegian young adults who partook in Broch's fieldwork altered their attitude to home during prolonged lockdowns and the progression of the pandemic. At first, they expressed satisfaction with being at home. Within half a year, their attitudes had changed. They began bending the rules, yearned to be with friends and expressed that digital sociality did not fully substitute being together. They started to reflect on staying at home and feeling stuck with digital social channels. Embla first saw the lockdown as freeing, as she could finally stay at home as much as she wanted. She thrived online and most of her friends were online. However, a while into the pandemic she wanted to meet up at the public library. It was good to sit there, even alone, as it felt good to have other bodies nearby (Broch 2022). For all the young women Broch spoke with, home felt safe but cramped. They wanted to dance, drink coffee and meet up with friends, side-by-side and outside of the home, regardless of state restrictions. At this stage, none of the young adults used the (voluntary) COVID-19 app for tracing infection that was introduced in early 2020. The digital could not make up for the physical presence during social activities to the extent they had claimed at the start of the pandemic. Something changes when prior actions committed by free will are forced (Broch 2022). When a choice is forced, feelings and appraisals of your actions and their consequences may change.

Our experiences as well as the studies of young women illustrate what Steiner and Veel (2021, 83) argue: even for 'well-functioning families, the home can become a sort of desert island – an entity cut off from the rest of the world, yet intimately connected to and utterly dependent on that world'. In dysfunctional homes, the home could instead become the stage of nightmares and worry, veiled off from sanctuaries outside and unattainable stability. Most people felt connected by and dependent

on mundane and formal meetings, which was magnified by the pandemic with confinement to the home by enforcement or social norms. The contrast of potential and absent social interactions, excursions and events could make a home feel like a desert island.

Patching the cracks in the wall of safety: the return of the solidified homestead

At the end of 2022, the experience of the pandemic as a threat and caution seemed disjointed from the objective spread of COVID-19, as if, psychologically, the pandemic was over. In both Sweden and Norway, more people were hospitalized with COVID-19 in August 2022 than in previous summers (Andreassen 2022; Persson 2022). By the year's end, variants were still spreading, with increasing cases (Kudo 2022), but without as much attention in the public mind. People and governments relaxed the stringency and caution of their restrictions (Mathieu et al. 2020). Vaccinations, overall fewer cases compared to previous peaks during the pandemic (Kudo 2022; Persson 2022), fewer deaths and changes in societal recommendations likely explained the lessened sense of threat.

In this psychologically post-pandemic life, the intrusions seemed forgotten. The pandemic served as a magnifier, shedding light on the house as home with contradictory potentialities. Homes can be safe and secure but also fragile and, again, violent and fleeting. Homes are private but also highly public. Feelings of security encouraged many to stay at home, yet home became a place to long to be away from and to escape (Broch 2022), towards the unknown and uncontained. Nevertheless, these disparate experiences of home appeared to be swept under the rug as we faded back, collectively, into typical everyday life. Marginalized voices, expressions of forced or semi-forced decisions to stay at home, as well as political voices entering our houses, were once more quietening down or ignored. People affected by injustice still try to make their voices heard, as before, during and after the pandemic. The question is whether, and when, the unaffected listen. In our separate homes with different conditions, we are still interconnected in Thunberg's celestial common house. The pandemic showed how we are dependent on the actions of others, for better or for worse. The declared end of the COVID-19 pandemic in May 2023 (World Health Organization 2023) begged the question of whether the idea of the home was altered to encompass a greater diversity of experiences, or whether a prior conventional narrative of the home once again predominantly represented

ideas of caregiving, safety and comfort. As we have emphasized, the meaning of home depends on individual experiences and with what people internalize or fill the term. Thus, a home has different connotations to different individuals and is realized on the basis of their ideas and experiences, and perhaps their dreams of it. During the pandemic, other voices, new stories and experiences, as presented throughout this chapter, came along that could fill out the term – home. But as always with symbols, their strengths are their paradoxical and ambiguous features, which allow idiomatic, idiosyncratic interpretations and simultaneously give individuals concrete points of reference.

We distinguish personal experience from the meta-narrative about the home, where the narratives may integrate memories and associations of others with dissimilar experiences. The symbolic home may have been frayed by internal, personal experiences as well as intruding, contradictory information from outside of what the home might mean to others. In addition, external control by social norms or regulations regarding permitted actions tied to the home setting might have frayed the idea of home. As restrictions and a sense of threat from disease faded away, autonomy was restored and the choice to stay or leave the physical home was once again fully free in our retrospective cities. Many did not have the option to stay at home during the pandemic due to the nature of their occupation and work duties. People without higher education worked less from home during the pandemic (Statistics Sweden 2022). The development of boundaryless work in terms of organization which relies on the decision of employees, flexible working hours, personal responsibility and shifting on-site and remote location, in particular for white-collar and clerical work, is a process that began before the pandemic (Allvin et al. 2011), and many physical homes host not only private lives but also remote work. The home became not only a place of family, rest and safety, but a setting for stress and professionalism, due to the concrete activities that took place in our physical homes. In contrast, many volunteered to work from home (Smite et al. 2023) and moved to the outskirts of rural areas to work remotely (Bratrud and Lien 2021). In that sense, the consequences of the pandemic instigated a paradoxical duality to many peoples' personal experience of home, depending on whether choices were forced or free.

Furthermore, the invading, contradictory ideas and lived experiences of an unsafe, violent or distressing home during the pandemic contradicted the core attributes of the metaphorical home as a safe haven. We are tentative to draw any firm conclusions of how the home might be seen now that the pandemic has been declared as over, even as infections continue in an endemic mode. However, we fear that

the narratives of people in distress are forgotten. The voices of despair that fractured the walls of safety, screaming at the world that the house as home is not safe nor equal for everyone, were soon forgotten; the walls of the home were patched in the aftermath of the crisis. Perhaps there was a need to move on and forget.

The trust in public institutions in Sweden and Norway might make individuals rely on the state to take care of the problems of their fellow people and society at large (Bendixsen, Bringslid and Vike 2017; Vike, Lidén and Lien 2001). Authorities in both Sweden and Norway emphasized the need to care for one another for the collective good in communications with the public during the pandemic. Similar to understandings of home, *dugnad* is a core concept in Norway meaning ‘coming together on equal terms to resolve a [shared] burden or work towards a common goal’ (Gross 2023, 3; authors’ parenthesis). The spirit of *dugnad* was connected with lockdowns in communications and kept Norwegians at home together with enforced restrictions. However, the concept of *dugnad*, as illustrated by Sørhaug and Borgan (2024) and Gross (2023), like home, was ruptured during the pandemic as the dark sides of the narrative came forth and uncovered how it costs the most for those least fortunate (Gross 2023). Staying at home in compliance with rules and regulations was easier for some, while the expected labor on equal terms for all, connected with *dugnad*, was not realized. However, it was alarming how fast these disadvantages were neglected and the everyday life took over as the crisis passed. The public seemed to forget and marginalize the experiences of those most severely impacted by the pandemic (see Goggins 2023). Core concepts in society appear dynamic through the magnifying glass and hindsight of a crisis.

The post-pandemic safe home could be interpreted as a solidified place separate from danger and others in distress. Alternatively, the idea of home has reverted to its pre-pandemic meaning, with the fortunate turning a blind eye to the discrepancies in resources and inequalities. The idea of a homestead, the house as a home, as a safe center of everyday leisure and work life for the ones closest to us, is solidified despite surrounding fires.

Notes

- 1 The study began with seven participants who Broch (2018, 2020) kept in contact with after her doctoral work ended. Six months into the fieldwork it expanded with participant observation among 18 young adults distributed among a total of five friendship groups from different parts of Norway.

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Time and chronicity at the frontline of the pandemic in Japan

Junko Teruyama, Sachiko Horiguchi,
Shuhei Kimura and the Covid Primary
Care Collaboration¹

The onset of the COVID-19 pandemic in Japan was marked by a particular incident, whereby a cruise ship named *Diamond Princess*, docked at Yokohama port, became the site of a major outbreak in February 2020, resulting in the infection of over 700 passengers (Jimi and Hashimoto 2020). As broadcast on Japanese television, images of doctors and medical professionals fully covered in personal protective equipment (PPE), hastily moving about in the quarantined ship to demarcate red/green zones, made a strong impression on the general public. Japan is perhaps different from many other countries in this sense, because this event marked the beginning of the pandemic in the national context. The *Diamond Princess* infections were quickly followed by increased infection rates nationwide, with intermittent spikes eventually forming ‘waves’ of infection coinciding with seasonal events and political decisions.

In this chapter, we examine the narratives of primary care doctors in Japan over the first 30 months of the pandemic, and explore the ways in which the temporality of this initial event evolved into an understanding of the pandemic as waves of infections and, finally, as chronic, a phase of ‘*with corona*’ (as of late 2022). Based on an ongoing longitudinal project interviewing 10 primary care doctors working at the frontlines of COVID-19 responses across Japan, we describe the four modalities by which time is woven into the lived experiences and narratives of the doctors we interviewed. Firstly, a temporal framework serves to apprehend the risks and dangers of immediate incidents, and on this basis, to make short-term decisions on provisional measures. This entails what Fassin and Fourcade (2021, 7–8) call ‘emergency time’ and the immediate and adaptive *accelerations* that accompany it.

Secondly, there is a conception of being ‘in between’ major incidents and outbreaks, when waiting, preparing and forecasting become an integral part of clinical work. The ways in which the ‘in between’ is conceptualized here is not mere *suspension*, characterized by immobility in Fassin and Fourcade’s (2021, 8) terms, but rather is about preparation and mobilization. Thirdly, there is the forecasting or ‘horizoning’ (Petryna 2022) of the long-term progression of the pandemic and its impact on society. And finally, there is a reflective perspective when doctors contemplated the impact of the pandemic on their careers. These reflections are envisioned as potentially leading to *structural transformations* (Fassin and Fourcade 2021, 9), although we also highlight the transformations at an individual level. We situate these narratives and the various temporalities in which the narratives are embedded by drawing on Ingold (2007)’s conceptualization of ‘lines’ and Leach’s (1971) typology of cyclical versus linear time. These modalities are not phases in the sense that they are sequential; rather, they overlap and coexist in doctors’ narratives. Before examining these modalities with which we examine our data, we introduce the background, the setting and the methods of our study.

Backgrounds, setting and methods

In general, primary care and/or general practice involves:

first contact with patients and their families in their pursuit of health care and health. ... Individual care involves the health and wellbeing of the whole person and their family throughout all ages and stages of life. ... Ideally, PC (primary care) and PHC (primary health care) work together to address a community’s health needs. PC services need to be context dependent with responsive, flexible, and adaptable interventions tailored to specific settings and populations. (Hartman et al. 2021)

The specialty of the primary care doctor has, therefore, been to provide broad and multifaceted medical care for a wide range of diseases. In the 1970s, the British system of general practitioner and the, similar, American system of family medicine began to be introduced to Japan. The Japanese government promoted this introduction, due to concerns about the ageing of the population and the decline in medical resources in areas outside major cities. Aiming to establish a comprehensive community care

system, the government authorized ‘general practitioner’ as the nineteenth ‘basic area specialist’ only in 2018 (JMSB 2022).² Therefore, primary care doctors comprise a relatively newly emerging category of doctors in Japan, and multiple labels have been used interchangeably to make reference to them: *primary care-i* (primary care doctors), *sōgō-shinryō-i* (general practitioners or GPs), *katei-i* (family physicians) or *kakaritsuke-i* (regular doctors). Only 0.5 to 1.15 per cent of medical students currently become general practitioners (Kato et al. 2019), however. With this shortage of doctors specialized in general practice, physicians trained in internal medicine-based residency programs have played a principal role in the primary care setting (Kaneko and Matsushima 2017). The roles of primary care doctors working under Japan’s universal health insurance and the free access health care system also remain ambiguous (Kaneko and Matsushima 2017, JHPN 2022). Primary care is practiced not only by doctors based in clinics but also by hospital physicians whose main role is in secondary care (Kato et al. 2019).

Japan’s response to COVID-19, which has often been deemed ‘successful’ because of the relatively low mortality rate despite its ageing demographics, has in fact been decentralized (Oshitani 2022). There is no Center for Disease Control and Prevention, as in the United States, nor a Government Chief Scientific Adviser, as in the UK, although an ‘expert panel’ was set up to advise the government on measures against infection control and prevention (Machida and Wada 2022). Instead of lockdowns, as imposed in many societies, Japan’s infection control was based on a policy of request for self-restraint, where people were simply encouraged to practice universal masking and to avoid the ‘three Cs’ (closed spaces, crowded places and close-contact settings) (see Figure 3.1) (Song and Karako 2021, Borovoy 2022). While the ‘State of Emergency’ was declared multiple times by the national government (see Figure 3.2 and Table 3.1), the Infectious Diseases Prevention Law stipulated that the prefectures, not the central government, are the main body responsible for the practices of response (Machida and Wada 2022). Until 7 May 2023, under the guidance of the Ministry of Health, Labor and Welfare (MHLW), prefectural governments and the local municipalities under them set overall standards and measures, and shifted them as needed. Approximately 600 regional public health centers (*hokenjo*) in each prefecture were tasked with COVID-19 measures, including case counts, coordination of testing, contact tracing, arranging the hospitalization of people with severe COVID-19 as needed, and coordinating with medical institutions in the region (Inoue 2020; Machida and Wada 2022). In this context, Japanese medical institutions have been able to provide

新型コロナウイルスの集団発生防止にご協力をお願いします

3つの密を避けましょう!

①換気の悪い
密閉空間



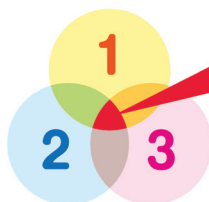
②多数が集まる
密集場所



③間近で会話や
発声をする
密接場面



新型コロナウイルスへの対策として、クラスター(集団)の発生を防止することが重要です。
日頃の生活の中で3つの「密」が重ならないよう工夫しましょう。



3つの条件がそろう場所が
クラスター(集団)発生の
リスクが高い!

※3つの条件のほか、**共同で使う物品**には
消毒などを行ってください。



首相官邸
Prime Minister's Office of Japan



厚生労働省
Ministry of Health, Labour and Welfare

厚労省 コロナ

検索



Figure 3.1 Poster exhorting people to ‘avoid the ‘three Cs’ (closed spaces, crowded places and close-contact settings). Source: Prime Minister’s Office of Japan and Ministry of Health, Labor and Welfare.

medical care based on their own decisions and procedures, that is, they have been able to choose or not to engage in COVID-19 responses. The majority of clinics and hospitals in Japan are privately run and have not been required by law to accept COVID-19 patients. Some publicly-run hospitals are designated to cope with infectious diseases (two primary

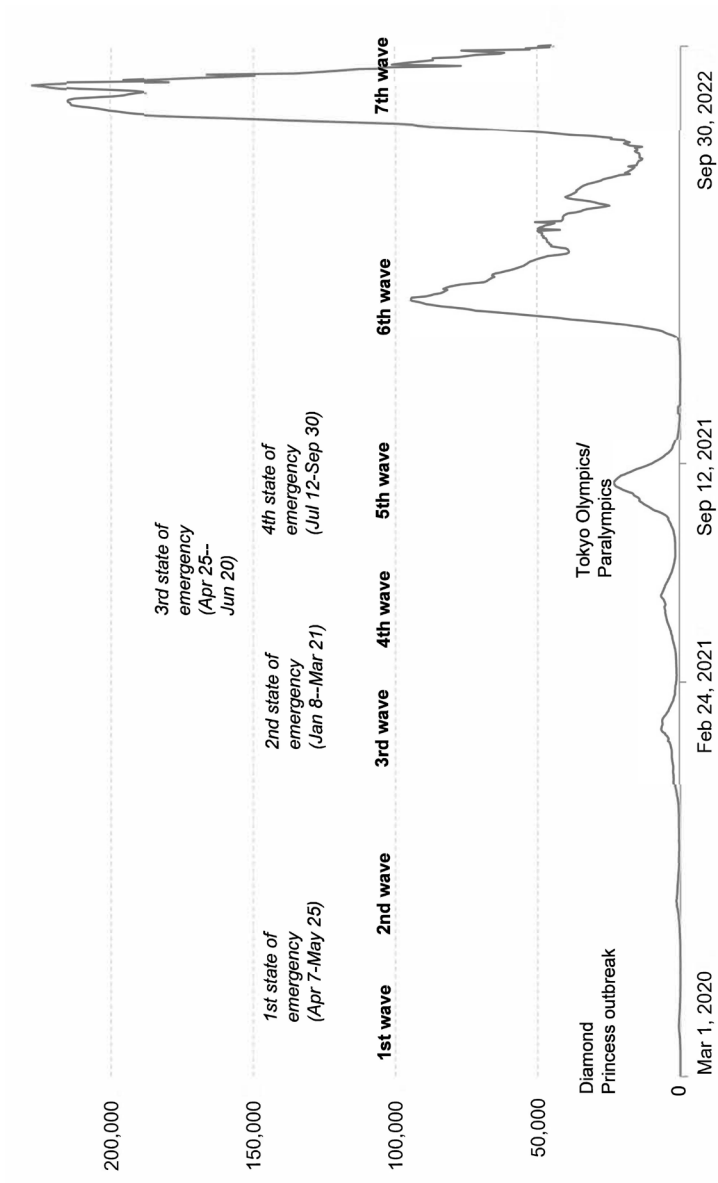


Figure 3.2 The number of daily new confirmed COVID cases and key trajectories of pandemic waves and events in Japan (March 2020–September 2022). Note: 7-day rolling average. Due to limited testing, the number of confirmed cases is lower than the true number of infections. Source: Our World in Data [2020–2022](#).

Table 3.1 Outline of the pandemic waves in Japan, 2020–2022.

Pandemic wave	Period	Key variants/terms	Key events	Reported sites of infection
1st wave	March–April 2020	‘Overshoot’	<i>Diamond Princess</i> outbreak in February 2020, start of new fiscal year (April) <i>Obon</i> family gatherings	Restaurants, gyms, live houses ‘Nightlife districts’, restaurants
2nd wave	July–September 2020			Homes, family gatherings, restaurants, medical facilities, facilities for the elderly
3rd wave	End of 2020–March 2021	‘Medical collapse’	New year family gatherings, vaccine rollouts for medical professionals start in February 2021	Restaurants, high infection rates in Osaka
4th wave	April–May 2021	Alpha variant	Start of new fiscal year (April), vaccine rollouts for the elderly start at the end of April 2021	Homes, workplaces, restaurants
5th wave	June–August 2021	Delta variant, ‘medical collapse’	Tokyo Olympics and Paralympics, ‘collapse of the medical system’, <i>obon</i> family gatherings, vaccine rollouts for adults start in June 2021	Facilities for the elderly/young children, schools, homes
6th wave	December 2021–May 2022	Omicron variant, ‘medical collapse’	‘Collapse of the medical system’, New Year family gatherings, boosters	Facilities for young children/the elderly, schools, homes
7th wave	July–September 2022	Omicron variant	‘With corona’, <i>obon</i> family gatherings	

care doctors in this study have been working in such hospitals, treating COVID-19 patients throughout the pandemic). This means that the actual state of medical responses to COVID-19 may be better described as ‘assemblages’ (Tsing 2015) rather than as an integrated system. In these ‘medical assemblages’, primary care doctors working in clinics and hospitals have been screening patients suspected of being infected by COVID-19, treating the patients and vaccinating citizens, in addition to providing regular medical services (Kimura et al. 2021).

In March 2020, we launched an interdisciplinary collaborative project with the aim of interviewing primary care doctors and archiving their narratives as they worked at the frontlines of COVID-19 prevention and treatment. This is an ongoing project as of June 2023, although for this study, we focus on narratives collected until September 2022. Our team includes ten scholars, five of whom are anthropologists and the other five are medical professionals. We sought interviewees through the personal networks of team members, and recruited 10 JPCA (Japanese Primary Care Association)-certified primary care doctors in diverse regions and clinical settings (see Table 3.2 for a list of interviewees; all names are pseudonyms). We should note a bias in age and gender: all interviewees were in their 30s and 40s at the start of the project, and female doctors are underrepresented, reflecting the dominance of men in primary care in Japan, and also because our personal networks, on which we relied in recruitment, were primarily male.³

Table 3.2 List of interviewees.

Pseudonym	Gender	Workplace	Institution
Dr Amano	M	Metropolitan areas: Kanto region	Hospital and clinic
Dr Bando	M	Metropolitan areas: Kansai region	Clinic
Dr Chikuma	M	Metropolitan areas: Kanto region	Clinic
Dr Doi	M	Regional cities and suburban areas: Hokkaido	Clinic
Dr Endo	F	Regional cities and suburban areas: Chubu region	Clinic
Dr Fukuda	M	Hospital serving COVID-19 patients in a regional/suburban area: Kanto region	Hospital
Dr Gonda	M	Regional cities and suburban areas: Chugoku region	Clinic
Dr Hanzawa	M	Hospital serving COVID-19 patients in an urban area: Kanto region	Hospital
Dr Iguchi	M	Regional cities and suburban areas: Kyushu region	University hospital and clinics
Dr Jinno	F	Regional cities and suburban areas: Chubu region	Clinic

From March 2020, we continuously interviewed these informants roughly every three months over Zoom, with each interview lasting one to two hours. In some cases we paired the doctors and interviewed them together, with the hope that a discussion with a counterpart would benefit our interviewees. Each interview was conducted by a team of at least one anthropologist and one medical professional, in the attempt to assure a cross-disciplinary perspective; each was recorded and later transcribed to be viewed by other members of the team. We asked not only about the participants' day-to-day experiences in the clinical setting, but also about their personal reflections, thoughts and visions regarding the pandemic.

Our project was primarily online-based. As noted above, we conducted our interviews and held regular meetings on Zoom, shared information and made plans on Slack and compiled data on Dropbox. To date, we have not met face-to-face as a whole team. This obviously reflects the same limitations that ethnographers encountered everywhere during the pandemic (Górska 2020). But in many ways, a project of this geographic scale and human resources would not have been possible otherwise, and in that sense, this is an exploratory work of digital ethnography as well. In what follows, we introduce the data gained in this digital ethnography and contextualise them using key temporal frameworks. All interview excerpts in the following were translated from Japanese to English by the authors.

Emergent temporality: a perspective on impending incidents and predicaments

Prior to the outbreak on Diamond Princess, COVID-19 was primarily perceived as a remote infection in a distant place. Despite Japan's geographical proximity to China, where the outbreak was first reported, most doctors admitted that it 'felt like it was occurring in a completely distant country'. It was only in February 2020, when news coverage of Diamond Princess swamped the media, that they began to perceive COVID-19 as an imminent threat to the community in which they were working, and started to take initial preventive measures. When the DMAT (Japan Disaster Medical Assistance Team) began disembarking patients from the cruise ship, the designated medical institutions in Kanagawa Prefecture, where the dock was located, were unable to handle all patients, and the DMATs began to plan a scheme to transport patients to other prefectures (Takeuchi 2020). Recalling that time, Dr Fukuda

said ‘it felt like it was becoming a national thing’ and he contacted the regional public health center regarding the availability of beds.

We usually have patients with tuberculosis or flu and we weren’t prepared in terms of training, so we couldn’t afford to take in too many. But we also have responsibilities because we are paid for that. As a designated medical institution for infectious diseases, we receive subsidies from the prefecture, so we obviously had to do something in this time of crisis, but we also had to do it within a manageable extent, so we decided to secure two beds. We thought a lot about how to bring those patients into the hospital, but we couldn’t draw a red zone through the entire passage so I had discussions with the hospital clerks and the nursing department and we decided to temporarily close down a part of the green zone to bring them in. But in the beginning, we didn’t realize it was going to be so large-scale or long-term, so we were just concerned about the temporal measures of admitting the patients, and I don’t think we drafted a manual. (Dr Fukuda, 26 March 2020)

The initial improvisational measures that the doctors took were largely driven by a sense of urgency and responsibility to respond to the immediacy of the crisis, in ways that were similar to the experiences of health care workers in the United States and the UK (Block and Vindrola-Padros 2021). Admitting and treating COVID-19 patients requires various logistical arrangements involving staff assignment, spatial zoning, procurement of medication and equipment and networking with regional bureaucracies and public health centers. The premonition that this may evolve into a pandemic of unprecedented scale, along with the lack of medical knowledge about the virus, seemed to create a momentum within the medical community, and people resorted to online sources to gather, share and accumulate information on COVID-19. Many doctors who we interviewed at this time mentioned that they closely monitored medical journal articles and reports issued by Japan’s Ministry of Health, Labor and Welfare and the National Institute of Infectious Diseases. Social media, especially personal blogs, Facebook and YouTube, also functioned as important fora of information exchange and discussion (Chan et al. 2020). As Dr Amano noted:

With regards to online medical consultation, I read on Facebook that this was going to be an option. I was thinking about how to look after patients who had mild symptoms, and considered

calling them over the phone or doing it online, and started looking for information. As I searched, I learned about how things were beginning to change, and found people explaining the procedure on YouTube. (Dr Amano, 14 April 2020)

Our interviewees also mentioned that they exchanged information with colleagues regarding the usefulness of various blogs and Facebook accounts set up by medical professionals which, while curating up-to-date information about the virus, revealed an insiders' perspective on what was happening, first on the cruise ship and then on best practices from their own workplaces. Where guidelines and manuals were yet to be standardized, individual doctors took on the responsibility to gather such information and put it into practice in an improvisational manner (Block and Vindrola-Padros 2021, 316–17). Dr Gonda actively shared on Facebook the advice he gave at morning meetings at the hospital, with the hope that his practices and strategies 'in a region where the pandemic is yet to hit' would benefit others in the same situation. This doctor referenced his own Facebook postings during our interviews, using this as a cue to remember the sequence and trajectory of events in answering our questions. Many interviewees, like Dr Gonda, had a difficult time recalling these initial stages as they scrambled to gather information and implemented various measures on a trial-and-error basis alongside their regular clinical practices. Our team drafted a rough timeline of major COVID-19-related events and news coverages, and shared it with our interviewees, and this was instrumental in helping them recall and contextualise their experiences during this chaotic moment.

Many used the word 'coming (*kuru*)' to refer to the spread of the virus in their respective communities, as in 'it's coming soon' or 'when it comes, our clinic will have to do something about it'. In this sense, the virus was seen as arriving from elsewhere; initially from abroad, then from Yokohama and the larger Tokyo metropolitan area, then to spread to regions throughout the nation. Dr Endo was based in a rural area, for example, and noted how 'the COVID-19 infection evidently spreads from Tokyo to the next largest metropolis, then to the next largest city, then to the countryside' (Dr Endo, 20 July 2020). The scale and speed by which it will 'come' was not clear, making it difficult for medical professionals and institutions to plan according to a timeline. Such apprehension of what was yet to come was a critical characteristic of the temporal framework during the earlier stages of the pandemic. It was widely publicized early on that the latency period of COVID-19 was up to two weeks. As the

media began reporting the daily infection counts released by the Ministry of Health, Labor and Welfare, it was repeatedly stressed that those figures reflected not what happened on the day of reporting, but what had happened two weeks earlier. In May 2020, when Japan was about to go into 'Golden Week', one of the longest national holidays where families and friends customarily get together or travel, the government called for citizens to 'stay home' and stressed that infection counts two weeks later would testify to the patience and compliance of citizens. This time lag came to be embedded in the narratives of the doctors, where holidays and major events always entailed the apprehension of rising infection rates in the weeks that followed. During the summer vacation in August 2020, one interviewee commented:

Because of tourism, and people returning to our prefecture to reunite with their families during vacation, we're starting to see a few people being infected here and there. Today being the end of the holiday season, we might expect an increasing number of infections up to early September, or we might just see sporadic cases. We'll have to pay close attention during this time. (Dr Doi, 17 August 2020).

For some doctors, this time lag was also associated with geospatial disposition. 'What's happening in New York now is going to happen in Tokyo in a couple of weeks', said one of our interviewees. Dr Fukuda works in a hospital serving residents in a regional/suburban area, and used the metaphor of a 'time machine' to explain this gap, suggesting that what he was talking about then, in terms of incidence of infection, would have been what another doctor working in a more urban area would have seen and experienced a month earlier (25 April 2020). In a later interview, he commented:

Although it [the pandemic] is happening all over the world at the same time, what is happening still varies depending on the region and the infection rates. So, it's like, what was experienced somewhere else (reaches us and I realize) now *this* is what they were talking about! ... In this sense, I really feel the information that's been shared and disseminated like this is useful in real time. (Dr Fukuda, 17 July 2020)

The speed by which the pandemic has unfolded in different locations, along with the speed by which a particular variant of the virus has

been communicated across national and regional borders, also fed into short-term predictions of infection rates and the measures that subsequently would need to be taken by the local medical community. The Japanese primary care doctors with whom we were working were forced to improvise in urgency in an unaccustomed manner (except for doctors like Dr Jinno who had prior experiences working with infectious diseases in the Global South, as we explain below). This is similar to the responses of health care workers in the United States and the UK, but in contrast to how health professionals routinely work in the Global South, where the need for improvisation is a 'daily imperative' (Block and Vindrola-Padros 2021; Livingston 2012, 181). The Japanese doctors also had more evidence to consult from the United States, the UK and European countries where the spread of infections and vaccine rollouts came earlier. Japanese primary care doctors were frustrated with constantly changing state recommendations, but the 'time lag' meant that they could prepare better by 'looking to the West' – a rather familiar theme for the Japanese, who have always placed 'learning from the West' on their national agenda in the context of modernization. In the case of COVID-19, the irony, however, is that 'non-Western' societies like Japan seem to have performed 'better', with lower mortality rates than the so-called 'West', and the lessons from the West were not only about emulating what they have done well, but also about seeing what not to do.

As we have seen, the COVID-19 pandemic in its early stages in Japan was experienced by doctors as unprecedented turmoil in which they were inevitably embroiled, forcing them to shift to 'emergency time' with a need for *accelerations* (Fassin and Fourcade 2021, 7). With the apprehension that it was 'coming' to their communities sooner or later, our interviewees were forced to live in the myopic time frame of the 'here and now', while striving to collect information and so gain a larger picture of the unfolding pandemic, which would help foresee what is to come. Dr Fukuda confided his hope that this temporal framework wouldn't last long:

Are we going to continue living in this fear, or taking this risk? Or is there going to be a game-changer? Whether that's going to be medications or vaccines or the attenuation of the virus itself, I think there are different opinions on that, but I personally have a slight expectation that at one point the larger picture is going to shift and that we're not going to have to sustain this forever. (Dr Fukuda, 11 June 2020)

As the pandemic began to take the shape of multiple ‘waves’ of rising infection rates, the experienced modality of time began to embody a new rhythm of ups and downs. This did not entail a smooth shift to predictability and preparedness. Rather, the temporal modality continued to dominate doctors’ narratives during the peaks of those waves, as they scrambled to meet the challenges of treating overwhelming numbers of patients who exhibited different symptoms depending on the variant of the virus. Dr Fukuda, who experienced the third wave while working the holiday shift at the end of the year in 2020, recalled,

I worked on December 29, 30 and 31, and the ward almost entirely turned into a COVID ward. We couldn’t catch up, and we had about 30 or 35 inpatients. I was working with a colleague, an internal medicine doctor who was around the same age or a year younger than me. He was supposed to work the New Year shift but decided it was too risky to take the year-end off so he came in for the three days, and together we treated COVID patients, but it was beyond our control. I texted the hospital executives in the morning of January 1st that it’s an emergency. The message was like, ‘Happy New Year. We’re falling apart’. (Dr Fukuda, 3 February 2021)

They immediately got in contact with the regional public health center and the local hotels where patients with mild symptoms were admitted, and found that the overwhelming number of COVID cases far outstripped their capacity to the extent that neither were operating functionally. As early as 6 January 2021, the hospital decided to send doctors into these facilities to restore an effective network, organizing patient transport and narrowly averting the collapse of the health care system.

Critical predicaments requiring immediate decisions were therefore experienced more or less during each peak of the waves. However, the elongation of the pandemic also entailed different modalities of time between these moments of distress, as we now discuss.

Intervals: sense-making of time in between

Although primary care doctors had to tackle the crisis right before their eyes, COVID-19 led them to have different senses of time for response. Firstly, they had to get used to the unfamiliar temporality of ‘waiting’, or in Fassin and Fourcade (2021)’s words, *suspension*. Waiting included the incubation period prior to the onset of symptoms, the waiting period

at home for persons in close contact, the waiting time to receive PCR test results and so on. These waits made it difficult for doctors and other health workers to assess the situation at hand, and they needed to respond to a more expansive spacetime than ‘here and now’. To make things even more demanding, sometimes, the waiting times contingently expanded or contracted. While the shifts in the prefectural criteria for discharge – dependent on the PCR test results – shortened the period set for hospitalization, and consequently helped doctors use hospital beds more efficiently (Dr Hanzawa, 17 July 2020), the doctors were swayed by changes in waiting time for PCR test results. One of our interlocutors complained that his patients had to wait more than a week for the result of a PCR test at one point, yet in the previous month, results were being received within a few days (Dr Bando, 29 July 2020). The PCR tests in Japan created bottlenecks. Legally speaking, testing had to be conducted according to specific officially recognized procedures; however, in many regions, the resources in the official institutions such as the public health centers were inadequate to administer PCR tests to all who were seeking them. The shifting waiting times led doctors to be more attentive to the local infection situation and helped them to understand what a ‘wave’ of a pandemic might mean to their practice.

Unearthing records of past pandemics like the Spanish flu, the ‘wave’ metaphor was frequently used in the wake of COVID-19. However, it took time for our interviewees to make sense of the ‘waves’. Experiencing changes in their own medical assemblages along with the rise and fall of infection rates, they came to understand what ‘a wave’ meant to them. For example, two years into the pandemic, Dr Endo clearly explained her view of infection as ‘waves’:

We have experienced several waves since the pandemic began. Even when a wave receded, I never thought that this would be the end [of the pandemic]. Although a lull continued for several months after the Delta wave, I was convinced that another one would come. (Dr Endo, 28 January 2022)

As apparent from this narrative, along with this ‘wave’ metaphor came a realization among the primary care doctors of the existence of ‘intervals’ of waves. However challenging it is to deal with a wave, they also understood and worked around a notion of a lull which would always come after a wave. Accordingly, the doctors came to employ two different modes of response. While they would just deal with one patient after another ‘in a wave’, they would check and reorganise their response ‘in

an interval'. After the second wave in his locality, Dr Doi, working in a public clinic in a small town in northern Japan, explained:

In our region, the infection rates were low for a while, so we enhanced our medical preparedness for the next wave. We reorganized the medical care system of the hospitals that would admit COVID-19 patients, set up hotels to admit patients in mild conditions, and, in collaboration with the local medical association, we arranged a system whereby family doctors can carry out PCR testing ... We developed a decentralized medical system in which every town in our region has at least one medical facility where PCR testing and treatment for COVID-19 patients are available. (Dr Doi, 29 October 2020)

Describing what he did 'in an interval', his narrative suggests that primary care doctors are among the vital actors in charge of maintaining and improving local health systems in Japan.

The alternative waves and intervals resonate with another sense of preparedness, *sai-kan* (inter-disaster, if we translate literally), which emerged as a term in the aftermath of the 2011 Great East Japan Earthquake. Witnessing the devastating damage from the triple disaster of the earthquake, tsunami and nuclear disaster, some commentators started using *sai-go* (post-disaster) as an era-defining word to replace the word *sen-go* (post-war). They claimed that this disaster, like the Second World War, should be seen as a turning point for Japanese society, following recession in the preceding two decades. In this context, sociologist Nihei (2012) proposed the word *sai-kan*. Instead of anticipating happier times to come after a catastrophe, he argues that we should be aware that normal times are merely intervals of past and future disasters. Calling for an escape from the linear logics of post-war or post-disaster Japan and economic efficiency, Nihei argues that the mode of *sai-kan* requires citizens and governments to create leeways or 'rooms to breathe' (*yoyū*) so that people can build relational, infrastructural, and other kinds of extra 'reservoirs' (*tame*) to survive disasters (Watanabe and Kimura 2018).

Japanese primary care doctors made sense of and effectively utilized the times in between pandemic waves, not solely experiencing them as times of immobile *suspension* (Fassin and Fourcade 2021, 7). This recognition of pandemic intervals also allowed them to reflect on the pandemic from a longer-term perspective. We turn to this now.

Metaphorically contextualizing chronicity: playing a game without an end in sight

The primary care doctors often drew on metaphors to express longer term outlooks of the pandemic, an important point we raised with them in every interview. At the start, some doctors foresaw the arrival of the new coronavirus as a temporary issue, akin to a disaster, expecting it to fade away in a short period of time. Other doctors foresaw a long battle against an unknown virus. For instance, Dr Amano, based in a clinic in the Tokyo Metropolitan area, noted:

I'm thinking that it's like a marathon. ... A marathon with a long way ahead, or something like that. I don't think we should expect a short-term battle. I should spend the days thinking that this can really go on for a year or so. So I'm doing a lot of things, but I know I shouldn't get burnt out. (Dr Amano, 14 April 2020)

Later, in the midst of the 'second wave' of the pandemic, Dr Chikuma, directing a clinic in the Tokyo metropolitan area, was ready for a long-distance race, raising similar concerns around potential burnout:

It's like 'hey, how long are we going to do this?' We were perplexed. We thought that we were running a sprint, but now find ourselves in a long-distance race. I'm puzzled as to how long this can go on. And I'm not sure if we can hold it up to the end, both in a physical and mental sense. It'll be quite important for all of us to have time to refresh ourselves. (Dr Chikuma, 8 August 2020)

At this point, the 'long-distance race' was no longer understood to be a matter of one year, but at least several years, as Dr Iguchi working in the Kyushu region commented:

Even in Japan, we'd have to continue with [COVID-19] measures, or have to live with it for at least another few years. It seems to me that it will be quite a long-distance race. (Dr Iguchi, 8 August 2020)

As the pandemic lingered on, Dr Iguchi raised concerns about the long-term effects of the pandemic on the local economy, along with a sense that the pandemic experiences in Japan were subject to its global trajectories. In the midst of the third wave (13 March 2021), he predicted that 'the fourth (next) wave will probably come again' and feared that

‘the real economy will be severely hit if we continue declaring a State of Emergency’. Dr Iguchi later expressed his pessimism and uncertainties regarding the future, and the inseparability of local and global contexts:

Even with vaccination rollouts, the number of cases will probably not be reduced to zero. ... The number of cases in Japan will not be reduced to zero unless the pandemic is globally controlled to a certain extent. I am not very optimistic that the Covid outbreak will be under control in other parts of the world. ... I’m not sure what to expect. (Dr Iguchi, 21 May 2021)

In an interview conducted around the same time, Dr Amano, working at a clinic in the Tokyo metropolitan area, utilized the metaphor of baseball innings, in an attempt to keep a distant exit in sight:

I suppose we are at the top of the fourth inning, which means, probably we haven’t reached yet halfway through. Vaccines may bring us to the sixth inning or so, but I’ve been prepared for quite a long road ahead. (Dr Amano, 30 April 2021)

Given the popularity of baseball with adult men in Japan, this metaphor was effective in this context, as it enabled him to describe the waves; viral attacks and human defences, the long road to the end, we do not know what will happen in the coming innings, even the possibility of extra innings. In tune with his innings metaphor, Dr Endo from a clinic in central Japan said:

Perhaps when the bottom of the ninth inning comes into sight, we will be able to judge whether this game or our play is good or bad. But now I don’t see the end and have no idea how many extra innings we might have. So, what we do is be committed to defending this inning. (Dr Endo, 30 April 2021)

The inning is an intriguing timescale. Although it is a temporal unit, neither the passage of time nor the coming and going of a wave is enough for a new innings to come. Assessing the effectiveness of vaccination, the emergence of the variants, and the situations in each country, the doctors calculated their own distance to the end and expressed it using innings as a scaling device.

By summer (July–September) 2021, when the Delta variant was raging during Japan’s fifth pandemic wave, the sense that COVID-19

would continue had become stronger. Living *with* COVID-19, or *wizu korona*, seemed likely. Dr Iguchi commented:

I think we're going to be stuck with COVID for a long time. Even if the inoculation rates have reached a certain level, it seems like herd immunity cannot be obtained. ... The vaccine is rolled out, and then the virus outdoes the vaccine. Another vaccine is administered, and then, the virus wins again. ... and so on. ... I think we will be stuck in this constant battle. (Dr Iguchi, 3 September 2021)

Dr Iguchi foresaw a cyclical pattern where the vaccines could not keep up with the mutation of the virus or the emergence of new variants and strains. Around the same period, Dr Fukuda reflected on the broad effects of the prolonged pandemic on citizens, and how this may have led to soaring infections in the fifth wave:

Don't meet friends, don't drink out (they say). It's already 1 1/2 years [into the pandemic]. And going on like this for 1 1/2 years seems to be a bit too much of a strain in many ways. It's probably like, the strain [on people] poured out at the wrong timing, with the outbreak of this Delta variant. (Dr Fukuda, 2 August 2021)

And it was the post-fifth wave period when an unexpected sharp decline in infection rates came that Dr Amano's earlier calculation was disturbed. His comment in November 2021 was a little disorganized:

In the midst of the fifth wave, I thought I was in the fifth inning, or just halfway through, but I'm a bit confused now ... Where are we? I guess we are not in the ninth inning yet, but we might be in the seventh or thereabouts. Definitely, one more wave will come, but it can come quite later ... If the New Year's holiday passes without another wave, we would say that the fifth wave was the peak of the pandemic. (Dr Amano, 20 November 2021)

Dr Amano's optimism was deflated with the rise of the gigantic sixth wave with the Omicron variant, recording about 100,000 cases per day at its peak (see [Figure 3.2](#)). He said:

Now it's like we're in an extra innings, but to be more precise, it's like we don't know if the game is over or not. Some people think it's over; others think it's not over yet. I think that doctors and

medical professionals tend to say it's not over, while those who say it's over are jumping out of the dugout (and act freely as normal). (Dr Amano, 27 April 2022)

This comment implies a limit to the utility of the 'innings' metaphor and a sense of the endlessness of the pandemic. Dr Doi, too, with a mixture of determination and resentment, explained:

I think that the lack of access to vaccines in developing countries has enabled the emergence of this (Omicron) variant ... I wonder if this cat-and-mouse game (*itachigokko*) between vaccine development and the emergence of a new variant will continue, perhaps for a long time to come. Perhaps we humans will have to live in such a situation in the future. I expect that this cat-and-mouse game might continue for 10 or 20 years. (Dr Doi, 30 November 2021)

As in other societies, living *with* COVID-19 means that while the citizens reclaim pre-Covid sociality, the risks associated with infections linger on. Unlike the early days of the pandemic, the primary care doctors have become aware that the general public cannot continue living forever in pandemic mode. The appetite for going *back* to normal remains, but these doctors are fighting a long game or race in their battle against COVID-19, with a perception that there is no real return back to the pre-pandemic normality. The end of the baseball game or goal line in the marathon seems to be obscured, though apparently, we are all heading towards the so-called 'new normal'. And the paths with ups and downs that medical professionals have been finding themselves in seem to be leading them towards various trajectories. In the following section, we examine how pandemic experiences have prompted doctors to re-examine their future career paths and professional roles.

Chronicity and beyond: reflecting on future paths and professional roles

The longer term perspective held by primary care doctors not only addressed upcoming pandemic waves, but also their future outlooks beyond the pandemic. Some interviewees reflected on how their experiences with the COVID-19 pandemic impacted their long-term outlooks of their professional roles and career trajectories. For Dr Jinno, who specialises in infectious diseases, the pandemic was an opportunity

to make her expertise useful for control and prevention in local and national contexts, in the same way she worked in developing countries before opening her own clinic in Japan. In addition, the COVID-19 pandemic turned out to be an opportunity to enhance and expand online consultation services, which she had started working on pre-pandemic. Her provision of online consultations was originally intended to reduce waiting times for outpatient services, but during the pandemic, with more established government policy guidelines surrounding telemedicine, she was able to experiment with their expansion. She jokingly said, 'I'm preparing for my own ageing' (Dr Jinno, 2 September 2022), hinting at how teleconsultations would allow for greater efficiency and a reduced workload.

For Dr Bando, who inherited his family clinic as a third-generation director in an urban area, the pandemic gave him a renewed sense of responsibility as director:

What changed before and after Covid? I realized that as a director (of my clinic), I had to make my own decisions, and I was pushed to do so. Before the COVID pandemic, ... I had always consulted with the staff, talked with them ... I was slow in making decisions. After Covid, I realized that sometimes it was better to make decisions quickly, and that I had to steer the ship to a certain extent. ... [I had been aware that] the level of commitment [of those doctors who start their clinics from scratch] was different from mine. [When I took over the clinic] I was still too scared to take over, so it was delayed until the end of the fiscal year. I wondered if I could really do it. (Dr Bando, 21 November 2020)

In our interviews, Dr Bando reflected on how his father would have responded to the pandemic differently from him in serving the unique demographics – from young hosts to the elderly – in the neighborhood in which he works. Compared with doctors running larger clinics or running or working in hospitals, he noted several times the limitations he had as the sole director and doctor of the small clinic, where he sets his priorities and boundaries. This included balancing fever clinic offerings and vaccine rollouts with the treatment of regular patients. In the decision-making processes throughout the pandemic, he gained a renewed sense of responsibility as *the* director of his clinic. The trajectories these individual doctors have drawn in their careers are independent from the 'lines' drawn in the forms of pandemic waves at the national level, as apparent in [Figure 3.2](#).

The pandemic became an opportunity for the doctors to reflect on their roles as primary care doctors in their local communities, whether with local residents, with the staff with whom they work, the local public health centers and the health workers who work there, members of local medical associations, local authorities and bureaucrats, local schools and teachers, or facilities for the elderly in the city (see Iida et al. 2021, Kimura et al. 2021, Haruta et al. 2021). Dr Fukuda, who forged collaborations with the local public health center to raise the number of beds for COVID patients in his locality, saw the pandemic as a once-in-a-lifetime experience, a turning point in his professional career:

I have been doing this for about 20 years in my long career as a physician, but this is the first time I have ever seen something like this. ... I think this is something I will probably never experience in my life as a doctor, so in a way, I think it is a very valuable experience for me. I think it would be very difficult if there were to be another one [pandemic] like this, and I feel that this would be enough for me. (Dr Fukuda, 21 January 2021)

Dr Chikuma, running a clinic in the Tokyo Metropolitan area, similarly reflected on the significance of building on and sustaining connections with the local medical association, staff at the municipality offices and public health centers and staff at day care centers and schools. In particular, his communication and engagement with public health centers improved during the pandemic, and he hoped to sustain and make good use of such local connections post-pandemic. The pandemic allowed Dr Chikuma to pursue projects at multiple levels: not only those aligning with his local connections, but also at the most immediate level within the confines of his clinic and in relation to a much larger national level endeavour. He explained how young doctors training at his clinic were not able to learn what they would've been able to in more 'normal' situations, but instead, were gaining invaluable experiences dealing with an unprecedented pandemic:

We have two residents working for us now in our clinic ... I told them that this is a disaster never to be seen again, asked them how many family doctors can get to have such a good experience. Normally ... we have many residents who want to learn to see children ... They also want to experience end-of-life care or learn about palliative care at a deep level ... But this time, [our strengths

in these areas] have collapsed ... [We feel sorry for them], and yet, they're experiencing things that they absolutely wouldn't have [experienced if it weren't for the pandemic]. (Dr Chikuma, 18 August 2021)

The training of young doctors can be situated as part of Dr Chikuma's larger project of educating the next generation of primary care doctors and raising the status of primary care doctors in society at large. Many interviewees pointed out that the vaccine rollouts brought out debates around what 'regular doctors' (*kakaritsuke-i*) means, since the paperwork involved to be vaccinated encouraged citizens to reconsider who their 'regular doctors' were, given that Japan's free access health care system lacks a registry system of doctors. According to Dr Chikuma, the ambiguity in the definition of what it means to be a 'regular doctor' surfaced during the pandemic (22 May 2021), leading to reflections on what the 'regular doctors' should do. He added that this was an issue that had to be addressed by the Japanese Primary Care Association and 'debated with the Ministry of Health, Labor and Welfare'. For him, the pandemic offered a 'precious opportunity for change' (22 May 2021) – a *revelation* of an issue that requires *structural transformation* (Fassin and Fourcade 2021, 7–9). He further noted:

I strongly believe that we [primary care doctors] need to be more open to change than doctors specializing in other fields ... Japan has very few doctors specializing in infectious diseases, so we have to be at the forefront, while working with our regular patients. I feel like this time, we painfully learned ... the importance of being able to change in response to the [shifting] local needs ... We always need to have volatility, the ability to transform ourselves ... This is the appeal of primary care, but at the same time, we need lifelong education and we need to continue thinking about many things. It can be a hassle, but we have to communicate to our juniors that this can be a fun career. (Dr Chikuma, 21 November 2021)

While the long-term visions gained by the doctors in the specific context of the pandemic had significance at personal level, in some cases, they aligned with national-level agendas involving primary care doctors' expanding roles in Japan.

Waves, lines and angels: concluding remarks

Thus far, we have discussed the four modalities of time that appear in the narratives of the doctors we interviewed. The first was the temporal framework which was evoked in reference to immediacy, emergency and provisional reactions, and the second was the realization and conception of being in an interval. Thirdly, there was the contextual perspective on the long-term progression of the pandemic, and finally, a reflection of the place of the pandemic in doctors' long-term careers beyond the pandemic, potentially leading to transformations at both individual and structural levels. These modalities were not necessarily clear-cut 'phases' that the doctors shifted from or to: they often coexisted and were intertwined in their everyday clinical practices.

All this time, doctors and other medical professionals were portrayed in the popular media as 'warriors' at the forefront of our fight against Covid, collectively leading our way toward the end of the pandemic. However, as reflected in the narratives of the doctors, there was no blueprint or premeditated script of this journey; rather, the doctors adopted ad-hoc responses and improvisations to emergent temporalities, invented creative metaphors to make sense of their situations, and reflected on their experiences by contextualizing them in their personal careers and roles within their local communities. Each decision they made and action they took in their clinical practices was a product of the confluence of these different modalities, rather than being based on a teleological master plan to bring the pandemic to an end. Ingold's (2007) conception of 'wayfaring' as opposed to 'transport' might help us better understand this process:

I have established a contrast between two modalities of travel, namely wayfaring and transport. Like the line that goes out for a walk, the path of the wayfarer wends hither and thither, and may even pause here and there before moving on. But it has no beginning or end. While on the trail the wayfarer is always somewhere, yet every 'somewhere' is on the way to somewhere else. The inhabited world is a reticulate meshwork of such trails, which is continually being woven as life goes on along them. Transport, by contrast, is tied to specific locations. Every move serves the purpose of relocating persons and their effects, and is oriented to a specific destination. The traveller who departs from one location and arrives at another is, in between, nowhere at all. Taken together, the lines of transport form a network of point-to-point connections.

In the colonial project of occupation, this network, once an undercurrent to life and constrained by its ways, becomes ascendant, spreading across the territory and overriding the tangled trails of inhabitants. (85)

Perhaps it could be argued that the journey was a ‘transport’ when it started; the goal was to restore the pre-pandemic social order and return social and economic life to the normal state. This was the intended ‘destination’ not only for medical professionals, but also within the public imagination and discourse that clung to the idea of returning to business as usual. As the pandemic lingered, however, it gradually became the chronic state, constituting the *de facto* normal or the ‘new normal’. This entailed the reconfiguration of our ideas regarding our daily practices and routines; the strange became familiar and the familiar became strange, displaying a strikingly anthropological inversion. This calls into question whether we live our normal lives at the heights of ‘waves’ or during these intervals.

To be sure, the multiple ‘waves’ that hit Japan were not experienced as repetitions or recurrences of the same old patterns. The doctors who we interviewed observed stark differences in each wave, often comparing and contrasting the characteristics in terms of the mutated variants of the virus and the accompanying symptoms, rates of severity, key social events as backdrops to the outbreak, and major sites and populations that became the target of infection. We have shown in [Table 3.1](#) (above) some of the marked differences of each wave. Each ‘wave’ was experienced as distinctive from the previous ones, and its sequential numbering continues to present, attesting to the fact that the ‘waves’ in Japan have been plotted along a linear timeline, rather than being embedded in ‘cyclical’ time (Leach 1971). Leach’s dichotomous conception of time has been dismissed as simplistic and without evidence (Munn 1992), and we are not trying to make a claim that the Japanese conception of sequential ‘waves’ is representative of its modernity nor that it was a universal view of the pandemic. Even so, rather than viewing the sequence as representing ‘reason, certainty, authority, a sense of direction’ (Ingold 2007, 171) as linked to linearity, our interviewees eloquently spoke about their experiences through various culturally and generationally specific metaphors. For example, Dr Fukuda noted:

Frankly speaking, the Omicron variant totally changed the picture. It’s possible that another variant would come along, and if that variant has a completely different quality, we’ll have to deal with

that. It reminds me of ‘Evangelion’, where a different Angel shows up each time, and as they disappear we’d be like, ‘wow, that was a tough one’. But then we’d expect the appearance of the next Angel, and we can’t take the same measures as the previous one. (Dr Fukuda, 21 January 2022)

By ‘Evangelion’, this doctor is referring to the well known Japanese anime TV series *Neon Genesis Evangelion*, which earned a worldwide cult audience in the 1990s. The storyline of this anime is as follows: a group of selected children undergo special training to combat beings called *Shito* (Angels) to emancipate the world from their destructive attacks. From where and why the Angels come largely remains a mystery, but they come in different forms and characters. Based on the sequence of their arrival, they are numbered and referred to as ‘the 1st Angel’, ‘the 2nd Angel’ and so on, bearing an interesting resemblance to how we have named the COVID-19 variants after Greek letters. The anime is known for its apocalyptic worldview as well as its in-depth depiction of the protagonists’ existential enquiry and crisis in facing their fateful mission to be the selected ones to combat the Angels. The doctors, of course, also go through rigorous selection and training, and it could be argued that it was their imperative professional duty to be at the forefront during the COVID-19 pandemic. Dr Fukuda never discussed his personal anxiety or distress, so his Evangelion metaphor left us to wonder how he identified with the protagonists.⁴

The past, in short, does not tail off like a succession of dots left ever further behind. Such a tail is but the ghost of history, retrospectively reconstructed as a sequence of unique events. In reality, the past is with us as we press into the future. In this pressure lies the work of memory, the guiding hand of a consciousness that, as it goes along, also remembers the way. Retracing the lines of past lives is the way we proceed along our own. (Ingold 2007, 122)

Notes

- 1 The researchers included Ryohei Goto, Yusuke Hama, Junji Haruta, Junko Iida, Makoto Kaneko, Junichiro Miyachi and Sachiko Ozone.
- 2 Although the Japanese government promoted the introduction of primary care, there was a long delay in the process, partly due to resistance from the Japanese Medical Association (see Kaneko et al. 2019, Fukui et al. 2017, Ministry of Health 1987). Under the current certification system, launched in 2018, physicians in Japan must choose from ‘the basic area specialties’ approved by JMSB (the Japanese Medical Specialty Board) after two years of general rotation.

- 3 Among the 1,186 primary care doctors in Japan, 71.6 per cent (849) are male.
- 4 The research on which this chapter is based was approved by the Ethics Committee, Japan Primary Care Association, No.2019-013.

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How time paused ... COVID-19 and everyday life in Vietnam

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Vietnam was hailed as a model of success for public health policy, keeping COVID-19 infection at near zero in the early months of the pandemic (Nguyen Thi Yen et al. 2021; Tran et al. 2020; Van Nguyen, Cao and Nghiem 2021). Living in places like Ho Chi Minh City in mid-2020 was relatively ‘normal’. But, even so, it was tempered by horrific stories from almost everywhere else in the world and by public health concerns and responses that drove and maintained a sense of fear and dread. Over time, some considered the policies in Vietnam as being too harsh, with strict measures such as national lockdown, intensive contact tracing and centralized quarantine for close contacts of patients (Doan 2023). Others praised these measures as necessarily comprehensive to contain the pandemic.

Given the history of epidemics in the region, Vietnam was able to rapidly develop a plan and implement it for COVID-19. When SARS infections in China (2002–4) extended beyond the border with Vietnam, the ‘edge of safety’ became non-existent (Herring and Lockerbie 2010, 182). Even so, Vietnam had few SARS cases due to the establishment of dedicated infection wards in hospitals and the rigorous and rapid isolation of patients once the risks to nosocomial infections were realized. This occurred in parallel with expanded media communication to the public to increase awareness and precautionary action. Vietnam was also one of the first countries impacted by H5N1, which quickly became known globally as the feared ‘coming plague’. The government initiated the strict enforcement of interventions to counter H5N1, including the extermination of chickens and mandatory vaccination, and ultimately initiated a plan to phase out live bird markets at which chickens were sold to households for domestic consumption (Porter 2019). The government

of Vietnam focused on small for-profit and household farms, despite the probability that a larger-scale outbreak would most likely occur in larger commercial farms (Herring and Lockerbie 2010). These measures therefore impacted most harshly the poorest families, where poultry was used for household consumption, for income generation and in social rituals which function to build community trust. Indonesia's failure to follow these same measures to contain H5N1 resulted in global organizations such as the World Health Organization (WHO) considering that country 'non-compliant' and creating a 'dangerous' scenario (Herring and Lockerbie 2010). Although H5N1 did not transition into a global pandemic, a culture of danger was reinforced through rhetoric related to the need for pandemic preparedness. At the same time, as H5N1 spread in Southeast Asia, social, political and biological relationships were disrupted (Caduff 2015).

Later, in spring 2009, a new strain of influenza A (H1N1) virus emerged in México and set off a similar chain of events (MacPhail 2014), again reinforcing global pandemic anxiety and creating similar 'geographies of blame' (Singer 2009). While a global pandemic was avoided again, this narrative of 'when, not if' regarding an eventual pandemic continued (Caduff 2015; MacPhail 2014, 26). The *when* finally occurred in December 2019, and set off a chain of events globally. In Vietnam, as we describe below, these events and responses built on prior pandemic experiences and the culture of danger surrounding past pandemics, as well as in relation to COVID-19 as it was unfolding.

The timeline in Vietnam

The first reported case of COVID-19 in Vietnam, identified on 23 January 2020, was an elderly man from China who had just crossed the border into Vietnam. Border crossing continued to contribute to transmission, fueling blame towards people other than Vietnamese, including predominantly the Chinese but also other foreigners, reflecting the high media coverage of COVID-19 outbreaks in China and beyond.

After the Tết (spring festival) holiday, 23–8 January 2020, the Vietnamese government mandated that the schools be closed and online learning implemented. The first reported case of COVID-19 in Hanoi on 6 March 2020 involved an (illegal) border crossing. In Ho Chi Minh City, a small outbreak occurred after celebrations at a bar on St Patrick's Day (17 March 2020), which had proceeded despite official requests that large gatherings be avoided; people identified as being at the St. Patrick's

Day bar celebration were placed in government quarantine camps. By the end of March 2020, only 212 cases had been identified country-wide, but even so, the government continued a firm, fear-driven response, including sending people who had been in the vicinity of any known COVID-19 case to government quarantine camps located in various spaces within and on the outskirts of larger cities. Country borders were closed to all foreigners from 21 March 2020, and there was a short nationwide lockdown from 1–23 April 2020.

These swift severe actions enabled the Vietnamese government to contain the pandemic, and life resumed internally other than the borders remained closed, masks were mandatory and large gatherings were discouraged. Vietnam celebrated 99 days, between 25 March and 24 July, without infection and consequently permitted designated repatriation flights for Vietnamese who had been caught overseas. Several small ‘waves’ of COVID-19 occurred after this, but each was managed with strict contact tracing and reporting, quarantine and local measures. For example, in July 2020 there was an outbreak in a hospital setting in Da Nang (central Vietnam), followed by another hospital outbreak in December 2020 in Hanoi (northern Vietnam) and several other smaller, but contained, outbreaks. Vaccines were introduced for health care workers and other essential staff from April–May 2021 and were distributed to communities at different time points, with prioritization reflecting local transmission of the virus.

The first major wave of infection country-wide occurred in May–June 2021, after many people had traveled between regions within Vietnam for tourism or to visit families during a public holiday period of four days. Reports of spikes in infection, rumors of strict lockdowns, and other severe restrictions led to public panic, with mass exodus of people from Ho Chi Minh City to rural areas to avoid these strict measures. COVID-19 continued to spread, and Vietnam finally had major lockdowns of varying lengths and strictness from July to September 2021. Between November and December 2021, depending on the location, Vietnam entered a ‘new normal’ period, although normality was difficult to define.

Depending on time and place, and the status of transmission at a given moment, varying levels of restrictions operated. One event could change a person’s routine in a snap second, without warning. Given such uncertainty, what do we make of the ‘everyday’ for people living in these moments? In Vietnam, the everyday could become quite extraordinary sometimes, mundane at other times, yet always infused with an atmosphere of fear. To examine how Vietnamese communities

maneuvered through the everyday in the pandemic, we frame our chapter around three main themes: ‘Emptiness and economics’, ‘Viral flows, social anxiety and agency’ and ‘Struggles through space and time’.

Methods: a pathography in the making?

For this analysis, we focus on the interactions between the virus, communities and pandemic responses, exploring ‘multiple layers of experience’, a sort of pathography in the making in times of complete flux (MacPhail 2014). We worked with communities across Ho Chi Minh City and Hanoi, in urban sites linked to national infectious disease hospitals and in Dak Lak and Nam Dinh, rural settings linked to an ongoing Oxford University Clinical Research Unit study,¹ as part of a larger two-phase project called Social Science and Public Engagement Action Research Project (SPEAR) (Van Nuil et al. 2021). SPEAR was conducted in Indonesia and Nepal as well as Vietnam, in a total of 13 sites, with both health care worker and community participants in each site. We conducted surveys and in-depth interviews, and collected digital diaries during the project. In SPEAR Phase 1, we explored the experiences and impacts of COVID-19 and the public health response, while in SPEAR Phase 2, we added a focus on acceptance and uptake of the COVID-19 vaccination. In this chapter we focus on Vietnam community participant data from in-depth interviews in both project phases.

Prior to initiating directed interview questions, we invited participants to ‘tell us the story of your experiences during COVID-19’. The responses to these narratives form the basis of the analysis; however, we also reviewed the full interviews for contextual and more detailed information. The sites remained the same; across the sites, we interviewed a variety of participants, different people in each phase, including people who had experienced COVID-19 within a hospital setting or spent time in quarantine in Vietnam, as well as staff from the quarantine camps and hotels. We also interviewed women who gave birth during the pandemic and people across a variety of other occupations (Table 4.1). In total, we interviewed 56 participants in Vietnam between Phase 1 (March–May 2021) and Phase 2 (April–July 2022).

Table 4.1 Research site and occupation of participants, by phase.

	Phase 1	Phase 2	Total
Research Site			
Daklak	2*	8	10
Hanoi	12	5	17
Ho Chi Minh city	7	5	12
Nam Dinh	12	5	17
Occupation			
Tourism/restaurant workers/transport	9	0	9
Healthcare/health-related	1	7	8
Shop owner/office workers	6	2	8
Skilled labour (engineer, carpenter, etc.)	6	1	7
Retired	3	4	7
Stay at home	3	3	6
Farmers	2	4	6
Lecturers/university students	3	0	3
Unemployed	0	2	2
Total participants	33	23	56

* In Daklak Phase 1, it was impossible to collect data due to movement restrictions, therefore only two interviews were conducted. In Phase 2 we were able to travel to the field site so were able to interview more people.

Emptiness and economics

I'm also not used to seeing this city [Da Nang, one of the busiest tourism cities] so empty ... I have never seen this town so deserted. (Mr Vu, doctoral student)²

Adriana Petryna (2015) talks about 'tipping points' as moments where irreversible change is inevitable, and when communities, nations and global forces need to reconfigure. This is exactly what was happening; it still is, to some extent. While country and community tipping points may have varied according to the unfolding of the pandemic, change was inevitable. The aftermath is chronic and ongoing. Yet the ways that we (collectively) respond to these changes are dramatically different and change over time. At the time of data collection, COVID-19 and the associated responses became tipping points both locally and globally.

Early pandemic imagery as distributed through television and social media sources around the world included photographs of dying and death, and narratives of dramatic sickness from COVID-19. In early 2020, while the Vietnamese government was planning its response, communities

started to see and hear about the pandemic through these media channels. Mr Duc, a business owner from Ho Chi Minh City, remembered the early media images from China: 'In the first wave in Wuhan, all the images on media were about death, like the videos where people suddenly die on the street'. Ms Vy, a village health collaborator who worked on health communications during COVID-19 in Nam Dinh, compared Vietnam with other countries where the situation was very different at that time: 'In Vietnam the situation is not serious but when I watched on the media and the TV, I saw that other countries had been impacted seriously'.

Closer to home, several participants referenced one early case of a foreign pilot who was hospitalized due to severe COVID-19 in Ho Chi Minh City and became very sick. He recovered over time, and while his case demonstrated the potential dangers of COVID-19, this was used as a success story for the hospital (and country). Mr Duc continued about the media: 'And also the case of the pilot. It made people think that if they got the virus they would die', although the pilot made a full recovery. Further, while there were still relatively few cases in Vietnam, it was possible to reference and track individuals' illness and health, with a few 'famous' cases, identified numerically, occurring over the course of the pandemic (see details below).

In addition to the stories and images surrounding illness and fear, there were stories of emptiness that was unlike any situation people had previously experienced. For example, Mr Vu was a doctoral student, studying abroad and with their degree almost completed. At the start of the pandemic they decided to travel back to Ho Chi Minh City, as cases were rising elsewhere across the region. Mr Vu experienced several forms of emptiness: empty spaces, empty good-byes and empty emotions:

On the day I left [South Asian country], the airport was deserted, I have never seen such a scene. It was unimaginable to see this [country] empty. I could not meet my supervisor or friends there. There were so many emotions on that day. But I knew because of COVID, I had to protect myself and the people around. I just said good-bye to the people that I lived with.

There was also emptiness in the aftermath. Many shops were forced to close due to long-term lack of business, and city streets were empty of foreign tourists because of travel bans. Many factories in the suburbs of Southern cities terminated their production due to prolonged social restriction policies, leaving these large industrial zones as empty spaces, while factory workers, who were mostly migrants, returned to their

hometowns. These forms of emptiness impacted economies. In some cases, it was irreversible and damaging; for some, COVID-19 became an opportunity to capitalize on people's fears. Ms Thuong, from a rural site in Nam Dinh, told us that she had to sign an agreement with local officials that she would close her clothing store after she became known as a potential risk through caring for her husband, who was being treated in the Bach Mai hospital during the outbreak that occurred there in December 2020. Even though she had tested negative for COVID-19 and had gone through 28 days of self-isolation, the local decision to suspend her business implied a heightened alertness towards COVID-19 transmission risks among communities. Ms Thuong explained to us that she had to be proactive and take care of herself and her community, even at the expense of her own livelihood: 'I heard that we would be supported [financially] by the government but my family, just us, wasn't supported with anything from the government. We just did what we had to, as long as it was good for the community'.

For some shop owners, this may have been viable by drawing on savings or extended family support. For others, including salaried workers and those in the informal economy, the economic impact included reduced salaries, reduced or lack of leave – including sick leave – and even termination of positions altogether. One participant, Mr Hung, was an airport employee in Ho Chi Minh City; his hours were impacted when the international section of the airport shut down due to travel bans. Mr Hung told us that he was lucky enough to keep the job at reduced hours and salary, as 20 per cent of staff were let go completely. Those lucky enough to keep their jobs were forced to 'share the burden' with the companies they worked for, as industries were also suffering and managers called on their staff to take part of the loss. Ms Chi, a bus station employee in Nam Dinh, narrated her experience over time:

In April 2020, the company stopped the transportation activities so the workers in the company were off [work] and there were only some administrative staff still working. At that time, I was still working in administration so we took turns to come to work every other day ... In terms of finance, the income of the company reduced so our salaries were decreased as well, you know, to *share the burden* with the company.

For Ms Chi, this meant a percentage of salary reduction in April 2020. Depending on their position, staff experienced salary cuts of 10–20 per cent, with people in management positions having larger

percentages of decrease. The company canceled health insurance coverage for some as well. Salaries were reduced again in September or October 2020 by another 10 per cent, so staff continued to share the burden as the pandemic progressed.

In Daklak province, a rural, remote area, the picture was slightly different. When the outbreaks progressed more seriously, accompanied by strict movement restrictions for prolonged periods, community members were at risk of losing their livelihoods altogether. These participants were mostly farmers and were unable to travel to their farms to take care of their crops. Their income depended on the produce, but most aspects of farming were almost impossible during periods of serious outbreak and mobility restrictions in 2021. In other cases, before COVID-19 many young people had migrated to cities in Southern Vietnam for manual work in industrial zones. But the major COVID-19 wave of 2021 in the south produced a wave of layoffs as factories closed down, forcing workers to return to their home provinces. There was accumulating distress about livelihoods over the course of the pandemic, as a farmer, Ms Di, reflected: 'If they [the government] keep restrictions like this, we will probably die of hunger'.

Ms Nha from Nam Dinh had a different experience. Although she was forced to close her coffee shop, which she had first opened in 2018, her main job was in pharmaceutical sales, which was much more financially lucrative during the pandemic.

The business [coffee shop] was struggling, but in the health care sector, as I work in medicine, honestly, it was the smoothest year ever [laughs] since I started working in this area [18 years ago]. I didn't have to do anything but the revenue was enormous because people were worried and stocking up. They were stocking up on everything, especially medicine or anything for prevention ... At the beginning of the pandemic, and then in last April and May 2021 when the second wave happened, every family like mine or the neighbors had at least several bottles of eye drops, then sanitizers, then the most essential things like medicines for abdominal pain or headache. We might not have it at the usual time [outside of the pandemic] but since it was the outbreak time, we were afraid that there was something that might happen or our neighborhood would be quarantined. That time was frightening.

Despite the productive sales and increased income, it was still a frightening time for Ms Nha since the strict controls (for example, being

sent to a quarantine center, having the whole neighborhood blocked) and the COVID-19 virus itself did not discriminate.

Viral flows, social anxiety and agency

All four directions are locked – it's unimaginable. (Mr Nam, flight attendant)

Vietnam had extremely strict controls compared with other places that often stripped agency from individuals. One example was contact tracing and quarantine policy. As part of its detailed contact tracing policy, Vietnam initiated the 'F-system of targeted isolation' to document and track potential contacts of cases and their contacts, with patients ranked from F-0 to F-4 (Hardy, Shum and Quyen 2020). This caused extreme social anxiety due to the potential of being placed in quarantine for being a contact of a case (applying to those ranked F-1, or F-2 at times) or being sent to hospital in confirmed cases (those ranked F-0). But it was not just the fear of being taken away from their families and homes which impacted individual freedoms; it was also the shame and blame associated with the tracking and labeling of those who acquired COVID-19.

Stigma and blame related to pandemic origins have been issues over time, as reflected in the persistent idea that viruses are 'imported' or foreign, that is, from outside (Wald 2008) – reflected in Vietnam's labeling of H1N1 as 'Mexican flu' or 'swine flu' and COVID-19 as the 'Chinese virus'. The words used to describe individual origins of pandemics have the ability to enhance the viral flow with social impacts, such as using words like 'index case' and 'super-spreader' (Wald 2008). These descriptions, while used by epidemiologists to identify and track epidemics on national and international scales, often have unintended consequences. The implications in past pandemics were significant, for example, stigma against whole regions or groups of people, but we also see a similar micro-impact in Vietnam. Here, it played out on a smaller scale, with the goal of identifying the local (community-level) origins of COVID-19 outbreaks (MacPhail 2014, 29). It had similar consequences.

As soon as someone became a F-0 or moved from F-1 to F-0, they were assigned a patient number and became a 'case'. The numbers were publicized on government websites daily in the early phases of the pandemic (later, less frequently) and local cases were often announced in communities over loudspeakers or other channels. The intent was

to track and trace potential contacts and break the chain of transmission. While the information publicized did not include all details of individuals, it did include their initials, location and often detailed reports of all the places they had visited for the previous 7–10 days. It was therefore quite simple to identify a person based on this information, and to know their movements, any of which was discouraged at this time. Most people who acquired COVID-19 in 2020 and into 2021 knew their individual government-assigned case number. Mr Duc, a business owner from Ho Chi Minh City, started his narrative with his number as part of his demographic information: ‘My name is Mr Duc, I was the 5xxth patient, I was born in 1978 ...’ Others knew the case numbers of everyone in their family, in addition to their own: for example, Mr Dai, a supermarket manager, said ‘The three other patients in my family were numbers 1xx, 1xx, 1xx, and I was 2xx’. As mentioned above, there were several ‘famous’ cases where many people still remember the individual stories and called them by their specific patient numbers. For example, Patient 17 was a young Vietnamese woman who flew back to Vietnam from UK at the start of the pandemic and failed to report her travel to the authorities. She ended up spreading COVID-19 to two individuals after 23 days of Vietnam being COVID-19 free.

Despite the importance of contact tracing in breaking transmission chains, the identification and subsequent blame had real impacts for many people. Take, for example, Ms Hang, a middle-aged woman working in the hospitality business. She acquired COVID-19 during the Da Nang hospital outbreak at the end of July 2020, while caring for her sick mother. She became identified as F-0 (that is, COVID-19-positive). She spent 30 days in one of the repurposed COVID-19-designated hospitals, an additional 15 days of quarantine in the district health centre and 15 more days self-quarantining at home. As part of contract tracing, Ms Hang listed all her contacts (that is, F-1s). They were subsequently brought into local quarantine facilities, knowing very well that Ms Hang was the one who had provided their names to the officials. Although none of them had acquired COVID-19 when they were tested in quarantine, they blamed her for bringing COVID-19 into the community and blamed her for not reporting her travels to the outbreak hospital, according to the rules, when she came back from Da Nang. However, the announcement about the hospital outbreak in Da Nang was made only two days after she returned so she was not aware at the time that she was supposed to report. Ms Hang even blamed the ‘American guy who was positive’ and started the outbreak in the hospital in Da Nang, her distant F-0 presumably. The trauma for Ms Hang extended

beyond statements of blame. She was evicted from her apartment, she lost her job and the majority of her friends turned their backs on her and blocked her from online social media groups. This all took place while she was in the hospital receiving treatment for COVID-19. The discrimination expanded into her social realm and she experienced real life consequences – ostracism from her community – from acquiring COVID-19 early in the outbreak. Her loss of agency, reflected in enforced quarantine, also had real consequences and, as she explained, the collective was not a collectivity for everyone. At the end of her narrative she reflected, ‘people are selfish’. The measures focused on interrupting viral flows had an incredible impact on (some) people’s lives.

Yet this was not always the case. Mr Duc, who owned a business, also contracted COVID-19 during the Da Nang outbreak; like Ms Hang, during his holiday travel. Yet, he felt that he had more social capital and knew that he was different from others. ‘When I was positive, I knew that I was not a normal person’, Mr Duc explained, and he decided to publish his experiences on a blog to dispel rumors that might damage his business reputation. In the interview, he shared that he was well aware of the potential rumors and disclosure of his personal information throughout the community. Instead of doing nothing and letting the rumors flow, he decided to instead develop an eloquent communication plan to prevent stigma for himself, his family and his company. His strategy included regular communication with his staff regarding how to communicate with their business partners about his COVID-19, and a 26-day online journal describing his firsthand COVID-19 experiences in the Hospital for Tropical Diseases in Ho Chi Minh City. Additionally, he actively published the history of his movements on his personal social media accounts, aiming to provide transparency and prevent misinformation.

To ensure information accuracy, I wrote very clearly ... what it was like when I got infected, the staff whom I contacted [who] all went to quarantine [after his infection was revealed]. I had been self-isolated at home the whole time [before positive testing] so it should not affect the company, and my company operated normally.

Mr Duc felt that he did not suffer discrimination, and prided himself on being able to learn and write about COVID-19. He even started to discuss ideas for prevention and control with local leaders in the community.

Placing Ms Hang and Mr Duc’s narratives in juxtaposition reflected a critical difference of how people with different socioeconomic statuses

and genders might be affected by the same public health response. Both of them had to go into quarantine when notified as a transmission risk and were hospitalized for treatment when infected. However, social stigma significantly affected Ms Hang who belonged to the lower socioeconomic stratum with almost no capacity and no voice to fight back against her ostracism by her restaurant managers, landlords, friends and relatives. She lost her job, could not find a new one afterwards as a result of being publicly known as a positive case, and she just 'gave in'. On the contrary, Mr Duc, who owned three different companies, actively wrote about his infection and COVID-19 information through his own research skills, maintained regular interactions with other people and kept his businesses running. Discrepancies in the existing socioeconomic capacities between social classes led to the difference in coping capacities towards the pandemic and strict public health responses, which subsequently created unequal pandemic experiences within and among the communities.

Over time, there was a change in the tone of the narratives. In the second phase of interviews, the narratives were less about fear and panic and often included a reflection on the actions taken during earlier pandemic phases. One participant from Ho Chi Minh City, Ms Hoa, stated: 'The prevention measures were horrible, it was not even effective and it messed up our lives'. She continued: 'We should have learned from their [other countries'] mistakes, but we did not, we closed our doors still and we still had zero Covid programs'. In her case, she was confined to her house for over one year, and many of her friends died because they could not access routine care. She equated this period to the American war and reflected that she 'was scared of the way they [society] treated people'. She also admitted that she thought COVID-19 was a conspiracy of 'big pharma':

And I think there's a conspiracy theory here [laughs] which is that they used COVID-19 to their own advantage, took advantage of the pandemic to make a profit. And it's not just our country, but all over the world. All of 'big pharma' benefited from it.

During the second phase of research, the pandemic policies were quite different. While people still recalled the chaos and fear that characterized early phases of the pandemic, the government stopped reporting peoples' names and locations; instead it listed only total case numbers on the government's social media channel of communication for COVID-19. The policies on quarantine and contact tracing were also less strict.

People's narratives started to include stories of acquiring COVID-19, sometimes multiple times, and they were able to decide individually whether or not they would go to the quarantine center or hospital (for example, Mr Thuan from Ho Chi Minh City had acquired COVID-19 four times before his interview). While lack of restrictions allowed people to move around, the same participants reported a lack of support from the community, including lack of monetary and food support that were available (albeit sporadically) in earlier pandemic phases, and from health centers for care and treatment of COVID-19.

Struggles through space and time

I think time is not lost, it just pauses. (Ms Yen, Ho Chi Minh City)

While measures were strict in Vietnam, participants still pondered where the safest place to be was during the first days of the pandemic. Some people had choices regarding where they could be, but most did not, and could only imagine which places were safer in comparison to other places in the world. Participants from SPEAR Phase 1 agreed that Vietnam's response was 'better than elsewhere' (Ms Thao, Ho Chi Minh City). Mr Lan, a participant from a travel company in Hanoi, commented: 'I found that Vietnam is doing well in pandemic prevention and control. Everyone is on high alert of the pandemic while Europeans and Americans don't really care because they are so used to freedom and democracy that sometimes it's difficult ... everything will gradually get back to normal'. Ms Yen, the student studying in the United States, came to Vietnam at the start of the pandemic to 'hide' from COVID-19, and likewise described people in New York where they lived as being 'not really careful' or not taking the pandemic seriously.

Within communities, there were also safe and less safe spaces. The strict containment policies of Vietnam created a separation of living spaces for the communities. In the first phase, whenever a community case was identified, the local authority would quarantine the whole ward (local government area) to monitor close contacts to prevent transmission. This created a sense of two different worlds, sometimes separated by just the width of an alley: the ward in *cordon sanitaire*, where no entrance and exit was possible except for the COVID response team, and the rest of the area where people conducted a relatively usual routine.

Later, in addition to spaces that inhabitants could not leave because of infection within, other spaces were also considered 'safe' or without



Figure 4.1 Barricades in front of an alley with COVID-19 cases. Source: SPEAR Digital Diaries project, by permission.



Figure 4.2 A postman stopped at the barrier in front of an alley with COVID-19 cases. Source: SPEAR Digital Diaries project, by permission.

infection; in these, no one was allowed to enter unless they lived there, so as to keep out potentially infected people.

People's experiences within their own spaces also differed dramatically. For example, two participants from the same rural community, Ms Han and Mr Than, were both quarantined because they had visited the Bach Mai hospital during the outbreak in December 2020. Ms Han, a farmer, went there for a routine health appointment. On her return home, she realized that there had been an outbreak there. She voluntarily informed the authorities that she had been at the hospital, and local health care workers went to her house to complete the health declaration. When the neighbors saw health care workers at her home, they started suspecting and spreading rumors that she had COVID-19. Worse, Ms Han was told that her name was announced on the community loudspeaker and on social media, although she was not sure if it was really her name as she never tested positive for COVID-19. Still, she quarantined at home as advised and 'felt ashamed' as rumors circulated around her. But when interviewed in April 2021, she commented: 'It's over, it's back to normal'. On the other hand, Mr Than was a retired official who had a heart attack and was admitted to Bach Mai hospital. He was there during the outbreak and went home for self-quarantine. No one from his family or friends visited him in-person during this time, even though he had had a heart attack and not COVID-19. But people did check up on him in other ways, for example, dropping off supplies of food, calling on the phone to check his health status and so on. He felt that no one treated him differently, and he did not feel at all ashamed of being quarantined at home.

Living through a pandemic can cause a disruption of perceptions of time (Caduff 2015). In Vietnam, as elsewhere, the pandemic's development was described in terms of waves, as there were times and spaces (before spring 2021) where there were no cases. People also referenced COVID-19 in terms of phases, for instance as being the 'last' phase of COVID-19, and spoke about times when the pandemic would be over.

Only when this pandemic is over, can I ... I'm thinking that after the pandemic is over and everyone has calmed down, could I reveal that I used to be like this [a person who had COVID-19 previously], otherwise only my family, like my mum, my parents, besides them, I can't tell anyone. (Ms Hang, Ho Chi Minh City)

Phase 2 narratives focused more on vaccination, random lockdowns of buildings (not neighborhoods), multiple testing campaigns and greater

freedom to move around. These were coupled with tense feelings and complaints about lack of access to basic food items as well as high shipping fees for the delivery of food to people confined to areas that were under stay-at-home regulations.

Even so, there were still some feelings of fear regarding acquiring COVID-19, as Mr Dung, a psychiatrist from Ho Chi Minh City, described: 'What really made me worry was that if I caught the virus, I would become *a national criminal!*' Simultaneously, Mr Dung spoke about how his job became more routinized, for example, working two to four weeks at the hospital and then going home to be with family for a week or two to avoid COVID-19 transmission to his family and community. He also mentioned that during this phase his work role increased within the community. For example, he started to call F-0s and provide mental health support. Many other participants talked about how they were waiting for allowances or government financial support because they had lost their jobs, but the exact date when these allowances would be made available kept moving forward, as Mrs Lan, a nurse from Ho Chi Minh City, experienced. Another participant, a retired woman from Ho Chi Minh City, reflected on the impact of COVID-19, and its uneven impact over time and between different groups. As time moved on, narratives also became more reflective.

The unknown and the unfinished

I have my life there [in the United States] and it suddenly came to an end. (Ms Yen, a student, Ho Chi Minh City)

The end of some things became new beginnings for other things. Many of the participants adapted to new forms of life while surrounded by unknowns. The unknown was also what happened to people experiencing unequal burdens of the pandemic over time. In 2021, there was an outpouring of media accounts of people losing their entire families due to COVID-19 in Ho Chi Minh City. The story of Ms Hang, stripped of all her agency after acquiring COVID-19, cannot be unique, as the outbreak disproportionately affected the poorest neighborhoods in Southern cities.

Togetherness and belonging, or sociality, is part of what makes us human, and these social necessities and interactions are the same actions that allow infectious diseases to thrive (Wald 2008). To completely isolate from each other goes against social life, yet the fear and danger

surrounding COVID-19 created the space for social worlds to unravel and showed the ‘power and danger of bodies in contact’ (Wald 2008, 13). The narratives of COVID-19 and the public health response also impacted how individuals and whole communities reacted to each other, and created spaces for stigma to thrive for some.

Individual experiences also point to larger inequalities that shaped how the pandemic and public health responses were lived over time. The pandemic was in a state of becoming (Biehl and Locke 2017); over time, the narratives changed. But was life experienced differently or were memories altered? The only certainty was that everything was uncertain. In this context, we have unfinished ‘stories of transformation’ for communities living through a pandemic. And we are missing narratives since the country entered the ‘new normal’ in late 2021. The pandemic may be ‘over’ but its effect is surely lingering across Vietnam.³

Notes

- 1 Oxford University Clinical Research Unit (OUCRU) is a research programme focused on infectious diseases in Southeast Asia with an aim of having local, regional and global impact on health. OUCRU has main offices in Ho Chi Minh City and Hanoi in Vietnam, in Jakarta, Indonesia and in Kathmandu, Nepal. OUCRU is affiliated with Nuffield Department of Medicine at the University of Oxford.
- 2 All names used in this chapter are pseudonyms.
- 3 We would like to acknowledge all the participants from the SPEAR Study, the SPEAR study team, and the OUCRU COVID-19 Research Group. We also acknowledge all of our collaborators across the study sites as the research would not have been possible without their support. Wellcome Programme core award (106680), Wellcome Provisions for Public Engagement award (106680), the Higher Education Innovation Fund and ESRC Impact Acceleration Account through the University of Oxford’s COVID-19: Economic, Social, Cultural, & Environmental Impacts – Urgent Response Fund provided funding for this study. The funding bodies had no role in the design, analysis, or write up of the study. The research was approved by the National Hospital for Tropical Diseases, Hanoi, Vietnam, number 19/HĐĐ – NĐTƯ; Hospital for Tropical Diseases Ethics Committee, Ho Chi Minh City, Vietnam, number 34/QĐ-BVBNE; Ethics Committee of Nepal Health Research Council, Kathmandu, Nepal, number 528; Institutional Review Committee, Patan Academy of Health Sciences, number drs2012011470; Ethics Committee of the Faculty of Medicine, University of Indonesia, number 1283/UN2.F1/ETIK/PPM.00.02/2020; and Oxford Tropical Research Ethics Committee, University of Oxford, number 547-20.

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5

Children of Covid

Lisa J. Hardy

Despite enthusiasm for participating in the project, Chris squirms around from beanbag chair to table in the little room at the school where we meet for an interview. Once comfortable, we begin our conversation about young people who experienced the beginning of the pandemic as children and teens. Describing this generation, Chris says, ‘like how you are the son of your mother or daughter of your mother ... *you are the child of Covid*’. These words echo what we learn in a youth-engaged project in the southwest United States: the impacts of the pandemic, layered with other life events, shape young people in deeply emotional, spatial and temporal ways.

The experiences of young people are perhaps most important to understanding ongoing chronicities. Children of Covid – people growing up during lockdown and subsequent political, social and viral tensions and waves – will, presumably, on average live the longest with their memories of the time. Their experiences demonstrate complexities of the pandemic itself, differences in health and life and emergent geopolitical lenses for exploring selves in relation to home and relationships to the world. Chronicities, multilayered and impossible to disentangle from existing structural inequalities, are ‘profoundly shaped by persistent injustice, inequality, poverty and physical expressions of structural violence’ (Manderson and Smith-Morris 2010, 1). Youth memories of living through Covid are interwoven with awareness of injustice and structural violence; characterized by the illusion of fixed continuity in the face of constant change (Manderson and Smith-Morris 2010).

Today, undergraduate students say that they do not talk about Covid much, although in interviews and focus groups their stories are filled with emotion and ideas about how they’re impacted and

what they've learned. They are nostalgic, depressed, anxious, aware of injustice and worried about the future of Earth. They are also connected, empathetic and creative in approaching change. Journalists and researchers show concern, evident in a flurry of articles in the recent past, that young people are struggling. They can't go to school. They're anxious, depressed and in trouble. According to *The Atlantic* there is a 'tragic mystery' on why 'America's teenage girls are not okay' (Thompson 2023). High school students including Asha, a non-binary junior leader in participatory research, say the troubles of young people are only a mystery because 'no one actually bothered to ask'.

Our research team asks young people, including Asha, about this 'mystery' through the development of their own participatory ideas in a youth-engaged project called YEAR (Youth Engaged Action Research). We collaboratively designed the project, temporarily housed in a high school class called Youth Participatory Action Research, for people aged 13–22 in the southwest United States to explore impacts of social, political, embodied and developmental experiences of living through and with the pandemic. Leaders and participants are non-binary, cisgendered and trans, of different ethnicities, and from different family structures ranging from extended family households with roommates to gay parents and single or double parent households and, for older participants, shared apartments or college dorms.

YEAR is multi-generational, with support from graduate students and researchers. I am the oldest person on the project, working as a collaborating anthropologist and outsider, and my experience is far removed from elementary and middle school, even with a teenager at home. As I grow to know and care for young people leading the project, I'm overcome by what they have been through. Intellectually, I knew prior to the project that their lives included more than a pandemic. I did not anticipate the disruptions that happened in relationship to and congruent with it. They tell stories of grief for family members and friends who passed away, long distance moves, deep isolation, parental job loss, food insecurity, caregiving for incapacitated parents, changing identities, extremely high levels of fear and stress about the future and dealing with obsessive compulsive disorder and other (at times challenging) forms of neurodivergence. They speak of efforts to feel comfortable with the present, the future and their relationships to others. They reflect on new curiosities and knowledge, describing creativity and mindfulness as coping strategies which they will bring with them into futures that are completely unknown. Their fears of everyday life center on dangers of political and environmental catastrophes that put their

wellbeing at risk. Interviews, focus group discussions and conversations in group meetings hold tremendous wisdom. My hope here is to honour those stories as a placeholder that young people will continue to lead.

Setting

YEAR is located in Flagstaff, a small city near the Grand Canyon, located 7,000 feet above sea level in the northern part of Arizona. Flagstaff sits at the base of the San Francisco peaks, also called Doko'oosliid in Diné (Navajo) and, for Hopi people, Nuvatukya'ovi, in an area that is sacred to more than 13 Indigenous tribes in a state that borders México. More than 60,000 people identifying as white, Indigenous and Latiné live in the region. Black residents are smaller in number, though integral to the history and present of leadership and community work, advocating for community-centered initiatives and growth as the city expands. Flagstaff is also home to a global population of faculty and students working at and attending Northern Arizona University (NAU), one of three state universities that are designated Hispanic-serving institutions. The university has higher-than-average retention and graduation rates for Indigenous and Latiné students, some of whom are among the over 40 per cent of first-generation students who are the first in their families to obtain a degree.

Arizona is a settler state, existing largely on lands obtained through extractive colonial theft and continued structural oppression (Simpson 2011, 493). State legislators exert exclusionary policies targeting Latiné people through anti-immigrant bills designed for 'attrition through enforcement' (Hardy et al. 2012) and the removal of Mexican American ethnic studies curricula (Thomas et al. 2014; Gutiérrez et al. 2011), both bills that stewarded in thousands of others across the United States. In the 1990s Public Enemy released the song, 'By the Time I Get to Arizona', depicting a Black uprising in response to the governor's removal of the national holiday for civil rights leader, Martin Luther King Jr – a decision then upheld by a public vote. The state reversed that decision, though Arizona legislature continues to introduce racist policies including those designed to remove content from classrooms. Attacks on educational content now extend into multiple attempts to remove critical race theory (currently vetoed) and successful attempts to ban words like 'diversity' from university hiring practices (Schermele 2023). Elementary and high school education in Arizona ranks 'dead last' in the nation for low graduation rates, spending per student and educator support (Roberts 2024).

Flagstaff, colloquially known as ‘poverty with a view’, has a cost of living estimated to be 15–18 per cent higher than the national average ([Salary.com 2023](#)) contributing to a poverty rate of 17 per cent (U.S. Census Bureau 2023). Harsh winters and low resources bring life-threatening risks to unhoused people in the city; health care is unaffordable and somewhat inaccessible. A single regional hospital system dominates emergency and specialist care, making national news for its poor leadership and provider turnover while proposing plans for income-generating gentrification into a ‘health care village’ with housing and shopping. Few other local options for care create a flow of traffic for specialist care down to Phoenix, over two hours away, without the availability of public transportation.

Dramatic tension in public over mask wearing and other public health measures during the first year of the global pandemic mirrored the political and economic setting in northern Arizona at the start of COVID-19. Conservative social and political power manifested in the early expiration of mask mandates, and this was followed by spikes in rates of infection along with anti-mask and Covid-conspiracy rhetoric. Vocal residents from rural Arizona revved the engines of their pickup trucks decorated with oversized American Flags in the truck beds and gun stickers on rear windows. Later that year, organisers held protests against police violence in front of City Hall and marched together through neighborhoods where conservatives stood holding rifles on corners and roofs. Raucous revolt against public health measures and overall politicization of the pandemic contributed to young peoples’ knowledge and perceptions of disease.

Children of Covid

COVID-19 upended understandings of established order. The nationwide shortage in the United States (as in many other countries) on toilet paper in the first days of the pandemic, at that point largely from panic buying, brought tangible realization of scarcity and fear of precarity and danger. Some saw how dangerous their lives were and others thought about their own safety in light of the precarities others endured, leading to empathetic connection with people in close proximity or distant from them. Young people listened to the news as some communities were hit harder than others with illness and death from COVID-19, and they watched as the coincident Black Lives Matter movement unfolded after the murders of Breonna Taylor and George Floyd.

When I speak with Chris, age 17, he follows referring to himself as a child of Covid with a caveat that so much is going on in his life that he is a ‘bad person to interview’. We can’t focus only on the pandemic, he says. There are too many other things going on. Every young person involved grapples with shifting and situated snarls that are typical experiences of coming of age during ages 13–22, a time to develop identities and learn about environments outside of themselves. The pandemic is significant in their development, but it is not the exclusive defining event.

Memories of the first years of COVID-19 are filled with reflections on the germination of relationships to institutional and political structures, and increasing empathy for both immediate and imagined people and populations. Participants shared stories of the pandemic through the vantage point of children and youth in elementary and middle school, already struggling. They think through ‘everyday flows’ of COVID-19 by reflecting on change and the future in stories of how they situate themselves and their everyday interactions through complexities of home, institutions and systems (Wahlberg, Burke and Manderson 2021). Participating children, teens and young adults talk about reacting to the pandemic with humor and relief, feelings which gave way to complicated and unequal experiences of grief and loss along with creative problem-solving and new directions.

Stories of generational coming-of-age provide a view into the everyday habits of school; hearing about social distance and risk/fear through avoidance of contagion; changing homes, schools, neighborhoods and family relationships; and homes as places where they were sequestered during a time of extreme social disruption. From the vantage point of computer screens, bedrooms, kitchens or yards, these young people began to grow into understanding their relationships to time and place. Some saw quickly what the pandemic meant for others near and far; others described taking longer to think about the world outside, challenging and rewriting geopolitical relations (Massaro and Williams 2013).

Generation

Known as ‘Gen Z’, this cohort, born around 1997 through to 2012, is characterized with broad strokes as a group that has never known life before the internet, is deeply worried by climate emergencies and, at the same time, has the skills and desire to work together along with care and concern for others (Katz et al. 2022). Participants in YEAR talk about

identities as Gen Z in ways that allow them to – at times playfully, and at other times with despair – discuss identity in inquisitive ways.

Gen Z shares the typical view that middle school or junior high (ages 10–13) is an uncomfortable phase of life marked by awkward physical changes like crooked teeth adorned by braces, embarrassing acne and clumsy growth spurts that happen seemingly overnight. These are days of intensifying social drama and social pressure enforced through exclusion as home lives become contentious, friendships and identities divert from caregiver expectations and social processes occur within larger systems of power (Bucholtz 2002). Difficulties of these years at home and in the classroom vary in severity in relation to gender, ethnicity, economic standing, abilities, immigration status and other axes of inequality in society at large, in the same ways that chronicities shape lives.

Attending school during lockdown in many already-underfunded Arizona schools meant learning in a vacuum of training and resource availability. Teachers had little support, at times leaving children in sparsely populated virtual classrooms devoid of instruction. A college freshman shared witnessing a teacher fall asleep during class, noting that friends gave up on education after these experiences. In rural Arizona, lack of reliable cellular service and internet access left some households with no options for education. This disconnection, along with extended and fractured time with families for young people during the first year of Covid, seemingly impacted the mental health of sexual and gender minoritized youth, among others, many of whom felt ‘less connected to their families and less safe at home’ during the pandemic (Mitchell et al. 2021).

The beginning: punctuated time

The first lockdown marked a revelatory moment for participants, who remember foremost going home for spring break, their annual week-long vacation from school, on or around the declaration by the World Health Organization of the global pandemic on 11 March 2020. Just before the United States closed schools and businesses in an initial lockdown, teachers told students to take everything home; they stayed there for the remainder of the year. In focus groups, participants share memories tinged with details of last conversations and things undone prior to the realization that ‘nothing would ever be the same’. Asha (age 17) and her friends remember this with laughter and, later, with pain:

Asha: I had not been allowed to take home some of my stuff from middle school ... I'm still mad because I left a perfectly nice water bottle and like my lunch box and stuff probably, but with a rotting sandwich still in it. [group laughter] Just like in my gym locker ... the first casualty of Covid was a perfectly nice water bottle ...

L: And a sandwich.

A: I wouldn't call that a casualty. I'd call that like a *bioweapon*.

Along with humor, there are shared memories of a peculiar sense of unreal. Jae, age 14 says: 'I actually made a joke to my friend right as we left for spring break. I said, "Imagine if we never come back and this is like our last day of the school year"'. And, 'I said to [a friend], "What if we never see each other again?" And I have not seen him since ... I did not think that it was real *at all* ... I was all "see you in a week" and then I didn't'. This acute, confusing disruption transformed into chronicities of constantly interrupted time, revealing structural inequalities of everyday lives. For many, inequalities meant that their lives were already hard.

Layla, a non-binary Latiné college freshman, remembers initial relief: 'I feel like in my little teenage 16-year-old brain Covid happened and I was like "the world is ending" and like when you're in high school you're constantly in that mode like "the world is going so fast like I need to catch up" ... when you're in that headspace, like "oh, the world ended?" Then you are just like "okay then, I can just chill" [laughs]'. Chris says, 'when we didn't come back after those two weeks ... I don't think I thought the world was ending', followed by, 'I've always been under the weather. I've always been kind of a sad boy. So, whenever that hit why I wasn't like "oh we're all gonna die", I was like "whatever happens, happens"'.

Layla experiences the foreboding and uncertainty of need as a queer Latiné person in a racist state, remembering relief about the possible end of the world: 'I don't have to do anything. The world is literally over, you know'. Layla's youth in the Phoenix metropolitan area was stressful before the pandemic: 'You've spent so long like, "if I don't get all As I'm never gonna make it out of here, *I'm never gonna get into college*, I'm never gonna get a job, I'm literally gonna have to die and my kids are gonna literally not be able to buy a house because they're gonna be in tons of debt because I died with debt", you know? At the ripe age of like 13.' And they repeat with emotion, *At the ripe age of like 13*. Relief of the closures of everything brought already-existing chronicities to the surface where they could pause and evaluate them from a different place.

Along with this punctuated disruption, these young people had experienced a slow, growing cognizance of what was happening around them: 'At the beginning I didn't understand the severity of it ... no one knew what was going on and just more information was being shared as time went on'. During these confusing days, new sensory experiences emerged:

[it was] the summer that every single fruit tasted like Lysol (disinfectant) [group laughter] ... It became this kind of dark joke that everyone was incredibly depressed and this is how we're microdosing on drinking bleachv... I ate a *metric ton* of, like, oranges and plums that *tasted like bleach*. And I'm never gonna get that taste out of my mouth.

Tastes of lockdown became aversions or pleasant memories – like the fresh-baked bread that was shared by neighborly swaps. Textures, colors and shape of creative activities that they had begun and pursued during those days, brought some sense of connection for some. Others had wondered where they would find enough to eat.

Relationships in families, friend groups and neighborhoods changed. Young people moved towns, schools, states and even countries as the result of parental job loss. Jay, 14, says his neighbors moved away, possibly because they were undocumented and couldn't find work. Layla's family stopped gathering together, to prevent their grandmother from becoming ill. Connections became unmoored from geography or routine. Home privacy also became unhappily permeable. Cameras revealed domestic poverty or chaos and teachers commented on family dynamics they witnessed online. Those without access to online learning had long, quiet days without the usual rhythms of life.

Interruption and reconnection

Changes, first punctuated by a memorable event and then leading to a slow realization of what was happening, created an unusual break in children and young adults' understanding of themselves in relation to time; this will likely have consequences as they grow and change. Immediacy of the removal of regular activities led to questions about everyday living in a failing system, indicated by social media discussions of the perils of class warfare and questions about the meaning of a social structure where people work until they die.

Adults ‘quiet quitting’, or scaling back on work to protect health and energy from extractive employers, and a ‘great resignation’ due to disillusionment and despair over high costs of living and unsupportive working environments had an impact on young people as they too questioned the value of institutional learning in the face of increasing economic inequality and need.

Remembering these breaks created painful confusion about how old they were then and how old they are now, often leading individuals to pause carefully and remark on grief about years they will never relive and an intense nostalgia and a sense of loss. Their social media feeds are filled with songs and images inspired by the aesthetics of *Fairycore* and the grunge-related *Whimsigothic*, depicting children holding hands in dresses, dancing through hazy fields that seem like memories. These posts are interspersed with odd-shaped creepy animals and masks that are supposed to cause feelings of being unsettled; they accompany lyrics about times past. Content creators quote Sylvia Plath or write their own text: ‘When every time you try and go to sleep all you can feel is gut-wrenching nostalgia for all the phases of your life and people you’ll never experience again and horrific anxiety because one day you’ll be thinking the same thing about this exact moment [sic]’. These posts are liked and shared by hundreds of thousands of others of similar age. YEAR leaders and interviewees spoke unselfconsciously of their missed opportunities and the mental health challenges they endure.

Kayla, a queer, disabled young adult, was not alone in discussing the severity of their mental health:

if this is TMI (too much information), just let me know, but um but I struggled a lot with um suicide and suicidal ideation ... it was 2020 ... when my parents were fighting and I felt like literally physically stuck with them and I felt powerless.

Youth leaders knew that interviewees in our project would discuss suicidal ideation due to widespread depression and anxiety. Existing obsessive compulsive fear of germs and social anxiety grew exponentially along with public health reminders about infection control, increasing attention on hand washing and the probability of unseen contagion and also the inaccessibility of resources to help. People began to talk about mental health more openly than generations before, sharing diagnoses and medications and encouraging one another to seek therapy. This openness about mental health is something that young people say that they like about their generation. They know that stigma still exists but

they talk about being proud of their ability to talk about it. They do, however, tend to hang on to an idea that they can't ever make up the time that they lost.

Phoenix, 14, shares that they missed out on basic rules of grammar and spelling, such as the difference between 'there', 'their' and 'they're' in fifth grade. Jordan, 16, laments that she will never go to real eighth grade after attending that year of school online. Nora, 19, points out that gaps in knowledge also constitute gaps in growing up:

I feel like with the Covid pandemic we kind of had to age ourselves? ... we kind of had to be like, 'okay, well, all this sh-- is happening', like you know? And I feel like now that it's like over and it's not like over ... we are just kind of like, we just kind of like missed that ... like teen hood. Like how do we make up for that? Like I was *sixteen*.

Young people express distress in their personal lives about what they seem to consider possibly permanent loss, just as journalists and researchers suggest. The World Bank issued a press release in February 2023 stating, 'today's students could lose up to 10% of their future earnings due to COVID-19-induced education shocks. And the cognitive deficit in today's toddlers could translate into a 25% decline in earnings when these children are adults' (World Bank 2023). Young people share these concerns. They also recognize the growth that they have made, including the development of identities and increased empathy and connection with others. Lina, 20, says that she was

sort of able to connect more with like, being Latiné ... cause like, spending time – spending more time with my family and stuff, I feel like that affected it. And it was like ... 'oh yeah, *I love being Mexican, isn't that so cool? I forgot*' [laughter].

Others began to think about who might be struggling around them, to be aware of inequality and be interested in becoming involved. Max, one of the youngest participants having just turned 14, describes these changes in a local public library that serves as a resource for community and unhoused people to stay safe from extreme temperatures and to provide them with access the internet, saying

If you told me [previously] that ... the library broke down ... I would be all 'okay I don't go to the library'.

Max says they would respond differently now by worrying about the impact of a library closure on others that could be

really upsetting for the people that do go to the library ... how are people going to return library books? Are they gonna charge other people a late fee? What's gonna happen to the people that hang out at the library? What is gonna happen to the people that have book clubs at the library? What is gonna happen to the people that only have computers at the library?

Max and others remember when they saw their own vulnerabilities and those of others near and far. Young leaders saw that neighbors had more or less than they did, aware that people were suffering in unequal ways. Those who had access to bicycles and parks worried about others who did not. Those who did not have enough food worried about others who also could not meet basic needs.

Chronic healing

YEAR leaders are adamant about generational interest in new passions and instruments for handling the world. They want to ask questions about these positive aspects of the pandemic, moving forward through learning and participating in politics and creative endeavors. They move from their place in a childhood role out into interests in the world around them, informed by what they observed and felt during the first years of the pandemic. Many developed new hobbies and interests during Covid, including those that helped them to build fitness and strength. Finn, age 18 says:

I got into martial arts ... because I was like, I need something to do away from my parents and I can actually like, feel fulfilled. So I did martial arts literally every single day ... it made me reflect, it made me like, try new things and to be like, okay, I need to get outside and stuff like that.

When asked what else helps them to deal with the pandemic and all of the other complicated facets of their lives, many leaders and participants talk about creativity and mindfulness. Mindfulness, while a trend in certain areas of the United States and beyond, seems to resonate with the group as they consider ways to control anxieties about the future by

maintaining a focus on the present moment, helping them to integrate their proximity to uncontrollable and unpredictable time. Setting aside moments to think and be alone also helped some. Gabe, 17, reflected in this way:

[The pandemic] made me really sit with myself because beforehand, I was hanging out with friends constantly and it made me really sit with myself and like, be in the company of myself, right? And I was like, 'oh, dang. I really actually like, just hanging out with myself, you know?'.

Others mentioned art and music, and their continued practice of these, as ways to stay present. These activities seem to provide tools for dealing with uncertainties of the future. Young people also turned to poetry, drawing, music and other creative arts to reconnect.

Where do I go from here?

Shifting proximities for youth continue as they deal with the present and future, switching tense when talking about the dangers of COVID-19 without having any clear idea if it will ever end. Some say that it is over with a 'before and after', and then think through the implications of this as COVID-19 infections are still occurring. Nationally, the United States declared an end to the official state of emergency of the pandemic and the beginning of what would become endemic to regular life, a shift that some say increases the danger of not taking the virus seriously.

Socially, there remains disagreement about the dangers of COVID-19, and what to do about them. In a 2023 autumn spike of a new variant when estimates from wastewater suggested 1 in 5 people were positive for COVID-19, students became ill. The university did not issue directives of how to handle the spike. The halls were filled with people coughing and sniffing from COVID-19 and other non-COVID-19 colds and flus, and few people consistently wore masks. Some expressed annoyance at others for failing to follow guidelines or acting as though there were no remaining risks. Some argued with friends and family members about how to deal with precautions.

If there is an 'after' to the pandemic, these young people do not have a life to return to that looks anything like the one before, although they also don't seem to think of the pandemic as 'over', given ongoing struggles. They do not, however, seem to expect continuity in the future.

Their chronicities continue to be multilayered and informed by precarity related to much more than COVID-19. Layla says, 'like, like – worrying about what you're gonna do personally but also, the state of the world'. Incorporating back into society is tinged with anxiety for some who are afraid to leave their homes, apartments or dorms.

The awareness that inequality and injustice persist in dangerous ways is ever-present in ideas of how to enter their immediate and future lives. They worry about political and unequal dangers present in everyday life, as they go forward: Simone, 20, says, 'When our generation was born it's just been one thing after another after another after another and you think that the pandemic was the worst'. And, 'now we're having like a genocide on trans youth and it's like when does this f– end, and Florida just passed a bill to allow people to carry loaded guns whenever they want without a permit'. They are starkly aware of precarities related to political and economic inequality and their place within it. Kayla, 22, says, 'because of like Covid, so many bad things [have] happened within our lifetime', and:

I think we've become disenchanted but also deeply caring at the same time, which is a very fascinating combination that I'm excited as we get further into adulthood to see how that would translate politically and in terms of the economy and the ecology, like, like what are we gonna do now? We're becoming the adults. I have to fix this and take care of this.

YEAR young people are fearful and lack hope while also, simultaneously, being engaged and energized to change. They don't want to go to school, they say, because school is not set up for them. They don't want to work until they die, they say, because that's not going to lead anywhere. While national stories report resistance to go to school among youth across the nation, young people are talking about why. It doesn't work anymore. They need something different. They want something else as they worry about the global scale of precarity and loss.

Conclusion

As I walk into undergraduate classrooms today, I note a heaviness in the faces and words of students talking about hopelessness, climate emergencies, late capitalism and class warfare. 'How will we ever get ahead?' they ask. Some experience mental health emergencies, some

deal with obtaining accommodations for learning, some bring service animals into class and some disappear throughout the semester. When we talk about inequality and justice, these students are well aware of global and local, structural and social injustices, and they talk about these with a realization that they too are suffering, even as they see their own privilege of gaining a higher education when others can't.

When asked what they would like to know about young people and COVID-19, students respond with ideas about peer pressure on public health behaviors, new hobbies, pets, long COVID, disruptive politics in families, wellness and perceptions of mortality. Always in research and classrooms there is talk of disconnection and a desire to look for positive change. Some days, they tell me, it is too difficult to get to class. They are sick with COVID-19 or colds and flus, or they are depressed and unmanageably anxious. But there is hope. Sonja Smith, a Diné (Navajo) then-college student in northern Arizona ends her article on 'bordertown blues' during lockdown with this: 'Although COVID-19 has exposed many injustices, it has also exposed the continued survival and fight for justice. Ahéhee' (Smith 2020).

The concept of 'chronic healing' is useful in framing these new chronicities of hope. Scholar and creative writer Kelly Keena (2022) writes of chronic healing through cyclical health and states of unwell, as she describes living with cystic fibrosis in what she calls her 'big, full life'. In moving between worlds of illness and healing, Keena reflects that the mental burden of chronic illness is, for her, the hardest. What does it mean, she asks, to move between illness and health? 'Fluidity and flux' of chronicities (Manderson and Smith-Morris 2010, 1) occur through chronic healing. This may apply to the new ways that young people understand time, connection and the future in the absence of expected routines.

Youth are increasingly aware and upset about injustice. They also hold the capacity to explore, learn and develop new ways of living, not devoid of the oppressive histories and presents of ongoing injustices but complex in how they deal with them. Not all young people find a way to wellness or even have a path available to them. Some weave a path toward healing. Imaginative meaning-making of chronic healing for young people grows awareness of structural inequality and their place within it, moving back and forth between darkness of hopelessness and glimmers of hopeful futures. Some are proud of ways they have endured multiple interwoven hardships as they have come into their own. Some think forward, into the future with new tools. In this way and others, the experiences young people talk about with regard to their place as

the ‘children of Covid’ represent chronicity in many forms, including ongoing challenges to health and life, and chronic healing as they continue to grow and make their way into new spaces and social and political worlds. Living through and leveraging chronicities of illness, healing and economic and political injustice will be shaped by relationships to time, space, place and systems in ways that have not recently been true. Entanglements are not a mystery to young people who live through – and with – the COVID-19 pandemic. These stories will be theirs to tell.¹

Note

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Overdose, COVID-19 and the unending churn of intervention in Vancouver, Canada

Danya Fast

Vancouver is internationally celebrated as one of the world's most beautiful, cosmopolitan and livable cities. It is also recognized globally as a ground zero for successive waves of public health emergency in Canada. For over two decades, the city has been significantly transformed by escalating wealth accumulation and rampant gentrification, and the social and economic impacts of events like the 2010 Winter Olympic Games (Barnes and Hutton 2009; Blomley 2008; Ley 2012). It has also been remade by a churn of public health emergencies and interventions (Fast 2024; 2021) that began with the HIV/AIDS crisis of the 1990s and continues into the present with COVID-19 and an ongoing, unprecedented overdose crisis driven by the proliferation of fentanyl and related analogs in local drug supplies (British Columbia Coroners Service 2022; Lupick 2017). These states of emergency have long intersected with an entrenched affordable housing crisis, widening inequality and growing visible homelessness and addiction. The city's Downtown Eastside neighborhood has long received local and international attention as an epicenter of these problems (Liu and Blomley 2013; Woolford 2001).

Since 2016, when an official public health overdose emergency was declared in the province of British Columbia (where Vancouver is located), over 10,000 people have died as a result of toxic drug poisonings, including over 2,000 young people under the age of 30 (British Columbia Coroners Service 2022). While Indigenous people constitute approximately three per cent of the population of British Columbia, the historic and ongoing effects of colonialism and white supremacy have resulted in a disproportionate number of these deaths occurring among Indigenous people; in 2022, Indigenous people accounted for approximately 18 per cent of overdose deaths

(First Nations Health Authority 2022; Turpel-Lafond 2020). Many of these deaths occurred in the Downtown Eastside, which is a racialized space (Razack 2007). The large number of Indigenous inhabitants in this neighborhood reflects the lively, continued presence of Indigenous people and communities on land owned and occupied by Coast Salish peoples for at least 10,000 years, as well as the disproportionate burden of social suffering carried by Indigenous people in Canada (Anderson 2013).

The provincial government's response to this crisis has largely focused on increasing access to a continuum of culturally safe substance-use care, ranging from harm reduction services, to in-patient and out-patient treatment, to abstinence-focused recovery programs (First Nations Health Authority 2017; Province of British Columbia 2019). In these efforts, adolescents and young adults have been identified as a 'priority population' requiring urgent intervention. Opioid agonist therapy (OAT), including methadone, buprenorphine-naloxone (brand name Suboxone) and slow-release oral morphine (brand name Kadian) are now indicated as essential treatments for young people diagnosed with opioid use disorders (British Columbia Centre on Substance Use and British Columbia Ministry of Health 2018). OAT has been made widely available in Vancouver across acute, community and residential treatment settings via intensive case management and outreach teams staffed by physicians, psychiatrists, nurse practitioners, social workers, outreach workers, drug and alcohol counsellors and Indigenous Elders (Vancouver Coastal Health Authority 2017). Addiction medicine consult teams have been created at local hospitals (including the local children's hospital) in order to improve the integration of treatment, including OAT, into these settings, and to ensure greater continuity of care (Providence Health Care 2020). Harm reduction programs and overdose prevention sites have also increased, although access among young people and in particular those under 18 years of age remains highly uneven (Canêdo et al. 2022).

Four years into this overdose emergency, the World Health Organization declared the COVID-19 outbreak as a pandemic (World Health Organization 2020), and British Columbia declared a COVID-19 public health emergency shortly thereafter (Government of British Columbia 2020). The pandemic has worsened the structural violence of poverty, white supremacy and the war on drugs. Globally, disruptions to the illicit drug supply chain have resulted in an even more toxic and unpredictable street drug supply (Mullins 2020b; Tyndall 2020). Simultaneously, during the first several waves of the pandemic, people abruptly lost access to a range of essential services due to physical

distancing and isolation mandates that required people to ‘stay home’ and ‘in bubbles’ with their immediate households. Libraries, public parks and drop-in centers that had been essential sites of sociality and material support were closed. Forms of income generation such as panhandling, recycling and sex work were significantly curtailed as the city went into lockdown (May et al. 2022). People who used drugs in the context of entrenched poverty, unstable housing and homelessness were forced to navigate unrealistic and conflicting public health messages. How do you wash your hands frequently if you don’t have access to soap and a sink – or to shelter of any kind? How do you follow COVID-19 distancing and isolation mandates *and* avoid using substances alone to help prevent overdose? How do you stay two meters away from people outside of your bubble when you live in crowded, substandard government-subsidized housing, or have recently been evicted and need to ‘couch surf’ for a period of time (Mullins 2020a)? For those who were able to socially distance and isolate, mental health crises often intensified (Ataia et al. 2020; Henry et al. 2020). Overdose rates rose steeply during this time period, and people who used drugs were also at greater risk of contracting COVID-19 in the context of underlying health issues, including compromised immune and respiratory systems (Centers for Disease Control and Prevention 2020; Palis et al. 2022; Volkow 2020).

The churn of intervention

As overlapping drug overdose and COVID-19 emergencies unfolded in Vancouver in the spring of 2020, homeless camps and squats were emptied and people were moved into repurposed commercial hotels and community centers, as well as government-owned and subsidized supportive and temporary modular housing facilities (City of Vancouver 2023b; Little 2020; Mullins 2020c). From the onset of the pandemic, there were significant fears about the potential disproportionate impacts of COVID-19 on Vancouver’s Downtown Eastside neighborhood in particular, where approximately 15,000 residents inhabit roughly 30 square blocks (Mullins 2020a; Rankin 2020). Even as the majority of the city became a veritable ghost town as a result of government stay home and social distancing and isolation mandates, the streets of the Downtown Eastside remained busy (Mullins 2020c).

Rapid re-housing initiatives were paired with the introduction of new Risk Mitigation Guidance (RMG) prescribing (British Columbia Centre on Substance Use 2020). This guidance remains active at time of

writing (June 2023) although the approach is increasingly referred to as ‘prescribed safer supply’ (British Columbia Centre on Substance Use 2022). RMG is a COVID-19-specific harm reduction strategy intended to displace at least some of the use of highly contaminated street drugs, reducing overdose risk and making it easier to socially distance and isolate as a result of a reduced need to go out and procure drugs, for example. For those who are actively using substances and at high risk of harm as a result of their substance use, RMG allows for the prescription of a limited range of controlled, prescription medications such as 12-hour sustained-release oral morphine (brand name M-Eslon®), hydromorphone tablets (brand name Dilaudid®), methylphenidate tablets (brand name Ritalin®), dextroamphetamine sulfate tablets (brand name Dexedrine®) and benzodiazepine tablets (for example, clonazepam). To reduce the risk of COVID-19 transmission, from the outset RMG prescriptions were dispensed as daily non-witnessed take-home doses, including via telehealth, and could be delivered directly to people’s doors by outreach and intensive case management teams. A shift to the greater provision of daily non-witnessed take-home doses of both RMG prescriptions and OAT during the COVID-19 pandemic and continuing into the present is a significant departure from pre-pandemic prescribing practices characterized by high levels of surveillance (for example, daily witnessed dosing of medications at a pharmacy) and monitoring (for example, frequent urine drug screens in clinical settings) (Andraka-Christou et al. 2021; Durand et al. 2022).

Even prior to the pandemic, recognition of the limitations of substance use treatment, including OAT, in addressing the overdose public health emergency had led to growing calls for the provision of a ‘safe’ or ‘safer’ supply of unadulterated drugs (Bonn et al. 2021; Canadian Association of People who Use Drugs 2019). The Canadian Association of People who Use Drugs (CAPUD) defines ‘safe’ supply as the provision of regulated versions of the drugs that people are using (for example, fentanyl, heroin, crystal meth, cocaine) at dosages that have ‘mind/body altering properties’ and in forms that allow people to get high via their preferred route of administration (for example, injecting, smoking, snorting) (Canadian Association of People who Use Drugs 2019, 4). This definition of safe supply excludes OAT and even injectable OAT (iOAT; daily witnessed injected doses of diacetylmorphine or hydromorphone), because the implementation of these programs continues to be primarily focused on the reduction of drug use and associated risks and harms. Practitioners and policymakers have defined ‘safer’ supply as the provision of prescription ‘pharmaceutical alternatives to

the unregulated drug supply', such as the RMG prescriptions described above (Glegg et al. 2022, 2). The term 'safer supply' is often used by government, public health organizations and clinicians to emphasize that prescribed opioids and stimulants are not completely safe. This softening of the language of safe supply chafes many drug user activists and groups, who argue that the term safer supply shifts attention away from the fact that illicit street drugs and not prescribed pharmaceuticals such as hydromorphone tablets are unsafe and the cause of an unacceptably high and still climbing death toll (British Columbia Coroners Service 2021; Bonn et al. 2021).

Living – and refusing to live – on the edge of change

In Vancouver during the spring and summer of 2020, it very quickly became clear that the new kinds of prescribing facilitated by RMG fell short of the definition of safe supply advocated by CAPUD and many drug user activists and groups. For example, RMG prescriptions of hydromorphone tablets (to a daily maximum of 14 tablets of 8 milligrams each) are not generally a sufficient replacement for daily, intensive illicit fentanyl use; even when the tablets are stockpiled and taken in high quantities, they do not produce desirable effects (adequately reduced cravings and withdrawal symptoms) and affects (highs) among many people who use street fentanyl (Giang et al. 2023). Nevertheless, the introduction of RMG and safer supply prescribing is widely recognized as yet another moment of sea change in Vancouver's progressive drug policy landscape (Mullins 2020b). It is a response to, and has perhaps further catalyzed, longstanding demands for 'real safe supply' by drug user activists and groups, including the Vancouver Area Network of Drug Users (VANDU), Drug User Liberation Front (DULF) and Coalition of Peers Dismantling the Drug War (CPDDW). During the pandemic and beyond, these groups took to the streets of the Downtown Eastside to stage a number of high-profile safe supply protests, during which tested and unadulterated heroin, crystal meth and cocaine were distributed to people who used drugs (Coalition of Peers Dismantling the Drug War n.d.; Drug Users' Liberation Front n.d.; Moakley 2021; Mullins 2021).

The unveiling of a new, progressive intervention in the face of ongoing states of public health emergency and growing activist pressure is, in many ways, business as usual in Vancouver. The city is home to much celebrated, world-leading harm reduction interventions and initiatives, including North America's first supervised consumption

site (Lupick 2017). What unfolds in Vancouver informs national and international discussions about drug policy and harm reduction; the policies, strategies, frameworks, guidelines and interventions generated in this setting and the province of British Columbia often go on to be emulated across Canada, North America and elsewhere. Yet, also as usual, the uptake of this new intervention has been highly uneven among those young people I have come to know in the city. Over the past 15 years, I have traced the intimate and institutional trajectories of these individuals as they contend with poverty, homelessness and addiction, and with the colonial past and present in and beyond the Downtown Eastside neighborhood.¹ The young people I have followed are in many ways relegated to the social, spatial and economic margins of this city. Yet, they are also often at the very center of city life and state projects (Henry 2019), including the protection of life in the context of COVID-19 and overdose public health emergencies (Das and Poole 2004). I am therefore interested in the multiple, shifting and affective forms of life that have emerged among these young people through engagement with Vancouver's ever burgeoning and contracting care assemblage (López 2020) and a seemingly unending churn of intervention in the city (Fast 2024; 2021; Fast and Cunningham 2018). I am also interested in the forms of life that have emerged *around* this care assemblage, among those who are evading sites and modalities of state-sponsored care.

What I've observed is that some young people refuse to be drawn into this care assemblage, refuse to live on the edge of the latest sea change – including, even, those couched in the progressive language of harm reduction and fueled by drug user activism. Here, I will describe one Indigenous young woman's ambivalence towards RMG and safer supply prescribing as well as the safe supply drug user movement, even in the face of unimaginable loss, and even as her long-time romantic partner found certain kinds of possibilities there during the first waves of COVID-19. My focus is on how the 'weighted and reeling present' of public health emergency and intervention in Vancouver can be productively explored through what Kathleen Stewart (2007, 1) calls ordinary affects: those visceral, surging forces that animate bodies, places, things, encounters and atmospheres, and constitute a 'felt knowledge' (Million 2013, 67) of a situation and its possibilities. In order to understand how the present is experienced, interpreted and acted upon (or *not* acted upon) by this young woman and her romantic partner, we need to track what affective rhythms and intensities do as they move through and accumulate in bodies, substances and pharmacotherapies, and also in

places such as government-subsidized supportive housing buildings across time. Constant states of public health emergency in Vancouver implore to us to focus on the *present*, on what is happening *right now* and on what we must *immediately* do about it. However, the young people I have followed often seem to inhabit a different kind of temporality, powerfully characterized by the unendingness of emergency and intervention in everyday life and even across generations (see also Garcia 2010). In this context, COVID-19 and its solutions are just one more assault that threatens to engender or deepen painful affective senses of isolation, loss, stagnation and boredom.

I am a white settler who has spent 15 years working closely with Indigenous young people who use drugs, including the woman whose story I tell here. I have attempted to write this story with great care (Garcia 2010), avoiding overdetermining analyses that attempt to neatly pin down her felt knowledges of settler colonialism, dispossession and loss. Instead, I have tried to write in a way that allows things to remain uncertain and unfinished (Biehl and Locke 2017). I describe moments of refusal (Simpson 2014), while honoring others by writing nothing at all. None of this resolves crucial questions about the extent to which I am speaking for an Indigenous young person in this chapter, ‘mining’ her words and experiences for my own scholarship (Todd 2019). I must sit with this lack of resolution, allowing the reader to judge for themselves the balance of care and harm that this chapter achieves.

Let me share an extended story to illustrate some of these dynamics at play.

Lula and Jeff, 2009–17

I met Lula and Jeff (pseudonyms) at the Lighthouse shelter in downtown Vancouver in 2009. At that time, Jeff was 19 years old, and Lula was 18. Lula is Kaska Dena First Nations but left the place where she was born when she was only a few days old, following her adoption by a loving family in Vancouver. Jeff is originally from Toronto. The Lighthouse shelter was an integral part of Lula and Jeff’s story. They met each other walking along Granville Street in early spring 2009, and fell instantly in love. They stayed together at the shelter for a few short months. During their first month there, Lula also spent time in jail on a shoplifting charge. While in jail, she couldn’t stop thinking about Jeff, and the rest, as Lula put it, was history.

Lula and Jeff cared for each other deeply, and were together, on and off, across the entire period of my fieldwork, from 2009 to 2020.

Like so many of the other young people I have followed, their union always seemed to be at the very center of their lives. They have two children together who are not in their custody, and Lula had a third child with another romantic partner in 2017. Over the years, Lula declared and re-declared her engagement and unofficial marriage to Jeff on Facebook, as well as Jeff's various transgressions and the couple's many breakups. They fought constantly and, at times, brutally. I watched as the drama between Lula and Jeff propelled them forward day after day. They loved each other. They hated each other. One of them was in jail because of an altercation between them. One of them had taken off somewhere because of an altercation between them. Jeff had a new girlfriend who Lula hated. Lula had a new fiancé who Jeff hated. Jeff had to take care of Lula no matter what. Lula couldn't live without Jeff. After the Lighthouse shelter was closed in summer 2009 and they began living in various government-owned and subsidized supportive housing buildings, they were barred from each other's residences over and over again. They would sneak each other in, resulting in frequent altercations with building staff and numerous evictions. These were always devastating, but they heightened the drama between them and an affective sense of being at the center of *something* rife with potential.

The drama between Lula and Jeff was fueled by the stimulating effects of their crack and, later, crystal meth use, to which they had both transitioned by 2012. Episodes of what young people often summarized as 'going crazy' and 'acting psycho' were also fueled by mental health challenges, including substance use-induced paranoia and hallucinations. Jeff told me he had ADHD and depression. Lula said she had been diagnosed with schizoaffective and anxiety disorders and depression. But to reduce the drama of substance use and romantic relationships to young people's mental health and addictions perhaps misses its vital, affective dimensions. This drama was the *something* in which the young people I followed were almost always deeply immersed. It gave them a powerful sense of forward momentum, and expanded to fill their time.

Over the first several years of our acquaintance, whenever we spent time together, Lula and Jeff were always charged up. I often found myself refereeing yelling matches. And then in 2015 Jeff dramatically reduced his crystal meth use and instead began using heroin/fentanyl² intensively. He also started to go on and off methadone for a period of time (while Lula remained completely uninterested in any kind of treatment program). Jeff's demeanor was completely transformed by this transition. At least when the three of us were together, his loud,

oftentimes aggressive way of speaking to Lula (and sometimes to me as well) was replaced by soft-spokenness. He moved more slowly, with an air of general contentedness, even when Lula railed at him. Jeff's transformation seemed to dissipate some of the drama between them. And yet, a new element of discord had been introduced into their relationship. Lula, who continued to use crystal meth intensively and would often stay awake for days at a time, disliked how Jeff seemed to be increasingly sinking into sedation and sleep when he was not out hustling for money and drugs.

'I miss the old Jeff', Lula admitted to me at the end of 2015. 'He never wants to *do* anything anymore, except when he's on the grind [trying to make money]. Like, that's the only thing that gets him going anymore. He doesn't even *want to have sex ...*'.

At the end of 2017, a year and a half into the declared overdose public health emergency, Lula told me, 'In this past year, I've lost about 30 friends down here'. She had been sharing Jeff's cramped single room ('a large closet' was how they often described it) in the Greystone Hotel for a year at that point, after being evicted from a different supportive housing building also located in the Downtown Eastside. She remarked, 'They want us in our rooms using alone so that we can die alone'.

I tried to listen for who 'they' might be. Housing workers? The government? Lula continued, 'I'm on so many housing lists but I don't want to go to [another] supportive housing, I don't want to go to modular housing because that's, like, a death camp'. She was referring to the high rates of fatal overdose in supportive and modular housing buildings among those who used drugs alone in their rooms. Lula said angrily,

I'm just sick and tired of watching my friends drop like flies around me. Everyday I'm wondering, who's next? Am *I* next? And the thing is, my friends who have died, they're just, like, a statistic to the government. Some of my friends have been saying, 'It's population control', or like, people are talking about 'fentrification'. Because it's like, what did they do when the Olympics came? They wanted to push us away [into supportive housing], get us out of sight for the tourists. But it's like, now they're slowly killing us [with fentanyl]. It's one big genocide. All these people dying is part of the plan.

Less than a year and a half later, the COVID-19 pandemic would become yet another catalyst for moving people indoors, and yet another threat to life.

Supportive housing and ‘community care’ in downtown Vancouver

In the years leading up to and following the 2010 Winter Olympic Games, issues of visible homelessness, addiction and related forms of ‘public disorder’ in downtown Vancouver generated significant political, academic and public attention. Under growing pressure to live up to promises made in Vancouver’s successful 2002 Olympic bid and guided by the Vancouver Agreement’s ethic of revitalization without displacement, in 2007 the city, provincial and federal governments began spending millions of dollars to purchase over two dozen single-room occupancy hotels (SROs) in Vancouver’s inner city. During the years before and after the Olympics, these hotels were renovated into government-subsidized supportive housing for various at-risk populations, including young people entrenched in homelessness and addiction (Murray 2011). This was in addition to the construction of over a dozen entirely new supportive housing sites in downtown Vancouver, funded by the state and managed via partnerships between a provincial social housing agency (BC Housing), the Vancouver Coastal Health Authority (VCH) and the Ministry of Social Development and Poverty Reduction (welfare) (City of Vancouver 2023a). The facilities are operated by a handful of community-based, nonprofit social housing agencies, some of which have a long history of operating in the city (Lupick 2017). Some supportive housing buildings are classified as ‘community care facilities’ under the provincial Community Care and Assisted Living Act, which allows young people to be released directly from the hospital, juvenile detention and jail (often via the community drug court) into the care of these facilities. There, young people’s traceability is facilitated by CCTV cameras and computerized fob systems, through lengthy intake questionnaires administered each time a person crosses a new institutional threshold and by databases and files that can be accessed by the various workers and teams that manage their cases. Individual pathologies are managed via bureaucratic partnerships between various state and nonstate actors and addressed through the delivery of integrated primary, substance use and mental health care.

Housing is a critical determinant of health, and most of the young people I knew, including Lula and Jeff, acknowledged that supportive housing buildings were much safer and cleaner than the ‘old’ shelters and SROs that they inhabited during the earliest years of our acquaintance. Yet, these more institutional housing environments engendered painful senses of disappearance from urban space, isolation and loss among all

of the young people I followed (Fast 2024; Fast and Cunningham 2018). As they were moved out of rowdy, communal places like the Lighthouse shelter and yet-to-be renovated SROs and into supportive housing buildings like the Greystone Hotel, young people described feeling increasingly ‘lost’ in the city. When they used the language of ‘getting lost’ in the context of residences in supportive housing buildings – and to describe their sense of place in Vancouver more generally – they seemed to be evoking the multiple meanings of the word lost: both a sense of not knowing (or perhaps not understanding) one’s whereabouts and a sense of something that had been taken away.

Supportive housing facilities were places where young people’s moves were increasingly traced and decided by others. Many entered supportive housing buildings via court mandates and hospital agreements; failure to comply with these living arrangements could mean re-hospitalization or jail time. Court-mandated living arrangements were often accompanied by red zones (court-mandated spatial restrictions that bar individuals from entering certain neighborhoods) and probation conditions that further limited young people’s movements: they had to stay not only in the city but often in the immediate vicinity of their supportive housing building. The forms of care embedded in supportive housing could map seamlessly onto these forms of control. They were also a means of encouraging young people to stay put: these were the places where they were now expected to eat their meals and drink their coffee and access medications and harm reduction supplies. This was where a significant portion of their welfare (social assistance) checks went each month. All these measures were intended to help young people. Yet the effect for some was a sense that supportive housing was simply one more in a long line of institutions to be endured. Most began to describe an affective sense of stagnation and ‘going nowhere’ desirable inside these places, in addition to feeling lost (Fast 2024; Fast and Cunningham 2018).

The pandemic would significantly deepen these experiences of disappearance, loss and stagnation inside supportive housing for many young people, including via the public health measures that were intended to help young people and keep them alive, such as OAT and RMG prescriptions delivered directly to the doors of their supportive housing buildings. Unlike in other settings where young people inhabiting the social, spatial and economic margins may have found themselves with nowhere to go (or nowhere safe to go) to self-isolate and socially distance during the first waves of COVID-19, those I followed already had a powerful sense of being ‘fixed in place’

(Roe 2009/2010, 75) and isolated prior to the pandemic (Fast 2024; Fast and Cunningham 2018). COVID-19-specific interventions then became just another layer of care and control that kept young people in place and oftentimes painfully bored, an outcome perhaps not anticipated and certainly not intended by the engineers of these housing and public health emergency interventions.

Lula and Jeff, 2019–20

In late 2020, when I asked Lula and Jeff about how things were going for them in the context of the second wave of the pandemic locally and renewed stricter social distancing and isolation mandates, Lula responded somewhat indifferently: ‘It already felt like we were in lockdown here [at the Greystone Hotel], so. Not much new, in a way’.

Even prior to the pandemic in early 2019, Lula talked often about how much she hated her shared room with Jeff at the Greystone, and Jeff talked often about how what he really wanted was more space from Lula. It was technically his room, after all. ‘The thing is, I have nowhere else to go’, Lula said flatly on one occasion, as Jeff headed out the door to go and score fentanyl and crystal meth from his long-time dealer in the building.

Jeff was still using both fentanyl and occasionally crystal meth, but not as intensively as he had been. He had recently gone on Kadian (slow-release oral morphine). It had been years since he had been on methadone at this point, which he had frequently complained made him feel ‘zombie-ish’. He said he had decided to try Kadian after hearing from a friend that it didn’t have the same negative side effects as methadone or Suboxone – in fact, it produced a fairly pleasurable buzz, and could really take the edge off dopesickness. Jeff was put on what he described as ‘the highest possible dose’, which was delivered to his door at the Greystone each morning by an outreach team (as would later become standard practice during the pandemic). He told me that he had gradually reduced his use of fentanyl to three days a week, and was reasonably happy with these changes. He didn’t have to hustle as hard for money and drugs. He was getting fewer abscesses because he was injecting less. He had started working a few shifts in the overdose prevention site (OPS) located inside the Greystone, where he handed out harm reduction supplies, watched people use and administered Narcan (the opioid overdose antidote) whenever there was an overdose. While he seemed happy to have the work, he said that everyone in the building now hated him because no one wanted to ‘get Narcanned’. Even though people accessed the

Greystone's OPS to avoid a fatal overdose, they nevertheless wanted to experience that high which existed on the very edge of overdose and on the very edge of death (Fast 2024; 2021).

This was a line that Jeff himself walked for years, and Lula and I talked many times about how scared we were that Jeff could overdose and die. Prior to 2019, he used more fentanyl than anyone else I knew. It therefore surprised me when Lula began expressing ambivalence about Jeff's decision to take Kadian. 'He's trying to slow down on the fentanyl, which is good, I guess', she sighed.

But when he's using more down [a slang term for opioids], like, he'll get up and want to go get more and more. He has to go and make more money for it, panning [pandhandling] or whatever. And he does that over and over and over. Sometimes he'll go out like five times a day. Come back here, you know, get more down, and then go out again. It's like, on repeat. But with Kadian he just takes it and sleeps all the time.

There was relief in the tone of Lula's voice, but also obvious frustration. She continued:

I feel like he's just wasting away now. You know what I mean? It's, like, great that he's not using as much. But he's not, like, *awake*. I don't want to say it, but I liked him better when he was using because at least he was up and active and talking to me. Instead of, like, sleeping. And I feel horrible saying that. Because of course I don't want him using down and overdosing. But at the same time, it's like, I end up getting bored. And then getting myself into trouble.

Across the years, I witnessed repeatedly how Lula struggled to fill her time when she was not embroiled in the drama of her relationship with Jeff. Her crystal meth use was intimately tied up with this drama. It fueled its intensity and helped to ameliorate the resulting emotional wounds. But crystal meth was also something that helped Lula to navigate boredom when the drama receded for periods of time. When she and Jeff broke up, or when he was sleeping for long stretches, crystal meth got her up and out and about on her old BMX bike, socializing with friends and new love interests across the downtown core. Lula tried to think through other ways to fill her time. She sometimes expressed the desire to get a part-time job, or to go to school or to work more wholeheartedly on her recovery.

This usually happened when she and Jeff broke up and she was in a new romantic relationship with someone whose goal was to ‘get clean’ and work. Occasionally she did detox herself off crystal meth by taking her quetiapine and zopiclone and sleeping for several days at a time at a new boyfriend’s place. But whenever this happened, Lula told me that she soon felt the familiar weight of depression and boredom. The new boyfriends helped her to get off crystal meth, but this never seemed to be a route to the part-time job or school program she desired. And so she went back to Jeff, and to crystal meth, repeatedly. The drama of that relationship eventually expanded again to encompass all of her time and energy.

The first wave

In the spring of 2020, the COVID-19 pandemic hit Vancouver. The first wave of the pandemic did not disproportionately impact the Downtown Eastside neighborhood, as many had feared. In fact, cases of COVID-19 were noticeably absent among the city’s poorest residents during the spring of 2020, even as the streets and camps remained relatively crowded (cases had begun to rise by September of that year, but never reached the crisis levels seen elsewhere around the globe; Mullins 2020b; Mullins 2020c; Rankin 2020; Woo 2021). Nevertheless, social distancing and isolation mandates resulted in the closure of meal and drop-in programs, which meant that Lula and Jeff became more isolated than ever in their closet-size room at the Greystone during 2020 and 2021. Lula’s biweekly visits with her children were canceled, and guests were no longer allowed inside supportive housing buildings. While the streets surrounding the Greystone were far from empty and continued to be the site of some income generation (namely, low-level drug dealing) and lively sociality, Lula and Jeff said that they felt like they had fewer and fewer reasons to get up, get going and get out of their room. Jeff couldn’t make as much money panhandling anymore because the vast majority of those with money to spare were working from home and almost exclusively using credit cards to pay for essential purchases. Prior to the pandemic, overdose rates had declined, but now they were climbing again (Mullins 2020b). Lula and Jeff said that they were far more scared of overdosing than contracting COVID-19. They seemed to be increasingly keeping to themselves more out of deepening depression and lethargy rather than out of a fear of contracting the virus. Lula was not getting out and about on her BMX anymore, even though COVID-19 mandates did not restrict this kind of activity. The weight of loss of

sociality and boredom intensified, and for months the only ‘lines of flight’ (Biehl and Locke 2017; Deleuze and Guattari 1987) seemed to be intensive drug use or sleep. There was nowhere to go except deeper into drug use, somnolence and the drama of their relationship, which was becoming increasingly violent.

During the pandemic, I kept in touch with Lula and Jeff by phone. That is how I know that, throughout 2020, Jeff stayed on Kadian and Lula continued to hate how he behaved while on it, herself turning to crystal meth to mediate persistent boredom. Jeff also eventually got on an RMG prescription of hydromorphone tablets. He acknowledged that he was still living on the edge of death, even as he remained on Kadian and hydromorphone. In early 2021, he was hospitalized following a life-threatening overdose.

‘I’m still, like, rolling the dice, right?’ he said to me over the phone a few weeks later. ‘Still playing Russian Roulette, even though I’m on all these meds.’

Jeff sounded resigned; Lula sounded increasingly angry. She had lost too many people by this point, and yet the deaths kept coming. From her perspective, it was not just that she and her friends were being left to die due to overlapping public health and housing emergencies and the absence of a safe supply of drugs, as many local activists charged. Lula seemed to increasingly distrust the professionalized housing, harm reduction and research infrastructures that blanketed the drug scenes in downtown Vancouver, which remained largely open and active throughout the pandemic. From her perspective, the entire situation – from the drug scenes of the downtown core to the interventions that were purported to help its inhabitants – was rooted not in compassion, but in control and even annihilation. Lula was contending with the chronicities of addiction, entrenched poverty and successive waves of public health emergency that now included COVID-19. She was also contending, perhaps, with the unendingness of settler colonialism and its ongoing, varied forms of dispossession and loss (Garcia 2010). Indigenous people have long been asked to cooperate in their own survival by submitting to various forms of intervention and surveillance (Stevenson 2014). But Lula and some of the other Indigenous young people I knew generally refused to be drawn into this relationship of cooperation with the care assemblage, even as culturally safe programs are made increasingly available (Fast 2024; 2021). These moments of refusal or ‘turning away’ (Coulthard 2014; Fanon 2008) from state-sponsored interventions were almost never explicitly politicized in the ways that Audra Simpson (2014) describes in her ethnography of the Kahnawà:ke Mohawks – or at

least, those politics were rarely made visible to me. However, they were generative of other lines of potential, such as unrestrained anger and the impulse to evade intervention.

Lula often seemed to refuse to be drawn into the care assemblage, refused to live on the edge of change via RMG prescriptions or even safe supply protests. ‘They are slowly killing us off’, she told me over the phone in 2021. ‘They decide to have another bad wave of dope [drugs] going around’. I tried again to listen for who ‘they’ might be. The government? But what Lula was critiquing seemed to go beyond that, to encompass every artery of downtown Vancouver’s poverty management and public health infrastructures, from supportive housing building managers to harm reduction workers.

Lula continued:

I notice that every time one of my friends dies from fentanyl, no one can *ever* answer the question of where they got their dope from, and from who. Right? Nobody can answer that question. And I think they get those harm reduction workers or whatever to come and just hand them the dope. And they somehow get them to use it alone in – in their housing, or whatever. They *want* them to use alone so that they will die in their rooms alone. Like, especially on welfare day, when every building has a ‘no guest policy’ – it’s just too easy.

Lula told me that she thought a lot about dying:

Most days, I feel like I can’t do it anymore and I just – I just really want to go home, and be with Cody. But then I always hear his voice in my head saying, ‘No, Lula, you need to stick it out. We will be together again one day, I promise you that. But, like, it’s not now. You’re still here for a reason’.

Just before Lula gave birth to her youngest daughter in 2017, one of her best friends, Cody, had overdosed and died in his supportive housing room. Lula was devastated. She tried to come to terms with his death, naming her youngest child after him. Over the years that followed, we talked about Cody frequently. For a time, Lula carried a print out from his celebration of life everywhere she went. Carefully smoothing the creased paper, she regularly showed me his photograph and obituary.

Five years into the overdose emergency in 2021, so many young people were gone, and yet they were still around. Many of my

interlocutors talked about sensing the spiritual presences of those they had lost (Stevenson 2014). Lula couldn't let Cody go. And maybe, she told me, he couldn't let go of her either. She often sensed his presence, and spent a lot of time talking to him. Eventually she started using an app on her phone to listen even more closely for messages from him from the spirit world. This was a line of potential in a time and place of profound loss, isolation and stagnation.

'One time, he said my name, so nice and clear: "Lula"', she told me again over the phone in 2021. I had heard this story countless times. The telling of it was perhaps a part of what kept Cody here, in this world, with her. Lula continued:

And I'm like, 'Oh god, Cody, I miss you, I love you so much'. And he's like 'I love you too and I miss you too'. And then this other voice came on, like, the voice of an [Indigenous] Elder, a Native man. And he said, 'That's it'. And Cody was gone. And then the second time I heard him, he only said a few words: 'Lula, your daughter needs you.'

She paused.

And it's true, I'm still here, somehow. And I still have a purpose here, even if I don't totally know what that purpose is beyond, like, being here for my kids.

It seemed to me that the telling and re-telling of this story was also, perhaps, a part of what kept Lula here in this world, too.

Afterword

In Vancouver, a churn of intervention that largely began with the HIV/AIDS emergency in the 1990s continues into the present with the overdose crisis and COVID-19 pandemic. What does this story about Lula and Jeff, spanning almost 15 years, tell us about Covid's chronicities in this setting and about endemic structural constraints and settler colonial legacies in pandemic times?

Since 2020, the overlapping COVID-19 and drug overdose emergencies have engendered new forms of life, harm and care. Yet, for those I followed, there was also much continuity with what had come before, including intergenerationally. The surveillance and monitoring

of young people who used drugs lessened in certain ways during the first waves of the pandemic; it was no longer necessary to take daily trips to the pharmacy to take OAT and pick up RMG prescriptions, for example. Financial pressures eased for many as they accessed the federal government's Canada Emergency Response Benefit (CERB), which provided CAD\$2000 per month in addition to monthly welfare payments. In other ways, however, surveillance and monitoring were ratcheted up yet again; the police aggressively emptied homeless camps and squats using the familiar logic of 'promoting public safety', even as those inhabiting these places insisted that they were safer in camps and squats than in the supportive and modular housing buildings and repurposed community centers and hotels to which they were moved (Mullins 2020c).

Lula and Jeff and most of the other young people I followed during this time period had already been moved into supportive and modular housing buildings when the pandemic hit; no one I knew found themselves homeless for long periods of time as the COVID-19 pandemic progressed. In this context, the burgeoning and contracting care assemblage and the affective intensities and rhythms it released were highly familiar to all of them, marking Covid as just one more in a long line of disruptions that could engender or deepen the familiar weight of dispossession, disappearance, loss, isolation, stagnation and boredom.

Heavily sedated on Kadian and a new RMG prescription for hydromorphone, Jeff slept the days away in his tiny room at the Greystone Hotel. This was similar to what had happened when he made the transition from crystal meth to heroin/fentanyl and methadone in 2015, although his somnolence was greatly intensified in 2020 while on fentanyl, hydromorphone and Kadian. Meanwhile, Lula was left sitting around in that same room, painfully bored while she waited for Jeff to wake up and increasingly depressed and angry about the loss of friend after friend to fatal overdoses. Once again, for Lula crystal meth became a possible means to mediate boredom and regain a sense of momentum and being at the center of something rife with potential.

During these states of emergency in Vancouver, Jeff found certain possibilities in the care assemblage – in particular, the new RMG prescription program and overdose prevention site in his building – although he continued to find himself living on the edge of death, much as he had been since illicitly manufactured fentanyl arrived in Vancouver sometime in 2011. Lula, alternatively, was increasingly suspicious of and actively evaded this care assemblage, as well as activist movements such

as the fight for safe supply. She engaged with and embodied the politics of place in Vancouver in ways that exceeded the assumptions of many of even the most progressive, harm reduction-oriented policymakers, practitioners and academics, even as she too lived on the edge of death. In 2021, she was hospitalized when she contracted COVID-19; she had also experienced an overdose that same year. However, she continued to refuse to be drawn into the churn of interventions generated by the overlapping COVID-19 and drug overdose emergencies in Vancouver, refused to live on the edge of the latest changes offered up by the care assemblage. Instead, her possibilities seemed to unfold through the memory and presence of her dear friend, Cody, and, as COVID-19 restrictions lifted, renewed visits with her children, including the child she had named after him. If Kadian and hydromorphone were the things keeping Jeff in this world – on this side of death – it was Cody, perhaps, who was keeping Lula here.

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Notes

- 1 I use the phrases addiction and addicted carefully, recognizing that many people object to their etymology – the earliest usage of this language in Roman law referred to a state of slavery – and modern connotations (Gomart 2002). However, the young people I followed regularly used this language to describe the magnitude of what they were contending with, and I do not want to sanitize the intensity of their substance use or the frenetic cycles of use, withdrawal and procurement that characterized their daily lives.
- 2 By 2015 in Greater Vancouver, heroin was heavily adulterated with highly potent, illicitly manufactured fentanyl. I use the term heroin/fentanyl to signal this transition.

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The numbers game: Laila, Covid and the Egyptian constitution

Nefissa Naguib

I had lost my way in a part of Cairo that residents – mostly single mothers – call ‘The Stable’, a term they’d adopted to describe their homes, which they consider more suitable as dwellings for livestock than humans. This place lies in one of the many pockets of what is generously called ‘informal’ housing, much built out onto what was once arable land surrounding Cairo. These settlements – housing for the desperate – spring up without organization, plan or building permits. The characteristic mix of Cairo housing stock within a single neighborhood and the seemingly uncontrollable sprawl means that ‘informal’ housing often abuts wealthy gated communities, surrounded by high walls with guards at the gates. Laila and her neighbors refer to their neighborhood as the ‘ring road’ – a ring road of poverty, not to be confused with the Ring Road, a multi-lane highway that encircles central Cairo. The highway was intended to ameliorate Cairo’s famously chaotic traffic circulation and discourage the spread of housing out onto agricultural land. But the ring road neighborhood is definitely not a superhighway. After spending some time criss-crossing the same rough and narrow unpaved alleys, trying to find the right turn for downtown Cairo, I stopped to ask directions of a young woman I recognized from the faith-based food bank project I had just visited near The Stable. ‘Pardon me. Where are we?’, I asked. ‘We are in Egypt, ya Hanem’, Laila replied, addressing me as ‘Lady’.

Since then, Laila and I have continued our conversation, with long talks about care, food justice, love, fashion. Since the Covid shut-down and its aftermath, our conversations have been mostly on WhatsApp – on the pandemic, the price of bread, electricity cuts and whether people will take to the streets as they did in 2011. Laila did not go to Tahrir Square in downtown Cairo, the epicenter of the demonstrations that took place

during the 18 days of the Arab Spring revolution that ousted Mubarak's regime in 2011. It may well be that she thinks revolutions are a waste of time. Even if she had wanted to participate, she likely would not have been admitted: some form of official identification was required for entry to Tahrir.

Egyptian citizens are obliged to carry a state-authorized identification card. Laila does not have a national identity number – the *sine qua non* for an ID card – hence she does not have an ID. An ID card is required for medical care in a public hospital, public housing, processing for a property title or inheritance, obtaining formal employment, education and banking services, and to use as a smart card that allows one to buy basic food stuffs at government-subsidized prices. Since Laila doesn't have a card, she's not eligible for any of these services. Like many of the vast, uncounted population of Egyptians without IDs, many of them single mothers, Laila subsists on informal labor – cleaning or cooking or taking care of the children in wealthier households – and charity, especially assistance from faith-based charities.

In principle, all Egyptian citizens above the age of 16 are issued a national ID card with a unique national ID number, obtained by presenting a birth certificate. In Egypt, such a certificate must include the date and place of birth, names of parents and religious affiliation, but because of the high rate of poverty, illiteracy and home births, millions of Egyptians do not have a birth certificate. Laila is lucky. Although she reached adulthood without that document, a doctor who had employed her to clean house helped her to get her birth certificate. Laila was pregnant at the time. If you are not so lucky as to have this kind of help, you can appear before a government officer – more on that below – and get a birth certificate with an approximate date, usually the first day of whatever year is estimated as the year of birth. The process is particularly challenging and demeaning for women. The officer determines the year by asking the woman when she got her period. Then a male guardian has to be identified and his name and the woman's religion – Muslim, Christian or Jewish – is recorded on the certificate.

Once the birth certificate is presented and a national number is obtained, the state will issue an ID card. A woman's identity card will include her name, date and place of birth, religious affiliation and her civil status. In the case of unmarried women, the name of the father will be included and, if she is married, the name of her husband. On the top of each ID card is a row of numbers: these constitute the unique national number allocated to a holder. This name opens the door for many services.

Laila's trials and tribulations in trying to get her national number, and hence an identity card, have been a long and tortuous numbers game. Considering health care in terms of constitutional rights would entail complicated arguments for a non-legally inclined anthropologist, but fortunately anthropology provides a tradition of thinking about such practices. While the Egyptian constitution is remote both in time and space for most people, sicknesses are near-life experiences. The constitution promises the right to an ID card, and the conditional right to food subsidies, health care and education. The gap between what is promised and what people actually get is wide, and the obstacles are many. Laila's story is about navigating that gap and trying to match the rights she supposedly has with the very different realities of her life.

Laila's story

On a cold January morning in Cairo, in 2012, less than a year after the revolution, Laila made yet another attempt to obtain the essential ID card, and I accompanied her. We thought maybe the revolutionary fervor might improve her chances and make this excursion successful.

Several government-run units scattered throughout the city issue ID cards. A taxi driver told us that his sister had been treated nicely by one of the officers who administers national numbers in this particular building. Now we – Laila and I – sit on wobbly plastic chairs in a public building in a lower-middle-class neighborhood in Cairo. We are not alone. There is a long row of women: young, old, some more affluent looking than others, carrying grocery bags, talking on their mobile phones, texting, reading the paper, pregnant, nursing a baby or nodding off. There are children everywhere. Most of the women have met before. Many, like Laila, have long stories to tell about their ID struggles. They exchange smiles, knowing nods. A couple of women get into a conversation; they exchange experiences, comment on the cold weather and each other's children. Give each other advice. I see mostly very tired faces. I get to talking to the woman with twins sitting next to me: she says, 'I want to register my children in school'. She is from a village. Travels long distances on foot selling milk and poultry and does not feel safe without identification. 'My husband left me. We were married like this without an ID card. I need this card to make a life for my children'.

Laila has taken out her brown envelope with her bits and pieces of paper that she thinks might be helpful. It is her turn. She stands barely five feet tall, with her feet planted squarely on the ground,

facing the officer behind a large dark wooden desk. Her face is framed in a hijab, which, she explains, she puts on for 'official' occasions. The officer is young. He ignores us; leans comfortably back, talking on his mobile phone. It's a personal conversation about the sale of his parents' apartment. On his left, two female secretaries share a small laminate desk. Paperwork and stamps are scattered all over the top of the desk. Four tattered black faux-leather chairs surround it. Laila once teased me about my research, saying that she also does her own 'national number' research and has come to the conclusion that 'the number of chairs symbolizes the importance of the officer'. With a sofa, he is 'super important'. This officer had a faux-leather brown couch placed against the wall. A laminate coffee table with a TV set switched on. The officer puts down his mobile phone. Laila hands over the envelope. He sighs. Lights a cigarette. Pushes a button on his intercom and orders coffee in a tired voice. He carefully moves other documents on his desk between piles anchored by paperweights. Picks up a paper from the pile and looks at it. Sighs again. Pushes Laila's envelope to the side and looks up at Laila.

She is about to say something but is interrupted when his coffee arrives. She tries again and begins by explaining that she has now followed all the instruction she got from the last meeting. Was that with him, he asks. No, it was the office next door. He sighs. Drinks his coffee. So, what did they tell you last time? She lists the documents she was told she needed: certified birth certificate, her children's certified birth certificates, certified certificate that she has no criminal record and a certified document stating that she has never left the country.

'Do you have your husband's ID?', he asks. Laila explains that she is alone with the children. She does not know if her husband is alive or dead. 'Ok, everybody has a tragedy. So, do you have your father's ID?'

She shakes her head. He sighs: 'How do I know who you are?' With tears running down her face and an angry voice, she looks him straight in the face: 'I want my right. I want justice. I am a respectable woman. I might be poor, but I exist. I know that it is my right. Without my right you are turning me into a beggar.' He shakes his head. 'It's problematic', he smiles at her and shakes his head from side to side. 'You want me to break the law. I can't just give the national number to anyone who walks in here.'

He picks up the mobile. We walk out. Back in the street she says: 'This one had a sofa and a television.'

She will try again in a week. He will have forgotten her by then, and with any luck she will be assigned an officer without a sofa and a TV, and with fewer chairs in his office.

A week later we are back, and so are many of the women. We greet each other like old friends. When Laila's turn comes, we are met by an officer who has no secretaries, fewer chairs – and no couch. He is also a smoker, but he is drinking tea rather than coffee. He is friendly, invites us to sit down on two wooden chairs. Laila tells him her story. She has been trying to get her national number for five years. He listens. She explains that her life is falling apart. Without 'a number' she is not eligible for social welfare. He nods, makes sympathetic sounds, but it's complicated. She must come back with a male relative who is willing to support and witness that she is who she claims to be.

That was all in 2012, nearly a decade before Earth 'shut down' with variants of COVID-19. Now it is the pandemic, and Laila is no closer now to getting her national number. But she got a cleaning job in 'a nice home with good people', as she puts it. They pay her well, and they took her, along with her grown children, to get vaccinated in a 'real hospital with very proper looking doctors'. The family, she told me, wants to keep her and so they made sure she does not spread COVID-19. Laila wants to keep the job, which means not much time to 'research the number'.

I called to tell her that I wanted to tell her story. There is a new wave of COVID-19 in Egypt, she tells me. The family took her to get a booster. She replies laconically to my questions about how she thinks her life will change once she gets her ID number, and the conversation lags.

Women, Covid and the constitution in contemporary Egypt

This numbers game of the ID card makes the obvious point that sickness – which, with the seemingly unending waves of COVID-19, is a very real possibility for everyone – is an eminently personal affair; for many it is also a lonely experience that marks what kind of person you are – or want others to think you are. But also, the situated nature of constitutional rights has urgent and extreme ramifications for what a person becomes when they are sick. Therein lie its power and tragedies.

What can a narrative about something as mundane as getting vaccinated tell us about women, Covid and the constitution in contemporary Egypt? Health care – that is, accessing it – doesn't only have the potential of healing bodies, it also conveys human value. Health and food were always the issues that Laila referred to when she talked about 'the number'. Physically and literally, health is both a practical necessity

and a contested symbol that makes the gendering of constitutional rights visible in a range of life-near ways.

The snapshots from Laila's life describe a legal and social position and, in Laila's own social world, her possibility of being seen as and feeling herself 'respectable'. Laila's tribulations to get her 'number' so she can access welfare services, including health care, tell us something more about how constitutional rights and gender raise deep questions about women's immediate needs and what it is to be an Egyptian woman.

Against the backdrop of the revolutionary fervor which centered in Tahir Square in 2011 – the site that emerged as ground zero for Egyptian aspirations for social justice and dignity for all citizens – it seemed that radical change was possible. One of the most remarkable aspects of the Egyptian revolution was the participation of large numbers of women who had not previously been active in Egyptian public settings. Never before had Egyptian women gone on prime-time television – local and global – to give live testimonials on the sexual harassment they had been and continued to be subjected to. Another remarkable feature emerging from the revolution was the amazing assortment and variety of embodiments of the political 'new woman', most emphatically announcing her societal belonging and demanding her constitutional right.

But still, health care remains a profound exposition of power, human agency and patterns of social life and value. In the intricate tapestry of Laila's life, the absence of a formal identification card reveals a tragic reality. Having an ID is not a mere bureaucratic formality: it is a constitutional right and a cornerstone of recognition and belonging. Yet, millions of Egyptians, such as women like Laila, find themselves excluded from this most fundamental entitlement for all citizens. In Egypt's rapidly expanding population (the 2023 United Nations estimate puts it at 112.7 million, set to double in 45 years), one can only guess at how many are not registered with a national ID number. Of course, the numbers are impossible to even approximate because anyone without an ID number is invisible, a cipher.

From the day in the bustling labyrinth of The Stable, amid the narrow, unpaved alleys and homes that bear the weight of poverty, Laila became my guide through a reality where obtaining a national identity number is more than a bureaucratic formality – it is a lifeline.

As our conversations evolved from matters of care and justice to the stark challenges presented by a global pandemic, Laila's story emerged as a poignant testament to the profound implications of a missing national ID. In a nation where constitutional rights intersect with the harshness of

daily life, Laila's journey to obtain her rightful recognition is a testament to the resilience of the human spirit.

As COVID-19's relentless waves swept across Egypt, Laila's plight transcended the bureaucratic confines. It became a battle for dignity, for acknowledgement of her rightful place in a society that demands from all its citizens their national number for access to even the most fundamental services. Yet that same society creates roadblocks and throws up obstacles that seem targeted at excluding women, and particularly those most in need of the services the government promises – women who are poor. Even the strongest among us, like Laila, risk being reduced to beggars.

Hunger's chronicities: Covid and nutrition in a Mam-Maya community in Guatemala

Emily Yates-Doerr, Rosario García Mez
and María García Maldonado

For as long as anyone can remember, women in San Juan Ostuncalco have prepared a food for travelers. The base of *xwoky*, as it was called in the Mam language spoken in the region, was masa – the soft dough made from boiled and ground maize. Women would roll this into large, flat rectangles which they cooked over a low-burning fire. Every so often they would flip the rectangles, slowly toasting them until they were dry and crisp – but never burnt. The toasted square would be left in the sun to dry even further and then, when there was no moisture left, the women would grind it, resulting in a food that Mercedes referred to with a smile as ‘the Corn Flakes of Guatemala’.¹ Men who trekked into the mountain for days at a time in search of firewood would take packages of *xwoky* with them, as would those who left for the hard and painful labor at coastal plantations – a trip that would take several days as they descended 2,500 feet from their cold mountain villages to the hot, humid jungles near the sea. When it was time to break to eat, they would dissolve the *xwoky* in coffee or hot or cold water, letting the dried maize expand. It would serve as the primary food for people as they traveled and it would last for weeks without spoiling.

Emily, imagining herself living on flakes of corn during days of hiking through the mountains, asked Mercedes if people didn’t get hungry with only this to eat. Mercedes responded with an emphatic shake of her head. ‘If they only had bread to eat, then they would be hungry’. But *xwoky*, made from their maize, was ‘rich’ and ‘delicious’ (see [Figure 8.1](#)).



Figure 8.1 Maize grown in San Juan Ostuncalco in 2022. Source: © Emily Yates-Doerr.

According to UNICEF, half of all children born in Guatemala suffer from chronic malnutrition (Escobar 2020). The World Bank backs up this claim, reporting that ‘Guatemala’s under five child malnutrition rate (at 47 percent) is among the ten highest worldwide’ (World Bank 2023). In Indigenous communities the reported rates are even higher, with government data suggesting that upwards of 70 percent of children in several mostly-Indigenous municipalities are chronically malnourished (USAID 2018). International organizations that monitor hunger note that cases are likely underreported. Data have been difficult to collect during the COVID-19 pandemic, but by many accounts, the pandemic has threatened Guatemalan food security, as supply chain failures combine with the effects of global warming to send food prices – and hunger rates – soaring. Maria Claudia Santizo, a nutrition specialist for UNICEF, emphasized that ‘child malnutrition is Guatemala’s greatest problem’, and explained the situation to journalist Lucía Escobar as follows:

When the coronavirus reached Guatemala, it had a strong impact on food security because of existing difficulties securing basic income: a lack of both formal and informal employment opportunities and

a downturn in remittances received by families from abroad. The result is less food in homes, leading to a decrease in available food for children. (Santizo, quoted in Escobar 2020)

There is a common association of hunger with thinness or even emaciation – consider, for example, the bleached hair and distended stomachs of children that are associated with the illness kwashiorkor (a form of severe protein malnutrition). But when it comes to chronic malnutrition, that is, malnutrition that accumulates over time, wasting – as measured through weight-for-age – is a notoriously capricious and unreliable calculation. Instead, global health experts assess chronic malnutrition through measurements of stature. They diagnose chronic malnutrition when a child (or population of children) is two standard deviations below the median global growth recommendations for height for age – a designation known as ‘stunting’. The concept of stunting, popularized by the British physiologist John Waterlow (1972), is premised on the idea that in conditions of nutrient deprivation, the bodies of growing children will conserve resources by becoming less tall. The rationale for equating stunting with hunger is that small stature reflects long-term and persistent undernutrition: low-grade, cumulative and irreversible damage that happens when children are not growing as they should. The World Health Organization (WHO 2015) notes that the consequences of stunting include poor cognition and educational performance, low adult wages, lost economic productivity and an increased risk of nutrition-related chronic disease later in life. Mercedes de Onis and Francisco Branca of the WHO describe childhood stunting as ‘the best overall indicator of children’s wellbeing and an accurate reflection of social inequalities’ (De Onis and Branca 2016, 12).

Our research on chronic malnutrition in San Juan questions the tendency to equate food insecurity, chronic malnutrition and stunting, drawing attention to shortcomings in existing global health frameworks for hunger. The field of public health nutrition and Mam speakers both distinguish between the felt condition of hunger and chronic malnutrition. Yet whereas nutritionists link chronic malnutrition to nutrient deficiency in maize-based Maya diet, people in San Juan emphasized how maize is filling and rich, and enough. As we illustrate, people did not report hunger during the pandemic, although they did have extensive stories of political and economic hardship. In many ways this resonates with scientists’ growing sense that what is frequently called chronic malnutrition is actually more a problem of stress – not of nutrition. Yet our research also questions this association. As we explain, Mam

speakers did not themselves focus on ‘stress’ but on social conditions, encompassing labor and land. We argue that as scientists work to evaluate hunger and malnutrition they must incorporate Indigenous knowledge into the science of global health.

The research setting

Our fieldwork took place near San Juan Ostuncalco, a region in Guatemala’s western highlands that reports some of the highest rates of chronic malnutrition in both the country and the world (Figure 8.2). The city center had a population of approximately 21,000 people at the 2018 census,² with twice as many people living in the two dozen rural communities that spread westward through rolling hillsides and steep ravines.

Nearly everyone identifies as Mam-Maya and speaks Mam as their first language. The origin story of the region, as relayed to us by a community member, was that an eagle living high in the mountains would capture the community’s children when their parents were absent, taking them to its nest where it would eat them. The ancestors of the



Figure 8.2 Women reach for tamales that they have prepared in anticipation of our visit. Source: © Emily Yates-Doerr

people of San Juan sought safety for their children by fleeing toward a lake, which they then blew away from the land with a giant straw to attempt to create a place to live.

That it took a degree of magic to make their homeland habitable resonates today. Rocky soils and intense commercial and governmental pressure to adopt Green Revolution technologies have led people to rely on agrochemicals to produce their food: maize, potatoes, black and broad beans and vegetables such as cabbage, radishes, onions, broccoli and cauliflower, much of which are exported internationally (Fischer and Benson 2006). The only health center is in the city center; social services are few and far between. Roads to the surrounding communities are in disrepair – washed out from increasingly heavy rains. Many houses lack plumbing, and children attend schools in barren under-resourced classrooms. While Mam is the predominant language of the region, many of the educators only speak Spanish, and many children stop attending school after just a few years. Mothers frequently discuss among themselves how teachers would hit or otherwise abuse their children.

Throughout colonial history, indentured servitude and anti-vagrancy laws forced almost all the men in the region to labor for mestizo or Spanish coastal plantations for much of the year. Today, the region continues to be pulled apart by migration, and stories of murdered children remain all too common. To overcome a pervasive sense of instability, roughly a quarter of the community – once only the men, but now also women and children – has left for the United States. Weathered adobe houses are interspersed with palatial cinder block homes, some that display the US flag, flying high in the breeze. We spoke with one woman with three children whose husband emigrated from Guatemala in 2019. She said she didn't know when he would be back, telling us 'he has to stay in the US because there is more he needs to do in Guatemala'. Her phrasing reflects the broad sense that international migration was the only way to sustain life at home.

We carried out our research in the summer of 2023, the first summer after national pandemic precautions were lifted.³ Several national and international maternal health organizations that had delivered food aid to pregnant and nursing women over the previous decade had ceased operations around the onset of Covid. Journalists had reported severe food restrictions and heightened food insecurity during the pandemic. A Reuters newspaper article authored by Guatemala-based journalists in May 2020 recounted that hunger was spreading under government restrictions, with Guatemalans flying white flags from their windows or

putting up desperate signs that signaled that they were in need of food assistance (Menchu and Renteria 2020).

We initially imagined the lockdown period of the pandemic in San Juan akin to the famous ‘Dutch Famine Winter’ during the Second World War, when people in the northern provinces of the Netherlands starved for months on end (Ramirez and Haas 2022). We thought that the quotidian, widespread food insecurity documented by development organizations would have been amplified during the pandemic, offering a meaningful opportunity to discuss the experience of living with chronic malnutrition. However, upon beginning our interviews, we quickly learned that we would have to adjust our expectations. The people we spoke with did not report feeling hunger.

The research question

The background question that animated our research was *What is chronic malnutrition for the people living through it?* This question might initially seem to be straightforward, but it is not. According to the science of stunting, the estimated 8.5 million people who are chronically malnourished in Guatemala may not, in fact, perceive this condition. Shortness, yes. But they may not correlate their height with the illnesses and deficiencies that scientists have linked to shortness, and they may never experience this shortness as *hunger*. In the English language, hunger is largely understood as a phenomenological condition: it is something felt in an individual’s body. But in global health discussions of chronic malnutrition people are ‘suffering’ (WHO 2024) from the consequences of hunger without knowing they are suffering. A UNICEF representative described chronic malnutrition as ‘the global crisis that you’ve never heard of’ (Lake 2012). The *chronicity* of chronic malnutrition normalizes it, making it imperceptible. This, in turn, offers a challenge for anthropological methods since they tend to rely on lived experience. We could not very easily ask people how they experience a condition that is not – or, at least, not necessarily – felt.

The movement between scientific and lived knowledge systems pertaining to chronic malnutrition is only part of the dilemma we faced. We also had to move between colonial languages (Spanish and English) and Mam-Maya, where direct translations for chronic malnutrition, stunting or food insecurity do not exist. That being said, it was the case that the concepts we were interested in were alive and active in San Juan in the form of development projects that focused on increasing children’s

height and nutrient supplementation programs to address food security. Women in San Juan are first-language Mam speakers, but they were familiar with programs to address *desnutrición crónica* and *inseguridad alimentaria* – the Spanish-language terms for chronic malnutrition and food insecurity (the technical Spanish-language terms for stunting, *demedro* or *retraso en el crecimiento*, were never used).

Still, we did not necessarily want to study Mam-Maya women's opinions of these programs. Instead, we wanted insight into how they might conceptualize and theorize the situation in Guatemala that scientists and public health officials were describing as chronic malnutrition. In their article *Words to Think With*, John Law and Annemarie Mol (2020) criticize the assumption that English-language concepts operate universally. They argue, 'When "international" academic conversations restrict themselves to using the intellectual tools available in English, they become limited and parochial' (264) and ask, noting the conceptual richness that can be afforded by working inter-linguistically, 'Might there not be further interesting words and ways of wording lying dormant in other languages?' (264). It further struck us as elitist – and possibly an inaccurate understanding of human culture – to think that people do not perceive or theorize the situations that shape their lives. If chronic malnutrition was a condition of suffering, we anticipated that people would have rich, nuanced ways of discussing it – although these theories might unfold in terms we didn't know and ways we didn't understand (see also Manderson and Smith Morris 2010).

The initial plan for our research was to talk with people about how they fed themselves and their families during the pandemic: What was a typical day of eating? Where did they procure and how did they prepare their food? What did they do when food ran out? What were their strategies of survival? We hoped that these prompts would lead to discussions of experiences of malnutrition or hunger that we could, together, analyze and discuss. We quickly learned that people did not report feeling hungry, but because our questions were open-ended this was not a problem. We could easily shift to engage in a discussion about food during the pandemic that would allow us to talk about aspects of malnutrition other than hunger.

Co-laboratory methods

In earlier research together we had developed a co-laboratory method for talking with women in San Juan about 'sustainable development' – a

term that poses many of the same problems as chronic malnutrition in the sense that it has come from outside the San Juan communities and is not commonly used locally (García Maldonado et al. 2016). Drawing from the work of Marisol de la Cadena (2015), the point of working together was not to reach a shared understanding. As she explains, co-laboring maintains attention on divergences in perspectives that exist as people interact. Rather than presume harmonious collaboration, co-laboring entails the labor of staying attentive to the equivocations that happen in translation across various systems of knowledge.

Emily Yates-Doerr is a white cultural and feminist anthropologist with settler-colonial ancestry and academic training in the United States and the Netherlands. Rosario García Meza is a mestiza Guatemalan nutrition scientist who holds a masters' degree in social justice research from Sussex University, UK and who frequently consults for international nutrition research in Guatemala. And María García Maldonado is a Mam-Maya lawyer who works as a cultural and linguistic translator for health and development projects in the region. Both Rosario and María maintain close ties to San Juan and Emily has carried out fieldwork in San Juan over the past decade. To learn about *sustainable development* we had previously spent time talking with women from San Juan about their lives in a way that did not use the words 'sustainable development' directly – for example, asking about their goals for the present and for the future and how they sought to maintain their communities over time. Recognizing their expertise in matters of intercultural exchange, we then explicitly talked about the translation of the term (Yates-Doerr 2025: 175–199).

For our question, *What is chronic malnutrition for the people living through it?* we took a similar approach of remaining curious about linguistic and conceptual frictions in the terms that people had to talk about eating, hunger and food. De la Cadena (2015) cautions that the method of co-laboring is not practiced to reach an understanding of the other's point of view, but instead to gain insight into all that is not known (see also Allen cited in Liboiron 2021, 22). We co-labor so that we maintain an awareness of the frictions, gaps and tensions between the concepts used in different communities of knowledge and practice.

The concept of *alimentarse* offers a good example. In Spanish, one word for nourishment is *alimentarse*, literally 'to give one's self *alimentos*'. Nourishment in English generally has a pleasant ring – nourishment is positive, caring or kind. Yet anthropologists working in rural Guatemala in the second half of the twentieth century, when scientists were popularizing the term *alimentarse*, encourage us to approach the term with caution. They note that the taxonomy of a food as 'alimento' was a result

of the transfer of ‘information from Western medicine into the indigenous system’ (Cosminsky, in Diener 1982, 254). Anthropologist Paul Diener describes how the *Institute of Nutrition of Central America and Panama* worked hard to characterize foods high in protein – chicken, milk, eggs and its own manufactured for-profit maize-based nutrient supplements – as ‘muy [very] alimento’. As people began to classify all kinds of for-profit store-bought foods as ‘alimento’, including white flour and sugar, Diener came to see the concept as far more oppressive than emancipatory (1982, 254). He explained that ‘alimento’ imposed a colonialist, nutrient-based ethos over food, encouraging people to think of eating in terms of vitamin and mineral content – not in terms of the impacts on community relations, for example. Teachers, health educators and radio advertisements encouraged people to eat healthful ‘alimentos’. Meanwhile, he found that when Indigenous people categorized a food as *alimento* they were noting that its purchase required their labor to be ‘siphoned off by the regional market system into Ladino [non-Indigenous] channels’ (Collier, in Diener 1982, 258).

Diener’s analysis of the varied usages of the *alimento* concept helps to highlight the challenges and possibilities of methodologically tracing how the concepts and terminologies that surround food and nutrition circulate and are used in practice. Anthropologist Julián López García (2003) has likewise argued that Ch’orti’ Maya concepts of food and hunger diverge from the way these terms are conceptualized in the west. The 684-page Mam-Spanish dictionary of the Academia De Lenguas Mayas (2010) offers roughly seven uses of hunger: *Ch’ul* – the sound that hungry intestines make; *Jamtz’il* – to eat hastily because of hunger, such as a coyote devouring a sheep; *Jomjin* – an emptiness, such as that felt in the stomach when it is hungry; *Jul* – the suckling of babies when they are hungry; *Oyb’e’tz* – a snack eaten to stave off hunger; *Q’aq’il* – the experience of not having food and wanting to eat; and *Q’ol Wab’j* – the person whose job is to give food. Also included are expressions for food being sufficient, filling or absent.

María García explained that she regularly used two expressions for hunger when speaking in Mam. One referred to the harvest and climatic shifts. Her father, a farmer, would look at the coming rains or drought and speak of a time of hunger that might be coming to their community as crops failed. She used the expression *uti txilil wuaj* – literally, ‘there is no food’, and said it related broadly to an absence (in Spanish, *la falta de*). This focus on what was happening in the surroundings differed from the term *wiq’ij* – the phenomenological felt condition. *Wiq’ij* or *wiq’aq* transliterated as *hambre* in Spanish or ‘hunger’ in English. María

described *wiq'ij* or *wiq'aq* as the anxiety that 'we need something in the body' (*ansiedad que necesitamos algo en el cuerpo*). When we asked further about this anxiety, she explained that the phrase *nching'aq'ena* (*tengo hambre* or 'I am hungry') transliterates to *estoy quemandome* or 'I am burning inside'. She explained that *q'aq* means fuego or fire – so that the expression of being hungry might be thought of as having a fire in the belly.

The moment we switched registers to speak of hunger in terms of illness or a sickness she, like others with whom we spoke, switched to the Spanish-language term *desnutrición*, or in English, malnutrition. The fire-in-the-belly kind of hunger is related to a desire to eat; *desnutrición* occurred in the absence of this desire. In *desnutrición* the body, which was sick, did not feel hunger. Or, in slightly different terms, hunger is the feeling that happens when you do not have tortillas to eat whereas *desnutrición* is a sickness that results when you stop wanting them. Maya people lacking maize to eat would be hungry; Maya people who did not want maize but filled themselves on bread would become *desnutridos* (malnourished).

To explore these conceptual frictions we carried out open-ended interviews with seven women and one man who was a university professor in the nearby city of Quetzaltenango. All people we interviewed were Mam-Maya and lived in the communities surrounding San Juan Ostuncalco. At first, we kept the questions we posed broad: How did you maintain yourself and your family during the pandemic? Tell us about what you ate and how were your meals? Following the co-laboratory methods described above, when people used terms that we found to be relevant in either Spanish or Mam, we often stopped to talk with them more about these terms. For example, when a woman said her maize was filling we asked her to explain the sensation (María and she both translated the sensation of a full-belly feel to Spanish as *llenarse* which seemed fairly equivalent to the English-language expression of 'being full'). When a woman spoke of not feeling afraid of becoming hungry during the pandemic (in the phenomenological sense of *wiq'ij*) we asked more about this and she switched to an environmental register to discuss hunger, explaining she did not fear hunger because she had land, and with this, maize. Our conversations frequently moved between Spanish and Mam, with María leading discussions about how to best translate Mam terms with the people with whom we spoke – all of whom could converse in Spanish, though they preferred to speak in Mam.

To complement these conversations, we also held a cooking-based focus group for women to discuss their experiences of cooking and

feeding their families during the pandemic as we prepared a meal together. We coordinated this gathering with a community leader, who had worked with the several NGOs in the region that had previously aimed to improve chronic malnutrition among pregnant women and new mothers. For our research on the local semantics of chronic malnutrition we did not need to restrict recruitment to new mothers. As a result, the community leader drew upon her contacts to assemble a group that also included grandmothers. In the end, thirteen women (and roughly twice as many children) from four of the surrounding communities arrived at her house to prepare a lunchtime meal of chicken and noodle soup flavored with epazote (a regional green, leafy herb). All women in attendance had children, except one who was pregnant for the first time. The women ranged in age from 19 to 55 years old. Reflecting the general pattern in the community, 11 of the 13 women had immediate family members living in the United States. Every woman brought tamales (made by wrapping maize dough tightly in banana leaves to be boiled), which were added to a community pot. We prepared the soup together, using the occasion to talk about past cooking experiences, with a focus on the early months of the pandemic.

We also attended one women's health meeting – part of a project run by an NGO working in San Juan to build solidarity and reduce stress among Mam women designated as vulnerable and in need of extra support. A community midwife we interviewed held the meeting at her home, and invited women to join the conversations with us and for us to also participate in her event. The meetings were a chance for women to process their life experiences with each other. When we attended, the midwife helped us to ask the women to reflect on their experiences feeding themselves and their families through the pandemic.

'The time of sickness'

On 13 March 2020, Guatemala closed. For several months, only medical workers, ambulance drivers and some supermarket food distributors were allowed to leave their homes. People in urban areas, with the means to do so, ordered food in regulated quantities from online distributors. Others followed the mandated hours that they were allowed to access grocery stores, which utilized a quota system to control entry. Schools closed for two years, as did offices. Some retail stores that did not traditionally distribute food began to do so as an excuse to open, but for many months during what people today call *el tiempo de la enfermedad* ('the

time of sickness'), many people in urban centers of the country were afraid and stayed inside.⁴

In rural communities, the effects of the pandemic were felt in other ways. People feared contagion, and did not want to break the law: at 4 p.m., when the national curfew went into effect, they generally returned to their homes. But they did not isolate indoors as did people who lived in the cities. In San Juan nearly everyone grows maize, the foundation of all their meals and of their community life. The major annual harvest is in November, so when the pandemic closed the country they still had ample supplies. In February 2020, as people around the world began to eye the emerging story of Covid, people in San Juan were busy preparing and tilling the earth. In March, when the world shut down, they were waiting for the rains to signal that it was time to begin to plant maize for the next cycle of harvest. When we asked if they stayed at home when the country went into lockdown, they said this would be impossible. They were afraid of sickness, but foregoing a cycle of planting would mean certain death.

Similarly, women tended not to isolate themselves from their aging mothers. When we asked at the cooking group whether women took the precaution of staying away from elderly family members, the women unanimously shook their heads. They knew this was the guidance but they relied too much on intergenerational ties to do so. Public health mandates to isolate from social networks were not designed with poor communities like theirs in mind. These were guidelines for middle class or wealthy families – not for people, like those living in the communities around San Juan, who needed to farm and needed each other to live.

Conventional economic understandings of hunger would have us write, 'despite their poverty not a single person we spoke to reported hunger'. Yet it was also *because of* their poverty that they could not adhere to the mandates of lockdown and continued to farm. The people we spoke with knew that COVID was dangerous and that it had contributed to deaths in the community, but they saw no option: they had to work together to facilitate the production and distribution of food. One mother had nine children to feed and no land of her own. Her husband had previously commuted long distances for his work in construction; public transportation closures meant he lost his job. But in her case, as with others in her position, neighbors with land stepped in to provide food. Another woman with six children who similarly did not own land reported that she switched from buying local maize to buying maize from the coast, which was cheaper. When this ran out, she was cared for by community members, who shared their maize with her. Food was

scarce, but as with every other person we spoke with, this woman said that during the pandemic she and her children never found themselves without food. The pandemic was a time of fear and sadness, but the maize people in San Juan had stored in 2019 would get them through 2020, and the maize they grew in 2020 would get them through 2021. By all reports, the pandemic was not a time of hunger.

In fact, several people mentioned that lockdown restrictions caused them to spend more time farming on their land than they had in previous years. Many San Juan households grow their maize in small plots disconnected from their homes. In addition to the time they spent at these plots, several women also started or tended to home gardens, filling these with broad beans, peas, and the many common green, leafy herbs that people grew and ate (for example, cilantro, peppermint, epazote, parsley, huauzontle). Children still ate chips and lollipops, much as they had before the pandemic.⁵ And eventually, the government stepped in to distribute food aid for families with school-age children that included processed and packaged foods such as oil, cornmeal, pasta, sugar-fortified cereal, rice, and beans. But these boxes arrived infrequently and food prices escalating rapidly. Access to city grocery stores was made difficult by the lack of transportation, and people in San Juan relied on home-grown foods more so than usual.

While they did not run out of maize, women did mention struggling with the closing of the public *molinas*. Typically they pay a small fee to the owners of these machines to mill corn into the masa that was the basis of the region's staple foods served at every meal. Without access to the mills, they had to roll corn out by hand, which was laborious and time-consuming work. Although this did not result in hunger, it added to the challenges of daily life during the pandemic. Our interviews were filled with stories of pandemic-related hardship: these included husbands losing their jobs because they could no longer travel by public transportation to work; electricity being shut off because they could not pay their bills; family members who had migrated to the United States just before the pandemic who stopped replying to calls for several months; family members who became sick, children who became sick; and many community members who died from suspected-COVID-19 and from other illnesses – exactly what those might be they could only guess, since they did not have professional medical help.⁶

In the background of these descriptions of pandemic marginalization is historic and widespread discrimination against Mam-Maya people. During Guatemala's armed conflict, the military targeted Maya people because of their cultural practices. The killing or disappearing of

more than 200,000 people included an estimated 83 per cent who were Maya (CEH 1998). The war officially ended with the signing of the Peace Accords in 1996. But the acceleration of Indigenous migration since the late 1990s suggests that ethnic and racist violence did not end. Today, Maya people continue to face widespread discrimination in accessing government services and employment. During Covid, by drawing upon their plots of land and their ties to their community they were able to feed themselves; hunger was not their problem. Still, they suffered in many other ways.

During the cooking group, Marta mentioned that her eldest three teenage children – two daughters and a son – had left for the United States during the pandemic. She said this casually and without apparent sadness, then adding that her 15-year-old son, who had joined us for lunch that day, would probably join his older siblings in Florida soon. Emily's two children were also at that moment in the United States, and she empathized with the difficulty of separation. Marta's neighbor, sitting next to us, added that after Marta's children had migrated, Marta had cried every hour of every day for months on end. The neighbor speculated that because it was common for children to migrate, this made it harder, not easier, on their mothers, who lived in fear of their children's imminent departure. Anthropologist Briana Nichols (2021), who has worked in a nearby community, has documented that many children, who witness the suffering and loneliness that results from emigration, want to stay. Nonetheless, the older they became, the more likely it was that they would leave.

Fear of their departure hangs over the process of children aging, and then once they leave, those who stay behind are left to worry about their children's disappearance or death. Just days before our visit, the body of a 23-year-old man was repatriated from the United States to San Juan for burial. Neighbors said that his death was an accident, but they had heard rumors he had suffered considerably from economic and ethnic discrimination in the preceding years. A few days later, another young person from San Juan – Mercedes Carolina Izara Vicente – died in Arlington, Virginia, shortly after becoming sick. At the funeral in the United States, which was broadcast to her Guatemalan community on Facebook, the pastor spoke of how hard it is for migrants to find appropriate health care.

But even though the trip to the United States is dangerous and life there for migrants is often extremely perilous, staying in San Juan was not a viable choice for many. The schoolteacher we interviewed told us about how much he worried about the community's youth.

Young people, he explained, had a terrible burden placed on them: they had few opportunities for educational advancement and the possibilities for local employment were demanding, low-wage jobs. These didn't pay enough for them to support their families or themselves. He spoke about the difficulty that young people in the community experienced as their life opportunities shifted north. He mentioned one young boy in the community who became lost to the helplessness of his future during the pandemic, committing suicide by drinking poison.

One mother we interviewed told us of leaving her two younger children behind in San Juan in 2021 so she could travel to the United States to reconnect with her older children who had emigrated before the pandemic began. She was apprehended by authorities before reaching them, and deported with significant debt back to Guatemala. By all accounts, it is money sent from abroad from family members – not government support – that keeps the communities of San Juan going. An article in *The Guardian* reports that remittances rose 35 per cent between 2020 and 2021 (Abbott 2022). The US\$15 billion-plus dollars sent to Guatemala from abroad in 2021 played an integral role in sustaining Guatemalan families during the pandemic. As journalist Jeff Abbott wrote, rural Guatemalans 'depend on remittances for survival while elites benefit from low labour costs' (2022).

The US government ended asylum proceedings at the start of the pandemic, citing a public health policy passed in 1944 that allowed federal authorities to prohibit migration so as to not spread disease. For 38 months, the United States turned away all Guatemalans who might have claimed asylum – and yet, still people in San Juan went north. Everyone knew that those traveling to the United States often experienced tremendous hardship. People were not leaving because they wanted to go, but because they found it impossible to stay. The pandemic had not left them hungry. Their maize was strong; they knew how to feed themselves. Instead, they were leaving their homelands because the pandemic had exacerbated already difficult social conditions including economic discrimination and violence against Maya people. People generally did not want to leave, but they saw no other choice.

Conclusion: a measure of societies

Chronic malnutrition is an indicator that measures a situation, not of children, but of societies.

Lesley Ramírez (Quoted in Redacción Con Criterio 2020)

Western scientists have long held that Indigenous Guatemalan diets are deficient in nutrients. For years, nutritionists were convinced that a maize-based diet lacked protein, causing people to live with moderate malnutrition that, while imperceptible, nonetheless wreaked havoc on their fitness, their intelligence and, ultimately, their lives. For the better part of the second half of the twentieth century, major attempts were made to fortify Guatemalan diets with protein, until many scientists began to realize that protein deficiency had never been a widespread problem.

Some degree of micronutrient deficiency may have existed in the ancestral Guatemalan diet (iodizing salt has helped to prevent goiter; as has adding vitamin A to sugar helped to reduce cases of blindness; see Ruz and Solomons 2019; Arroyave et al. 1981). But it is also the case that the corn-bean-squash-chile based diet, the staple food of Indigenous communities, is remarkably healthy in terms of nutrient composition, containing the nutrients people need not just to live but to thrive.

This was an observation made in the early 1950s by Guatemalan anthropologist Antonio Goubaud Carrerra, who argued that nutritionists' disdain for the Maya diet was driven by their Western ideology. His research on the food practices of Indigenous Maya people led to a 'public revelation' that the typical diet of rural Indigenous Guatemalans was not actually 'as bad as recently thought' (Adams 2016, 81). In her retrospective account of Goubaud Carrerra's work, anthropologist Abigail Adams writes that Goubaud Carrerra criticized those who held racist explanations for why Indigenous people were shorter than Europeans. Refuting the idea that the Maya diet was inferior to the Western diet, Goubaud Carrerra published a newspaper article in which he argued,

Do not the Holy Scriptures say, 'Man does not live by bread alone?' If we find that the material bread of indigenous people is fine, then it would be the height of ignorance to think that their spirit must receive whole wheat bread. (Goubaud Carrerra cited in Adams 2016, 81)

After we concluded our research in San Juan, Emily spoke with Dr Noel Solomons, who runs a nutrition research center in Guatemala (where Rosario García Meza also works). Studies conducted at his center have pointed to the nutritional merits of the traditional Guatemalan diet (Valdés-Ramos et al. 2001) and he characterized the idea that Guatemala is a country with endemic food insecurity as 'misinformation'. While global warming could certainly radically upend food supplies, he argued that the research coming from Guatemala does not point to *chronic malnutrition* – understood as persistent food insecurity – as a historic problem in the

country. Rather, he suggested that what is imprecisely called chronic malnutrition is not caused by a deficiency in available nutrients but rather by an environmental trigger that he referred to as ‘stress’ (see also Solomons 2019). He explained, ‘the problem that women and children experience is that of early life “stress exposures” that can compromise physiological development’. The problem that policymakers are calling *chronic malnutrition* does not actually relate to nutrient intake, and the problem ‘will only go away when these environmental stressors are overcome’.

He pointed us toward recent research using large datasets of child growth to analyze the relation between stunting and wasting. This research, affiliated with the Bill and Melinda Gates Foundation, the Emergency Nutrition Network and the Knowledge Integration Child Growth Consortium (Mertens et al. 2023; Benjamin-Chung et al. 2023; Sadler et al. 2022), suggests that unless a child experiences a stress event – such as an infection or acute wasting – being short, also known as stunting, is a benign experience. In other words, shortness on its own is not a problem and it should not be equated to chronic malnutrition.

In important ways, this ‘cutting edge’ scientific analysis is an echo of what we heard from community members in San Juan: the problems they struggled with during the pandemic were not principally those of food scarcity or hunger but, rather, were those of extreme and persistent sociopolitical hardship. Consider, for example, the filling, delicious meal of *xwoky*. For centuries, Mam women have prepared this for men in their communities ahead of their travel to plantations. Recall Mercedes’ insistence that *xwoky* was a tasty food that could sustain people over long distances of traveling and periods of time. Her reframing of *xwoky* as delicious – not deficient – helps us to see that the problem scientists were calling chronic malnutrition was not a problem of Maya physiology or Maya foods but a problem of colonial dispossession and the brutality of labor that Indigenous people were forced, by law, to undertake. The science of chronic malnutrition has tended to focus on inadequacy of bodies and diets. In naming *xwoky* as a food of abundance, Mercedes was helping us to recenter our stories of malnutrition on the harms of a political and economic system that saw Maya bodies as expendable and did not care if Maya people died.

Geographer Julie Guthman (2013) writes of how nutrition scientists and policymakers frequently contribute to what she describes as ‘problem closure’ in their frameworks for malnutrition. She explains: ‘a specific definition of a problem and socially acceptable solutions are used to frame the study of the problem’s causes and consequences’ (2013,142). In the case of Guatemalan malnutrition, global health workers regularly

embed taken-for-granted assumptions about the deficiency of the Maya diet into their models of health, foreclosing other explanations for why people suffer.

We argued above that the refusal of women of San Juan to categorize *xwoky* as insufficient is instructive; it helps us to see how malnutrition's origins lie not in maize but in the conditions of labor. As scientists begin to shift their focus away from 'nutrients in foods' to 'stress in bodies', we might also take heed of the disinclination of Mam speakers to use the term *éstre*s (stress) – a term that has no Maya language equivalent. Women certainly know and can use the Spanish language term for stress, but we find its absence telling: scientific discussions of 'stress' run the risk of biologizing hardship, turning problems of social injustice into problems of bodies and hormones.

When describing the hardships they encountered in the pandemic, people we interviewed in San Juan kept their focus squarely on conditions of labor and land. They spoke of the pandemic as a time of challenge and difficulty, but the *chronicity* of chronic malnutrition lay in the persistence of political structures that disenfranchized Maya people – not in the persistence of bodily hunger. People did not run out of maize during the pandemic. When some families struggled with provisions, other families stepped in. The concerns they relayed to us were those of enduring exploitation, and the related challenge of building community when so many families and neighbors were separated, spread thousands of miles apart. For centuries, state laws forced San Juan men to labor on coastal plantations where they produced the sugar for wealthy landowners (Oglesby 2013). Eventually the government would fortify the sugar with micronutrients that scientists said Indigenous bodies lacked, and sugar companies would sell the sugar they helped to produce back to them with marketing that described the product as 'healthy'. Today, many of the community's residents – including their children – are still forced to migrate to work, as a living wage remains out of reach in San Juan.

Uti txilil wuaj – or the climatic condition of being without food – is devastating and deadly, but *nchinq'aq'ena*, 'fire in the belly', is not necessarily bad. Just as managed fire is crucial to the regenerative milpa agriculture used to grow maize for millennia, *nchinq'aq'ena* is a feeling that comes in anticipation of a feast. In contrast, not feeling hunger – *desnutrición* – is a clear condition of illness. This happens when medical care is impossible to access, when children have untreated parasites, when infection endures, when communities fall apart or when there is nothing to eat but candies or bread. The chronicity of malnutrition from which people suffer was not to be found in their bodily tissues, but in

political structures that devalue their lives. In the words of Guatemalan nutritionist Lesley Ramirez, ‘Chronic malnutrition is an indicator that measures a situation, not of children, but of societies’ (2020).

As scientists debate the equation between stunting, stress and food security they might take heed of San Juan women’s conceptualization of chronic malnutrition as a sociopolitical problem – an indicator of societies. The shift in this framing also shifts the terrain of possibility for solutions. Instead of asking how to fortify foods with nutrients or how to make people taller, they might instead ask how to repair the harms, not only of the pandemic but of history. How do we ensure that people have land on which to grow their food? How do we redress economic discrimination and racist violence? When the pandemic is finally over, how can we support people to gather with their families and communities to feast? (Figure 8.3). People in San Juan know how to care for hunger – they do so through their land and community. But today, much of their community has traveled so far away that they no longer have access to *xwoiky* to extinguish the fire in their bellies. Without community there can be no maize and without maize there can be no community. Without both they will find themselves in a time of absence – a season of hunger, *la falta de, uti txilil wuaj*.



Figure 8.3 Women in San Juan Ostuncalco gather around a meal of chicken noodle soup in 2023. Source: © Emily Yates-Doerr.

Notes

- 1 We use pseudonyms for the people with whom we spoke in San Juan Ostuncalco. Ethical approval for this research was granted by the Ethics Review Board of the Amsterdam Institute of Social Science Research.
- 2 See Guatemala census data at <https://www.citypopulation.de/en/guatemala/cities/>. Accessed 28 September 2024.
- 3 Covid was still present but vaccines were widely available and there were no longer quarantine or curfew measures in place (masks had been required until 18 July 2022 and on public transportation until 17 October 2022 – see online updates at <https://bit.ly/3N5USIG>). Accessed 28 September 2024.
- 4 A mask mandate was in place until the summer of 2022; masks were widely used inside and outside and not highly politicized as they were in the United States. Even after the mandate ended, many people continued to wear masks.
- 5 At our cooking group, shortly before soup was served, an ice cream truck pulled through the neighborhood and the cooking activities came to a halt as women and children purchased cones to eat. Without judgment – the three of us will also enjoy an ice cream cone on a hot day – we asked about whether kids ate more or less candies and chips during the pandemic than before it. The unanimous reply was that the consumption of chips and candy remained the same.
- 6 The subject of food arose when discussing pandemic-related deaths. Normally ritual foods are served at funerals, but during the pandemic it was impossible to gather to eat together and collectively mourn. The concern, however, was that without collective eating the healing process would be interrupted, and not that maize had run out leaving people hungry.

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Chronicities of care: Mesoamerican immigrant and Indigenous farmworker families during COVID-19

The COVID-19 Farmworker Study Collective,¹ with Tomás A. Madrigal, Jennifer Martinez-Medina and Dvera I. Saxton

Lea, a 29-year-old flower nursery worker from Michoacán, México, migrated to the United States seeking asylum with her two eldest children. She became a widow and single mother of four when her husband died in a car accident. As the COVID-19 pandemic emerged, Lea struggled to maintain the wellbeing of her binational family.

Lea was one of 1,431 farmworker participants in the COVID-19 Farmworker Study (COFS): a 33-month long (March 2020–November 2022), tri-state, rapid-response research-to-action project that aimed to collaboratively and systematically document pandemic harms *and* shift research dynamics and networks of support in farmworker communities in California, Oregon and Washington states². COFS mobilized research findings to create tools for action, redistribute critical resources and advocate for policy changes in support of US Pacific Coast farmworker communities. All three states share agricultural, geographic and labor migration connections, and immigrant farmworker populations include significant groups of Indigenous peoples, displaced by structural and political violence and climate disasters from México, Guatemala, El Salvador, Honduras, Venezuela and Perú.

Sandra Martín, a resident services outreach worker for Bienestar, a farmworker housing and advocacy organization based in Oregon, collected Lea's interview. Sandra shared how the pandemic affected farmworker families economically and emotionally on both sides of the United States–México border. 'For two years during the pandemic', Sandra narrated during a Spanish-language podcast named Voces Del

Campo, co-produced by Oregon COFS partners, ‘I was interviewing farmworkers at the apartment complex where I live, as part of my work as a research assistant with the Oregon COVID-19 Farmworker Study’ (Martín et al. 2023). Originally from Guatemala, and occasionally accompanying her husband in the fields, Sandra was one of over three dozen farmworker-serving community-based organization staffers who contributed their labor, lived experiences and expertise to COFS alongside farmworkers, academic researchers, public scholars and university students and alumni who are the children of farmworkers, and the California Institute for Rural Studies.

Lea shared with Sandra that she faced cuts to her hours at the nursery and was laid off from work for five months. This meant that in addition to struggling to take care of her children in Oregon, she was no longer able to send remittances back to Michoacán to support her parents and extended family, a loss she grieved:

Well, the truth is, the pandemic has affected me so much, as much economically as emotionally. I’d like to say tremendously, because I am the head of household for my family, and it’s hard to have four kids. I know I have to support them for their wellbeing ... I am the only one who helped her [my mother] ... It was also difficult for her. That I can’t help her anymore, as she is sick, she has to buy her medicine, so she’s had to start working over there [in Michoacán].

In all three states, well over half of all COFS participants shared that they had lost wages and hours during the first 10 months of the pandemic. COFS data demonstrate that there were significant disparities in wage, hour and job loss along the lines of gender (54 per cent of women) among farmworkers across the three states. Indigenous farmworkers also faced major barriers in accessing public health and occupational safety information, training and equipment (CA COFS 2021a, 2021b, 2021c; Oregon COFS 2021, 2022; WA COFS 2021).

The many ways in which farmworkers subsidized the food economy intensified during the pandemic along the lines of their under-paid labor in the fields and their caring labors for their families and communities, regionally and inter-hemispherically. As feminist scholar Silvia Federici (2021) observes, without all this unpaid provision and care work, entire industries would collapse. US farmworkers were unable to recuperate their wage losses. Those who were not citizens of the United States were excluded from federal unemployment benefits and the one-time

pandemic stimulus payments offered by the federal government to alleviate economic hardships during the lockdowns and layoffs. Undocumented farmworkers have long been ineligible for unemployment and disability coverage even though their wages pay into these and other US safety net systems. In addition, many immigrant farmworkers feared even attempting to apply for resources for which they would have been eligible, like food assistance and subsidized health insurance for their citizen children, due to the Trump administration's incessant threats to immigrant communities.

As Lea acknowledged, the economic hardships farmworkers endured cannot be separated from the mind-body health harms. Unable to meet her family's needs, Lea felt hopeless and depressed. Even when she tried to access boxes of food distributed by community-based organizations, she couldn't always make it in time. When she returned to working regular hours, she couldn't ask for time off to retrieve a box of food that, while welcomed and appreciated, would not come close to meeting her family's needs. At the same time, Lea and others faced a lot of pressure to pay for food, utilities, rent and wireless internet for their children's at-home schooling. COFS participants also expressed intense worry about the emotional, social, spiritual and physical health and wellbeing of their children and loved ones in their home country communities during this time.

This layering and patterning of inter-hemispheric and intergenerational harm over time and geographic space, and within individual mind-bodies, households and communities, represents a syndemic (Singer 2009) and a continuation (Manderson and Smith-Morris 2010) or *chronicity of inequality* in US Pacific Coast farmworker communities. Due to the multiple forms of structural violence and chronic diseases they were already enduring, farmworkers experiencing COVID-19 fared far worse than the general population. Today, farmworkers are still reeling from the pandemic's ongoing consequences, compounded by exposure to high heat, wildfire smoke, flooding and the ever-rising costs of basic needs like food, fuel, water, utilities, transportation, childcare and housing. As Amelia, a 47-year-old nursery worker from Northwestern Oregon, put it:

Farmworkers are essential, they work in nurseries, canneries, that go to markets and to stores. Fruits, vegetables, chicken, eggs, all of these are [from] farmworkers. Not just anyone does this work and the work is for the benefit of the community itself. Well, pride, it is not the word, but we are astonished that [we did] so much work

in the field with so much exposure to everything: chemicals, to COVID, to many things, and here we are.

Prior to the pandemic, wage and hour protections and occupational health and safety regulations for agricultural workers were applied and enforced very unevenly across the United States (Rodman et al. 2016). Requiring farmworkers to work with weak or absent enforcement of health and safety protocols while others quarantined both contributed to heightened incidences of COVID-19, long-term disabilities and excessive deaths in food and farmworker communities (Chen et al. 2021; Lusk and Chandra 2021; Villarejo et al. 2022; WDOH 2023).³ State and federal governments formally cancelled COVID-19 funding and programs and lifted emergency orders in April 2023, before fully understanding the long-term impacts of recovery for vulnerable populations excluded from protections as essential workers. This occurred even as evidence that women and Hispanics, who represent the vast majority of COFS participants, were at higher risk of developing long COVID (Bejarano 2023).

Farmworkers up and down the Pacific Coast of the United States have long faced multiple and systemic hazards, structural violence and everyday injustices (Greene 2018; Holmes 2013; Horton 2016; Saxton 2021a). Syndemics and chronicities have helped anthropologists to think holistically about the ways that these structural violences and vulnerabilities (Quesada, Hart and Bourgois 2011) intersect and layer in bodies and communities, intensifying and exacerbating physical and emotional health disparities (Horton 2016; Manderson and Smith-Morris 2010; Saxton 2021a; Singer 2009). In this chapter, these frameworks also enable us to think about multi-layered hemispheric and millennial legacies of care and cooperation that have helped Mesoamerican farmworkers cope, in pandemic times and otherwise. Many immigrant and Indigenous farmworkers have long histories of cooperative labor, collective decision-making and relationship-based support networks on which they relied during the pandemic. These *chronicities of care* were enacted throughout the pandemic and shifted COFS' research dynamics and networks of support in ways resembling those mobilized in Indigenous and immigrant farmworker communities.

Below, we first present evidence of the syndemics and chronicities of inequality during the pandemic from the voices of COFS farmworker participants. Second, we explore the 'chronicities of care' that Mesoamerican immigrant and Indigenous farmworkers mobilized during the pandemic to cope and provide support to one another.

These were emulated by the COFS research team and modelled by COFS community-based organization partners. Throughout our analysis and discussion, we also challenge entrenched ideas about the demographics of farmworkers in the twenty-first century, reflecting biases that are consequential for farmworker health, state and federal policies, and for the organization of labor. We argue that community knowledge and chronicities of care must inform research, activism and policymaking practices.

Research-to-action in a pandemic

The COFS collective developed a mindful and intentional recruitment and research strategy, relying on a network-based sampling strategy facilitated by farmworker-serving community-based organizations (CBOs) composed of community outreach workers and *promotoras de salud* (community health educators) like Sandra Martín. These COFS partners had a pre-established rapport with farmworker communities. This facilitated participant recruitment and robust, representative, farmworker-friendly and collaboratively designed rapid response research instruments. Collective members carried out phone surveys (2020), in-depth phone interviews (2020–1), and in-person *pláticas* (small, informal group conversations) (2022) at different stages of the pandemic across the three states. In total, the COFS Collective completed 1,431 surveys with a team of over 95 interviewers and at least 27 organizations.⁴ The staggered state-by-state implementation of the rapid response survey mirrored the decades of movement of migrant farmworkers following the Pacific Coast migrant circuit. Even though some farmworkers indicated following this migrant stream, none of the participants indicated having taken the survey twice.

The survey focused on six core topics: demographic characteristics of workers, including COVID-19-specific agricultural working conditions; economic and household hardships; changes in living and transportation conditions; health care access challenges; and workers' suggestions for systems change and improving workplace safety. Oregon COFS added specific questions about stress, gendered impacts, hemispheric ties and Indigenous languages spoken by farmworker families. The Washington COFS Collective incorporated California and Oregon COFS questions and added questions specific to farmworker housing and communications preferences. The qualitative interviews completed in California and Oregon allowed a selection of participants (CA $n=63$, OR $n=48$) to

elaborate on their pandemic experiences. In Washington, efforts shifted to an emergency response survey project and mutual aid efforts in the wake of torrential flooding in 2021 in key farmworker communities (Madrigal 2023). In 2022, *pláticas* across all three states allowed CBO and researcher partners to check in on how farmworkers were fairing two years into the pandemic, and to share feedback for the development of tools for action, campaigns and policy advocacy.

All research instruments were translated into Spanish using a collaborative and iterative process. Indigenous CBO partners orally interpreted survey and interview questions and *plática* prompts to participants.⁵ Languages spoken by COFS participants included Spanish, English and variants of Mixtec, Zapotec, Triqui and Mam, among others (CA COFS 2021c; Oregon COFS 2021, 2022; WA COFS 2021). A ‘train the trainer’ approach helped to teach tri-state CBO interviewers how to implement the survey using SurveyMonkey, and later, to orient folks to conduct in-depth phone interviews and facilitate in-person *pláticas*. At each phase of COFS, farmworker participants were introduced to the study, orally consented, gave their responses and received cash compensation for each phase they participated in.

All COFS qualitative data were analyzed using an iterative process involving CBO partners, researchers, graduate students and undergraduate trainees from farmworker families. The involvement of these diverse partners in COFS created spaces for deep and grounded analysis based on lived experiences and the intimate knowledge gained from belonging to farmworker households and communities. This facilitated enthusiastic farmworker participation in COFS.

Extrapolating COFS data to the United States Census of Agriculture estimates suggests that on the Pacific Coast at least 427,874 (49 per cent) of farmworkers are female and at least 152,521 (17 per cent) of farmworkers are Indigenous (USDA 2017). These demographic findings impacted the research-to-action components of all three states, leading to the introduction of policies that supported Indigenous-language-speaking farmworkers and addressed such things as childcare and paid time off requirements for farmworkers in the absence of sick leave protections and other policies specific to agricultural laborers who were female and/or Indigenous. The ongoing feminization and Indigenization of US Pacific Coast food and farmworker communities is a significant finding of our study that helps to contextualize the chronicities of inequality, as well as the chronicities of care we documented and emulated through the research model.

Farmworker health and wellbeing: vulnerabilities and care during COVID-19

COVID-19 exacerbated many chronic conditions in farmworkers' lives, households and inter-hemispheric communities. Data from all three states show patterns of the synergistic relationships between physical and emotional (that is, mind-body health) among farmworkers that are tied to numerous structural forces beyond their individual control. Here, we blend farmworkers' testimonies of how these forces affected their collective mind-bodies with structural analysis.

Farmworkers' salaries are already punctuated by seasonal and industry-planned market-driven un- and underemployment. The average annual farmworker salary in the United States is estimated to be around \$25,000 per year, even less for Indigenous and undocumented workers (NFWM 2022). This is below the Federal poverty level (\$30,000) for a family of four (US HHS 2023), and nowhere near close to Oregon's modest adjusted \$73,380 per year 'survival budget' for a family of four (United for ALICE and United Ways of the Pacific Northwest 2023). Farmworkers' incomes are chronically depressed via longstanding stagnation in wages, routine wage theft, exclusion from benefits, commodities price gouging and evasion of state-based overtime pay laws by employers and supervisors (Cabrera-Lomelí 2022; CA COFS 2021c; CAUSE 2015a and 2015b; Costa et al. 2020).

Despite their federal designation as essential workers, farmworkers faced economic and emotional brutality (Bloodsworth-Lugo and Lugo-Lugo 2022). Some employers laid farmworkers off or shortened their hours due to pandemic-related disruptions in the food-chain or efforts to enforce social distancing by decreasing the size of work crews. As a result, some farmworkers sought jobs from different and multiple employers to try and secure enough hours and wages to meet basic needs. This heightened their exposures to COVID-19. Other workers lost supplemental employment and income outside of agriculture, including women providing childcare. The pandemic intensified food and housing insecurity, already endemic for Pacific Coast farmworker households (Brown and Getz 2011; López 2007; Minkoff-Zern 2014; Villarejo 2015), putting additional stress on caregivers. Women in particular lost income from working in the fields and having to stay home and take care of young children when schools and day-care centers closed.

My wife took care of children and earned a bit that helped with the rent. And now all the children that stayed home that aren't going

to school, they're taking care of themselves. And my wife isn't taking care of kids and with this she's not making an income for our household. (Fernando, age 38, Central Coast California)

Rents and costs for other necessities are exorbitant in most US Pacific Coast communities. In all three states, many farmworkers live in overcrowded and substandard conditions in communities rife with systemic disinvestment and failing or absent infrastructure and services. This made it impossible for people to adhere to many recommended COVID-19 prevention measures promoted by state and federal governments and county departments of public health, such as isolating infected people in separate bedrooms and bathrooms. Finding housing is especially challenging for undocumented and Indigenous farmworkers with children.

COFS participants articulated how workplace, household, mind-body health and community vulnerabilities exacerbated one another syndemically:

What worries me is getting infected at home, because I live in a very small place and share the same bathroom with the whole family. And well, psychologically people are affected and also economically because when that happens, you also stop working and then you have certain expenses for your home or the things you need. (Alejandra, age 52, Central Oregon)

At work, many COFS participants observed the lack of enforcement of basic workplace rights such as access to clean and well-supplied bathrooms and handwashing stations, shade, water and rest breaks and COVID-19 occupational health and safety guidance, like social distancing and masking. This heightened multiple vulnerabilities, including succumbing to the virus. Farmworkers felt pressured by employers and household economic obligations to report to work, even when they were symptomatic or had tested positive for COVID-19. In some cases, supervisors threatened to fire farmworkers for demanding sick-leave pay.

The foreman just yells at us that the work must continue and that he doesn't care if one has Covid or not. They don't even wear facemasks. The employer kept quiet and didn't tell anyone until some died. They never pay attention. (Pedro, age 45, Desert region Southern California)

State and county governments and farm labor supervisors' failures to inform workers about safety precautions and rights – in accessible formats and in the languages spoken among their crews – further exacerbated farmworkers' vulnerabilities. For example, during in-depth interviews with Oregon farmworkers, 41 per cent (20/48) stated they were not aware of sick-time eligibility (COFS Oregon 2021). This information was often not included in employer *pláticas* with workers about COVID-19 precautions. COFS Oregon findings demonstrated how these disparities in sick-time and paid family leave fell more profoundly on women who tended to manage the health and wellbeing of their families, including taking time off for COVID-19 testing and taking care of their children and family members when in quarantine.

Many COFS participants shared that employers did not consistently provide protective equipment to employees, or grant them paid time off for testing, quarantine and caregiving. Farmworkers felt conflicted over protecting their and their communities' health or losing wages. In addition, farm work jobs rarely include employer-provided benefits like health care and disability coverage, retirement plans and paid parental or sick leave (Rodman et al. 2016), even when the law requires it.

If you go home and take the test and you come out positive, they pay you [sick time]. I said, 'if I stay at home and I don't come out positive, they won't pay me my days that I'm going to be home and what will I do?' So I kept working (Amelia, age 47, Northwest Oregon).

These intersecting vulnerabilities and chronicities of inequality contrast starkly with record-breaking profits, in the hundreds of billions of dollars, for key actors in the global food industry during the pandemic (Oxfam 2022). Chronic and historically deep-rooted realities perpetuate a patchy landscape of workplace rights and protections that are under and unenforced, largely with impunity or minimal fines. Growers and agribusinesses could rely on crop-protection insurance, federal pandemic-era Paycheck Protection Program (PPP) loans and increased international trade crisis relief payments to agribusinesses (Environmental Working Group 2022; USDA 2020; Weintraub 2020). Meanwhile, farmworkers were afforded limited, if any, assistance in most states across the United States. Data from California and Oregon partners showed that slightly more Indigenous farmworkers with children reported difficulties paying for basic needs, suggesting that

Table 9.1 Farmworkers struggling to make ends meet financially.

State	Food	Rent	Childcare	Water	Utilities
CA (<i>May–July 2020</i>)	70%	63%	60%	51%	60%
OR (<i>August–October 2020</i>)	59%	60%	16%	28%	59%
WA (<i>September–November 2020</i>)	51%	47%	17%	44%	47%

Source: COVID-19 Farmworker Study (CA COFS 2020; Oregon COFS 2021; WA COFS 2020).

they faced more work loss than non-Indigenous co-workers (CA COFS 2021a, 2021b, 2021c; Oregon COFS 2021, 2022). Eventually, some states did offer food aid, rent relief or stimulus support payments to undocumented workers; however, not all farmworkers had access to these supports. Table 9.1 shows the minimal improvement in relief efforts trickling down to farmworkers in the three states as the pandemic progressed through 2020.

Conditions were worse for undocumented and Indigenous farmworkers who struggled to supervise their children’s at-home online schooling. When someone in the household fell ill, farmworker women were primarily responsible for nursing their loved ones back to health. Men, too, felt tremendous pressure to stay healthy to provide for and care for their families, and so kept working even amidst dangerous conditions. Compounding this, undocumented farmworkers feared that receiving any aid would jeopardize their possibility for applying for US residency. This was a direct effect of the first Trump presidency’s ‘Public Charge’ policy, which stated that undocumented people who applied for or utilized certain kinds of federally funded assistance would be barred from applying for permanent residency and work permits (USCIS and DHS 2021). Even prior to the threats of Public Charge, many undocumented and Indigenous farmworkers feared accessing health care, even in emergencies, due to high costs and barriers communicating with public health officials and health care workers. And although many state-sponsored and managed services, including food assistance and emergency health coverage plans, were not under the purview of Public Charge, enrollment dropped significantly in the months prior to the pandemic (Barofsky et al. 2020).

We were in need ... of food, but they said we could be a public charge. So we stopped asking for food stamps. Maybe it will affect [us]. It makes me sad because many people have children and a single salary is not enough for food, or for other expenses. (Alejandra, age 52, North Central Oregon)

It is currently unknown how many farmworkers died as a result of COVID or how many are living with the debilitating conditions of long COVID. Preliminary analysis of death certificates by the U.S. Centres for Disease Control and Prevention (CDC) suggest the numbers are in the thousands (Ahmad et al. 2022); however, this is likely an undercount given that vital statistics often attribute causes of death to pre-existing or COVID-induced chronic conditions, like diabetes and high blood pressure (Horton 2016), which are among the many chronic and work-related diseases prevalent in US farmworker communities (Bejarano 2023). Many state and county departments of public health are over-centralized, understaffed and disconnected from immigrant and Indigenous farmworker communities. This worsens undercounts and minimizes or erases significant problems.

As each state completed rapid response surveys sequentially in 2020, we observed a significant increase in the number of farmworker participants who contracted COVID-19 themselves and/or who knew someone in their networks who became ill from COVID-19. During in-depth interviews in 2021, 52 per cent of sampled farmworkers in Oregon reported contracting COVID-19 (Figure 9.1). This represents a community-level chronicity that worsened as the pandemic continued.

The existing literature is dense with references about farmworkers’ pre-pandemic experiences with hypertension, diabetes, musculoskeletal injuries, cancers, poor mental health, substance use, cardiovascular and respiratory conditions, reproductive injustices and more; it is sparse when it comes to exploring what it means to live with all of this, all

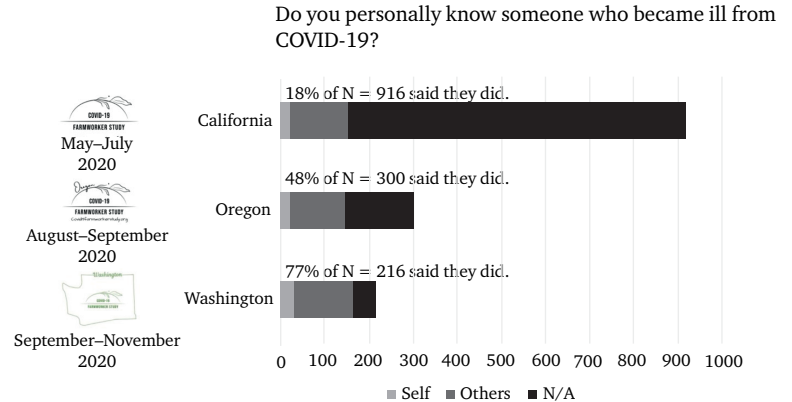


Figure 9.1 Findings from the COVID-19 Farmworker Study: Answer to Question: ‘Do you personally know someone who became ill from COVID-19?’

at once, over lifetimes and generations. The pandemic magnified this (Saxton 2021a, 2021b). On top of the high risks of contracting COVID-19 in industrial food and farm workplaces, Pacific Coast farmworkers continued contending with the compounding effects of chronic health conditions, wildfire smoke and pesticide exposures, lax enforcement of COVID guidance and other occupational safety rules, extreme weather events like record-setting temperatures and floods and quotidian hazards and indignities at work. COFS farmworkers described these multiple and intersecting injurious conditions on their personal, household and community health and wellbeing:

These symptoms [of COVID] ... I feel them when I have asthma, I can't catch my breath, my lungs hurt, I can't talk, I can't breathe, I have to use a machine [nebulizer] to be able to breathe. So I say, do I have asthma or do I have COVID? What do I have? ... How do you know what you're sick from? What I felt with the fires!?! The smoke, it burned my eyes, my throat, in fact my throat is still irritated. (Clara, age 53, San Joaquin Valley California)

Mind-body health struggles are recurrent in farmworkers' testimonials, even though they were not always prompted about emotional health. Their responses show syndemic patterns, wherein structural forces outside of their individual control (COVID-19, workplace conditions, household gendered labor challenges and pressures and other health conditions) are embodied in ways that intensify and exacerbate one another in chronic and enduring ways. Still, farmworkers found ways to cope and care for each other.

Chronicities of care

COFS data show women and Indigenous farmworkers' presence in the US Pacific Coast communities and the agricultural labor force. This radically transformed the provision, economic dynamics and expressions of care. Here we focus on immigrant and Indigenous agricultural workers who originate from communities in the Global South with long traditions of subsistence agriculture.

We call these millennial hemispheric practices *chronicities of care* – deeply embedded in cultural, traditional and ancestral ways of knowing that have been adapted across time and space and have survived colonization (Bade 2004; Daria 2019; Kearney 2000; Stephen 2001).

Usos y costumbres (UyC) governance systems of Indigenous and rural communities across Oaxaca, for example, prioritize collective decision-making and rotative models of leadership over hierarchical forms of political organization.

Our care chronicities model is based on four elements: situated place-based knowledge, *cargo*, *tequio* and *mando*, or *confianza* (trust); see Figure 9.2. These are rooted in Indigenous farmworkers’ knowledge systems of self-governance practiced by many of the COFS Indigenous respondents and the Indigenous-led CBOs. While not all communities use these same terms, the knowledge, values, morals and overall guiding ethics of these ideas are shared by many Mesoamerican immigrant and Indigenous communities across the hemisphere (Congreso Nacional Indígena 2017).

Indigenous and immigrant farmworkers hailing from rural communities in the Global South hold situated place-based knowledge, ‘land-based literacies and rhetorics’ based on ecological relations and embodied ways of knowing that are sustained through diaspora (CA COFS 2021c; Hernandez 2022; Rios 2015). Farmworkers like 37-year-old

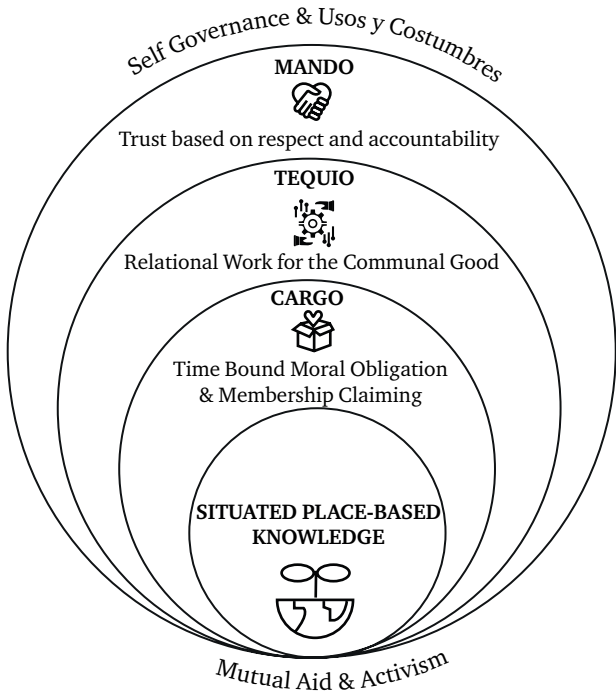


Figure 9.2 Care chronicities.

Gloria, working in an Oregon packing house, reconcile ecological values of reciprocity, interconnectedness and responsibility within the vast agricultural harm industry and extraction systems:

The essential worker is the first hand that holds the seed, the plant, until you go into the furrow to plant and then you trim what becomes exposed. The essential workers do everything in the field, from seeding until the fruits and vegetables are cut.

Place-based knowledge is maintained through *pláticas* (informal chats), *cuentos* (stories and storytelling) and *testimonios* (testimonies). These large networks are intertwined with the land, facilitating intergenerational worldviews and knowledge that have been adapted into care strategies. They help people attain necessities for the wellbeing of their families and communities in the food and farm labor diaspora.

The *cargo* system is a time-bound, civil, ceremonial and moral commitment to community composed of a series of rotative ranked responsibilities called *cargos* (Velasco Ortiz 2005, 33). For example, in Nuu Savi (Mixtec-Speaking) regions of Oaxaca, México, communities complete projects and meet other collective needs through volunteer labor and exchange (Velasco Ortiz 2022; O'Connor 2016). The *cargo* system is sustained through the tightly knit social organization of *pueblos originarios* (home villages) in diaspora (O'Connor 2016). In these ways, membership to a community is not automatic but continuously earned through service to that community at home and abroad. As people migrate, they must maintain their obligations to the community.

Tequio is relational work for the communal good, organized through *cargos*, community assemblies, or offerings and support (Velasco Ortiz 2005, p. 33; Tobón Mentado 2017). *Tequio* systems prioritize collectivity and sharing resources and knowledge between kin and community (Tobón Mentado 2017).

The *bastón de mando* (leadership mandate, accountability) is practiced in several Indigenous communities throughout the Western Hemisphere. It represents the trust (*confianza*) a community places in its leaders selected via assemblies to represent their common good (Krøvel 2019). Above all, it represents accountability; whoever receives the mandate must abide by the will of the community in accordance with forms of self-governance (Gutiérrez 2019).

COFS data show that immigrant and Indigenous farmworkers have retained these relational connections that surface throughout the course of daily life while confronting pandemic and quotidian brutalities

and chronicities of inequality. Farmworker communities continued exchanging information, resources, remedies and expressions of love and concern. These chronicities of care occur through phone, WhatsApp and social media, or carpool, lunch break and parking lot conversations. They help maintain family and community interhemispheric allyship in diasporic families and communities.

In contrast, deficit models stigmatize farmworkers' presumed lack of knowledge, unwillingness to learn new information, and risk behaviors as explanations for health disparities (Geleta et al. 2021; Salvatore et al. 2008; Goldman et al. 2004). These approaches fail to recognize the lack of control farmworkers hold over their workplaces (Holmes 2013) and the chronic failure of federal, state and regional governments to prioritize farmworkers' needs. They also underestimate the complex and historically backed informational ethic farmworkers practice. Chronicities of care are constantly recreated by farmworkers to alleviate the pressures and harms wrought by chronicities of inequality.

Mesoamerican immigrant and Indigenous communities in general, and especially farmworkers in the United States, experience tremendous barriers to accessing critical information and resources in culturally, linguistically and geographically accessible ways, especially in times of crises (Soto-Vásquez et al. 2021; Silesky et al. 2023; McDevitt and Butler 2011). Pandemic misinformation paired with limited access to supports diminished farmworkers' already strained levels of confidence in public health and health care infrastructures and networks. The pandemic, as a high stakes public health moment, coupled with Donald Trump's attacks on immigrant communities and disinformation techniques.

This set an example of the deep effects caused by how little is understood about how farmworkers build on hemispheric knowledge and networks to sustain themselves in both ordinary and extraordinary circumstances. Take, for example, the following quotes from farmworkers about how they supported one another in collective ways:

Well, the group that we have is a group of our people who speak Mam ... There are people in need, and who get sick ... or they get injured, and they do not have families, because many people are here without family, just alone – even without siblings or cousins ... So, when they get sick, who is going to take care of them? Who is going to give them food to eat? Who is going to pay their rent and the bills? So that's why we formed a group to support those in need, those who get sick, those who have an accident. (Juan, age 46, Mam, Northwestern Oregon)

In addition, farmworker-serving rural clinics and community-based organizations – those that had already invested decades worth of time and energy to build culturally and linguistically appropriate networks of care and support and a strong foundation of trust – were well received by farmworkers in COFS. This pushes back against another trope that surfaced from state and industry during the pandemic – that farmworkers, even when provided with information or resources, were disinterested or non-compliant. It is clear from COFS data that delivering information, resources and support through familiar and trusted networks was welcomed, appreciated and reciprocated by farmworkers throughout regional and diasporic networks.

Due to the grave and multi-layered structural assaults described above, farmworkers employed these critical information and resource exchanges through cross-border kinship networks (Martinez-Medina 2023). Their information ethos is based on a moral economy of information to support subsistence and survival. Concepts of trust, commitment and reciprocity allow farmworkers to sort relevant information. As a daily effort of life, farmworkers filter information through historical and intergenerational knowledge that originates from their experiences as subsistence communities. Cultivation knowledge – such as frames of time tied to harvest seasons and trust tied to community relationships, cooperative labor and support systems – are central to how farmworkers co-constructed the pandemic and survived it.

Farmworker communities and CBOs engaged in vast forms of resource exchanges, including sharing information by *corriendo la voz* (spreading the word). *Promotoras* and farmworkers were both eager to extend resources and information as acts of mutual aid, care and activism. These information economies proved to be critical lifelines amidst multiple and unfolding crises, including COVID-19, climate disasters like wildfires and floods and inflation. This contrasts with the deficit model imposed upon Mesoamerican immigrant and Indigenous communities, as being unable or unwilling to understand public health measures, and suggesting that they, not institutions, are the ones with language and cultural barriers. Information about workplace rights was also critical, including knowledge of workplace outbreaks that were not often reported to farmworkers by employers or supervisors.

The Binational Center for the Development of Indigenous Oaxacan Communities helps us when we need support. They inform us if there is help available. I only trust them because they speak my language and we understand each other well ... Fidelina [a staff

member at CBDIO] was the one who told me where to go to get a free COVID test. (Irma, age 34, Mixtec, San Joaquin Valley, California)

Indigenous people used Facebook even though some don't know how to read or write, it's easier to share and reach others. We make a page and share. We can have a live conversation, more than anything personal, talking. (Juan, age unknown, Mam, Central Coast Oregon)

Farmworkers coped with the isolation and uncertainty of the pandemic by sharing their worries with their families, co-workers and neighbors. Being separated by borders and thousands of miles of distance in some cases did not stop people from trying to make sense of and survive the pandemic and systemic violence together. These inter-hemispheric connections made farmworkers feel less alone and allowed people to share emotional and practical support and information. These spoken words or shared experiences between kin across borders often convey urgent matters as a form of bearing witness and truth telling (Caxaj 2015).

For example, 25 per cent of farmworkers (76/300) in Oregon reported emotional and spiritual symptoms of stress with the concept of *susto*, loosely translated to 'fright sickness' in English (Herrera and Orr 2020, 69). *Susto* develops in adults and children after witnessing or experiencing violence, abuse and traumatic events, causing their souls to leave their bodies (Herrera and Orr 2020, 69). Farmworkers, following their families' directions, used traditional healing remedies to cope with COVID-19 and accompanying stressors. Farmworkers across the sample shared similar tea recipes. Originally from the northwestern part of Oaxaca, an Indigenous farmworker named Chano recreated his mom's tea recipe which included *un montón de ingredientes* (a ton of ingredients) as he described it: lime, eucalyptus, rosemary, spearmint and many other herbs. Many farmworkers relied on these herbal teas in lieu of formal medical attention, which they could not always access. Farmworkers cited lack of health insurance, lack of paid sick leave, geographical distance, the high costs of emergency and hospital care, worries about lack of interpreters for Indigenous language speakers and fears of dying alone. These concerns, rooted in prior traumatic and demoralizing experiences with health care systems, were reasons for avoiding formal health care (CA COFS 2021a, 2021b, 2021c).

These knowledge sharing practices were not just about sharing tea recipes to help people recover from Covid at home at a time when

there were no biomedical treatments and the advice from doctors was limited to rest, hydration, quarantine and self-monitoring of symptoms. Farmworkers' communication networks also provided spiritual and emotional relief and hope, even when other care practices like sending remittances to family members back home were put on hold due to household economic constraints.

Similarly, as farmworker families experienced food shortages and insecurities across their respective countries, communities exchanged subsistence knowledge and resources. Many families resorted to ancestral food practices and traditional diets by planting their food when possible, increasing their intake of beans, rice and soups and reducing meat consumption. Many farmworker families also shared food. Those with access to food assistance often reported sharing it with friends, especially when households were dealing with COVID-19 infections (CA COFS 2021b, 2021c).

Trusted networks and community organizations remain important yet undervalued systems of care, support, information and resources for farmworkers, especially around workplace rights, accessing institutional resources and language access. COFS replicated these systems of care, exchange and political organization. Early on, collective members divided into committees to design and implement the surveys, interviews and *pláticas*, and to find funding. As capacity and bandwidth evolved, a natural rotative facilitation emerged among the collective. These cycles of exchange also enabled farmworkers and COFS Collective members to collectively analyze data, make clear political evaluations, develop grievances and propose solutions (Figure 9.3).

Conclusions

As an interdisciplinary and collaborative web of knowledge, COFS became a powerful trans-regional network of farmworker research-to-action, solidarity and support. Farmworkers' powerful *testimonios* became the basis for a series of reports and presentations leveraged to pressure policymakers to direct resources and support to farmworker communities and to consider longer term systems changes.⁶

Coming together as a community-driven response to the crisis of the COVID-19 pandemic, COFS illuminated the everyday structural assaults that are routinely normalized and therefore invisibilized. COFS findings surface the experiences of agricultural workers, women and Indigenous peoples who have often been muted by ideological biases.

COFS 12 Demands
1. Reforma migratoria integral (Comprehensive immigration reform).
2. Salarios dignos y justos (Dignified and livable salaries).
3. Programas de redes de seguridad, emergencia y desastres que sean accesibles para todos y financiados por el gobierno (Accessible government-funded safety-net).
4. Atención médica de calidad con cobertura SIN COSTO que sea lingüística y culturalmente apropiada (Access to quality culturally and linguistically appropriate healthcare with NO COST coverage).
5. Vivienda segura, de calidad y al alcance garantizada (Guaranteed and increased units of dignified housing).
6. Creación de espacios multilingües inclusivos en donde las lenguas de los Campesinos Indígenas sean valoradas y respetadas (Achieve language justice with Indigenous Campesinos).
7. Más personal, apoyos y recursos en lenguas indígenas para las escuelas (More personnel, support and resources in Indigenous languages in schools).
8. Acceso al Internet y equipo esencial como un derecho básico de los estudiantes (Access to Internet & essential equipment as a basic right of students).
9. Políticas de justicia climática, para reducir la exposición al calor, y al humo de los incendios forestales (Climate justice policies, to reduce exposure to heat, and smoke from wildfires).
10. Reconocer el estatus profesional y la humanidad de los Campesinos (Recognise the professional status and humanity of farmworkers).
11. Una nueva agencia de salud y seguridad ocupacional, dedicada a los trabajadores agrícolas (New occupational health and safety agency dedicated to agricultural workers).
12. Incluir a los Campesinos en las decisiones políticas para abordar los problemas y promover soluciones (Include farmworkers in policy decisions to address problems and promote solutions).

Figure 9.3 COFS 12 demands.

COFS emulated farmworkers’ chronicities of care by prioritizing ‘tools for action’ instead of academic publications as the main ‘outcomes’ of the study. Protective policies and occupational health and safety measures, while crucially important, did not do enough to protect farmworkers, were routinely and flagrantly un- and underenforced, and often conflicted with the profit-driven values and priorities of industrial

agriculture. The lack of responsiveness, let alone respect, demonstrated to immigrant and Indigenous farmworkers by industry and state agencies became a key rallying point for CBOs, farmworkers and farmworker advocates across the three states.

The chronicities of inequality experienced by farmworkers have not ended. Farmworkers continue reeling from the pandemic's ongoing effects on their lives and having been sacrificed for food industry profiteering. It is only now, after the official closing of the study, that we have had time to reflect on the power and evolving potential of farmworker friendly methodologies. In co-creating these tools for and by farmworkers, farmworkers and allies '[explored] the way forward together' (Lynd 2013, 4), as 'co-authors' (El Kotni et al. 2020) of shared demands and visions for rights, justice and the recognition of farmworkers as human beings, modeling the chronicities of care in farmworker communities.

García Peña (2022) describes how the concept of accompaniment comes from Latin America liberation and theory activism. It relates to the idea that social change is a process: it is not given but emerges from the people. Allies (including researchers) cannot create social change alone. They cannot 'bring' justice and equity to oppressed peoples, but they can accompany them in the struggle with patience and courage. Our work as researchers working and living in community with farmworkers continues as an ongoing form of accompaniment and as part of farmworkers' chronicities of care. The role of the researcher should be to nurture and defend solutions that farmworkers bring to life through their millennial and hemispheric chronicities of care. Immigrant and Indigenous people living in diaspora modelled chronicities of care that must be embraced and replicated in reactive and proactive, community-centered and collaborative ways, in our research-to-action endeavors and in ongoing efforts to protect life itself.

Notes

- 1 The COVID-19 Farmworker Study (COFS) brings together a collective of community-based organizations, researchers and advocates to provide critical missing information on farmworkers' experiences working during the COVID-19 pandemic and abilities to protect themselves and their families. The study uses a variety of research tools, including phone-based quantitative surveys, focus groups, in-depth interviews and storytelling to bring the voices of farmworkers into the public conversation about policy responsive to the pandemic and its aftermath.
- 2 The original COFS reports and select tools are available on this website at <https://cirsinc.org/COVID-19-farmworker-study/>. The research on which this chapter is based was approved by Advarra (formerly IntegReview), Nos. COFS P2, Pro00051181, Pro00059884, and the

Department of Social Health Services, Washington State Institutional Review Board. All farmworker names presented in this paper are pseudonyms.

- 3 There are no formal counts of farmworkers in the United States. The United States Department of Agriculture estimates there are about half a million farmworkers in California, a quarter million in Washington, and just over one hundred thousand in Oregon. The collective used 2017 Census of Agriculture estimates and California Rural Legal Assistance's projections for farmworkers' dependents across the three states to estimate the impacts of the pandemic in concert with COFS' findings (USDA, 2017; Kissam and Williams, 2013; Villarejo 2020).
- 4 The sample size collected by COFS is well above the National Agricultural Workers Study's (NAWS) established threshold, however farmworker response rates and their willingness to participate in the COFS project were distinct enough from the NAWS project that NAWS survey administrators sought to replicate the COFS methodology in their most recent survey. See Villarejo 2020 for a fuller discussion of the COFS sampling methodology.
- 5 For future projects, we recommend starting study design in Indigenous languages and Spanish and then translating to English. Indigenous ways of expressing emotions, stress and health concerns are not directly translatable to English or Spanish. Significant resources may be needed to interpret.
- 6 To access reports and recordings of various COFS presentations and press conferences, visit <https://cirsinc.org/COVID-19-farmworker-study/>.

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Chronic vulnerability, COVID-19 and the long fight of Indigenous Amazonian communities

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COVID-19 is a serious disease that has tested the resilience of our societal commitments. Although the impact was widespread worldwide, the consequences for marginal, mainly rural areas was especially high and exacerbated the unique vulnerability of Indigenous peoples. As the pandemic emerged, Indigenous people and communities were not given priority health attention or adequate information about COVID-19 because of their physical, cultural and ideological isolation. Unequal attention continued as new variants emerged and post-pandemic cases rose. By 2023, several changes in the health of community members, and the communities themselves, were evident. The virus not only exposed nation-states incapable of coping with this type of emergency, but also left many community members with nervous system and respiratory sequelae and deepened the painful furrows cut by generations of inequity since colonial times.

Faced with this reality and without adequate answers from the institutions responsible for Ecuador's health, many Indigenous communities sought their own forms of response and use of traditional knowledge to prevent disease, protect their families and relieve suffering within their communities. In Ecuador, the COVID-19 pandemic represented simply the most recent threat to Indigenous peoples amidst ongoing and neo-colonial dangers to their territories, such as mining and oil extractivism, environmental destruction and degradation and the violation of collective rights, both human rights and rights of nature (as legislated in some countries). We direct our attention to these chronicities of vulnerability and the inter-relationship between COVID-19 as aggravator and lightning rod.

We begin by providing a brief commentary on the Ecuadorian context for this collaboration, and the local experience of COVID-19. We then offer a case study of the effort led by Indira Vargas to gather and disseminate ancestral knowledge of medicinal remedies for treating people with COVID-19, or as a preventative. This case study offers two lessons: first, concerning the chronic vulnerability of Indigenous peoples attempting to retain their communal (and sometimes remote) lifeways; second, about what an appropriate response to suffering (from COVID-19 or any other ailment) should be. This communal response addresses the chronicity of a community member's vulnerability, rather than just their physical symptoms. We conclude by suggesting the relevance of chronicity's expansive temporal view on the lifespan as being more compatible with the experience of these Kichwa women in the Ecuadorian Amazon.

Background

Indigenous communities in the Central Amazon of Ecuador often number in the hundreds, have recognized and elected leaders in addition to spiritual and other specialists and report strong, relational bonds and consensus-building across their members (Choque 2000; Iza et al. 2020; Henriquez-Trujillo et al. 2021; Noroña 2022; Makere 2005; Stewart-Harawira 2008). Unión Base is a community situated on the periphery of the small urban center, Puyo, in the province of Pastaza, Ecuador. It is one of many Kichwa communities across Pastaza and other parts of Ecuador, just far enough from the town to support agricultural subsistence, yet near enough to allow access via a regular bus route. Unión Base is home to approximately 150–200 inhabitants from 40–50 families, and is the site for the headquarters of CONFENIAE (Confederation of Indigenous Nationalities of the Ecuadorian Amazon),¹ the regional Indigenous organization with an elected Council of Governors representing the 11 Indigenous nationalities and nearly 1,500 communities of the Ecuadorian Amazon: Kichwa, Shuar, Achuar, Waorani, Sapara, Andwa, Shiwiar, Cofan, Siona, Siekopai and Kijus. This large organization regularly hosts assemblies and multi-community events, and these influence the cultural and Indigenous identity of Unión Base residents (Simpson, Tapia and Smith-Morris 2024). Unión Base community members claim strong familial or extended familial kinship ties with others in their community.

Communities in the region are typically organized around extended family and other closely bonded community members over time (Simpson, Tapia and Smith-Morris 2024; Smith-Morris 2020).

According to Simpson and colleagues (2024), ‘the nuclear home environment is the most crucial site of cultural transmission, acting as a nursery for the development of communal values’. In these communities, men are occupied daily with fishing, cultivating the *chakras* (agroforestry subsistence²) or working in urban Puyo, and while many (but certainly not all) women occupy domestic roles, they often cultivate *chakras* as well. Homes take diverse forms across the region but are primarily framed houses, often built by their owners with the help of the community through the practice of *minga* (collaboration).³

Indigenous communities in the Central Amazon of Ecuador have been traumatized by threats to their land, lifeways and communities since the colonial period. The less isolated Indigenous communities are also exposed to immeasurable messages and influences from dominant culture and the capitalist market, with the corresponding actors and values transmitted via mass media. In general, members of the Unión Base community are conversant on topics such as the expansion of oil, agro-industrial and logging activities and the multi-national (development) Initiative for the Integration of the Regional Infrastructure of South America (Noroña 2022; Sawyer and Gomez 2012) because of their exposure to this information through CONFENIAE and its local radio station. It was through advocacy work on these topics that the relationship between this chapter’s authors began. Tapia and Smith-Morris first collaborated virtually to report on digital mapping efforts by Indigenous communities during the early months of the COVID-19 pandemic (Smith-Morris et al. 2022), and later joined with Vargas to better document other local efforts in response to Covid as a syndemic threat with ongoing colonial and capitalist forces in their community. These larger threats were not the focus of our current research and intra-author interviews that inform this chapter; however, the environmental and informational vulnerabilities that influenced how the Covid pandemic was experienced by the community, and the ongoing and synergistic effects of Covid with global capitalist and biomedical priorities, are issues very much at the heart of Covid’s chronicities for these Kichwa speakers.

The COVID-19 pandemic in Amazonian communities

Indigenous deaths due to COVID-19 were almost four times higher among Indigenous populations than the general population (Cuéllar et al. 2021). In August 2020, across 13 Kichwa communities in the province of Pastaza, in the central Amazon of Ecuador, there was an

estimated mortality rate of 0.16 per cent in an approximate population of 9,500 inhabitants (Sirén et al. 2020). Yet, according to information compiled by CONFENIAE for the same time period, a total of 2,103 COVID-19 tests were recorded among the Kichwa nationalities, resulting in 1,367 positive results, or an infection rate of 65 per cent and 19 deaths – a mortality rate per case of 1.4 per cent (Sirén et al. 2020). Such disagreements between statistical evidence and, in addition, the difficulty of accurately assessing mortality rates in remote and vulnerable communities inevitably (re)produce long-term inequities in experiences of and recovery from the disease.

During the pandemic, many Indigenous populations resorted to the knowledge held by grandfathers and grandmothers with respect to ancestral medicine. Such long-held knowledge offered preventive strategies and improvements to the symptoms of COVID-19, whereby medicinal plants helped strengthen the body's defenses to better face the symptomatology of the disease. Drawing on such long-held knowledge is Kichwa tradition and inspires an equally long view toward solutions to the pandemic. For this reason, Indira Vargas and the Kichwa women of the Unión Base community in Pastaza, Ecuador saw the importance of compiling and distributing a manual of selective medicinal plants, both to support local efforts to prevent and treat COVID-19-related symptoms and to do so in a way that strengthened community knowledge sharing and bonds to their local environment.

In this chapter, we reflect on the COVID-19 pandemic not solely as an infectious disease event but also as one moment in a chronic state of vulnerability for Indigenous peoples. In our discussion, a woman leader and healer (author Indira Vargas) speaks directly to the relational care that has allowed her people to survive such chronic and insidious threats as COVID-19. The vision and work involved in producing an ethnobotanical guide for medicines relevant to COVID-19 symptoms illustrate the many layers of community care involved in this response (Simpson, Tapia and Smith-Morris 2024) and the inter-generational commitments that correspond to the chronicities of a global pandemic (Manderson and Wahlberg 2020; Rovere-Querini et al. 2020). The three authors prepared this text collaboratively, not only to convey the leadership of Vargas and the Kichwa women of Unión Base but also to reflect on local ethnographic and trans-organizational strategies active among the Kichwa in Unión Base to survive the broader chronicities of state neglect and isolation. Efforts by women in this Indigenous community of several hundred people to prevent and educate about COVID-19 were many, including informational radio broadcasts via the Indigenous

community radio station based in Unión Base, training of local teams to share health information and the leadership of healers and herbalists to educate communities about the native resources of their lands. By highlighting the communal infrastructure and deep store of plant knowledge that was deployed in response to the Covid pandemic, we illustrate the failure of a single-disease lens on a community's survival of COVID-19. The 'chronicity' most relevant in Unión Base's experience of Covid was not the symptoms of the disease but the perpetual threat of community loss to individualist bias in medicine and state mechanisms of aid. Indigenous peoples are in a chronic struggle to maintain health in ways that align with their self-determined values; COVID-19 was simply the latest skirmish in that chronic vulnerability.

Our chapter is modeled after the Latin American 'ensayo', in which ideas and teachings are narrated directly from the speaker to the audience; in this case, to readers. The use of this form within academic publishing is a strategy of resistance to the colonializing forces of global homogeneity, uniting the spoken world of leaders in the oral tradition with the written world of institutionalized education (Escobar 2018; Smith-Morris and Abadia-Barrera 2024). We have adjusted the prose only minimally for differences between a more complex conversational flow and the linearity of reading. The value in preserving this spoken voice lies in the respect it offers the original speaker, the context in which the speech occurred and the specific relationship between the original interlocutors. We therefore invite readers to hear rather than to see the experiences of the healer and leader of Kichwa woman Indira Vargas in conversation with community member Andrés Tapia and anthropologist Carolyn Smith-Morris (translated from the original Spanish by Smith-Morris). During the course of our collaboration to evaluate the impact of CONFENIAE's community radio programming, the three of us held a series of discussions, in 2022 and 2023, on the lingering impact of the COVID-19 pandemic in local communities. The research collaboration enabled us ongoing access to five diverse communities served by CONFENIAE where impacts of the pandemic could be witnessed. Vargas' work with elder women of Unión Base provides a focal case study to illustrate the long-term and inter-generational context for this community's response to the crisis.

Kichwa women turning to medicinal plants

During the height of the COVID-19 pandemic, many Indigenous communities took their health and self-preservation into their own hands.

These communities used territorial control and closures, and round-the-clock monitoring of community boundaries, to manage contagion and other threats. They used forest-derived medicines to strengthen their bodies' defenses against the effects of COVID-19. For example, Vargas recognized in the pandemic an emergency need for local healing responses. She researched local medicinal plants and their cultivation with elder women from her own and surrounding communities. She then designed a manual for sharing this knowledge in an accessible yet detailed way, collaborating with photographer Bryan Garcés, who is part of *Lanceros Digitales*,⁴ to produce a manual that would be comprehensible to Kichwa and Spanish speakers of diverse exposure and experience with these plants and how to prepare them. Vargas then distributed the manuals to Indigenous organizations throughout the region. Driving or walking to each household, community by community, Vargas and youth leaders she identified as assistants imparted the knowledge acquired from wise women through conversation, visits to *chakras* (gardens) and other sites for harvesting and discussion of the manual. In discussion, she described what she found:

The situations that people in my community experienced due to the confinement and isolation of Unión Base, since many of the Indigenous communities did not have knowledge of the area recipes and plants that could help to control the symptoms of the disease – even though they were able to gather plants close to home – the situation was terrible. [So,] in the community of Unión Base, women generated circles to discuss the importance of transmitting ancestral healing knowledge to the new generations, even to heal spirituality with the sacred fire used in the preparation of some of the plants. And with the manual, I was able to conduct interviews with wise women, and to disseminate the material with their permission, and with our own lived experiences.

Digital communication systems also strengthened the effort, including conventional FM radio where Vargas delivered radio shows on these lessons. The community radio also made available to community members a high frequency radio for two-way communication during emergencies, such as calling an ambulance or helicopter for medical evacuation, especially in areas where cell and internet signals did not exist. In short, Vargas recognized her community's rising need for knowledge and support in accessing ancestral knowledge of medicinal plants and, with other women and elders of her community, acted to

collect and circulate this knowledge more widely to their community members.

In May 2021, the manual, *Plantas medicinales ancestrales para el COVID* [Ancestral medicinal plants for COVID] was published online⁵ and 300 print copies were distributed throughout the community (see Figures 10.1 and 10.2). Vargas described how she led this effort:

I became the author of this manual because I thought it was very important to generate a material resource for the Indigenous communities and people interested in helping those who were sick



Figure 10.1 Front cover of *Plantas medicinales ancestrales para el COVID* ('Ancestral medicinal plants for COVID'), prepared by Indira Vargas and women of Unión Base, Pastaza, Ecuador. Source: © Bryan Garcés.



Figure 10.2 An elder woman preparing a medicinal treatment. Source: © Bryan Garcés.

with the coronavirus. For me, as a professional, it is important to generate contributions that can help the communities to which we belong. Learning ethnobotanical theory and practice have led me to know the scientific names, uses and properties of plants that can help the prevention, cure and alleviations of certain diseases. But my experience was important too. I grew up with my grandparents who taught me to live with the jungle and the importance of caring for and drawing on ancestral knowledge about health. Then, I had the opportunity to study in a bilingual (Spanish and Kichwa) school where I learned to study more about the importance of ancestral wisdom and alternative medicine that is adequately connected with the experience of Indigenous communities.

My goals in creating the plant manual were to systematize the reality in which we lived at the time of the pandemic, and to show how communities fought against a disease that came from another side of the world. It was completely unknown but with flu-like symptoms and accompanied by multiple ailments similar to common illnesses. Compiling the manual was also an effort to systematize and draw attention to the role of women across generations in the community, with all their wisdom and *minga* through time, to be able to help patients with COVID-19. A second of my goals was to create a manual that could help other communities and nationalities in this larger region. There is a great diversity of knowledge in Indigenous communities, but some communities do not have much knowledge of jungle plants, and therefore I thought it was very important to share the knowledge we generated across our community.

Books of medicinal plants used by Indigenous peoples to prevent diseases, such as influenza, malaria, yellow fever, etc. have been written by other authors and researchers. These are the diseases brought during colonization to the Amazon. But there was no specific manual for the prevention of COVID-19 because it is new, what we are currently experiencing. Writing the manual, for me, was necessary to leave a history of the experience we lived and acted in the hardest moments of this pandemic.

Vargas was not alone in recognizing that need. In North Dakota, herbalist students at Sitting Bull Tribal College on the Standing Rock Sioux Reservation developed and shared for public use an *Herbal Guide to Collective Protection and Healing during COVID-19* under the guidance of ethnobotanist Linda Black Elk and local elders.⁶

‘Established capitalist systems across our world right now are forced to slow down and stop’, the guide shares. ‘We hope this will help you and your communities stay strong and resilient in the months ahead. The earth has always been our pharmacy’. Likewise, the Cree Literacy Network (<https://creeliteracy.org/>), which has long published learning and teaching resources for the Cree language, offered *Stay at Home: Learn Cree*, a daily language learning video for people self-isolating during the Covid crisis.

Vargas commented further on the role of the manual (and see [Figure 10.3](#)):

It was very important to me that the manual be read by community leaders, and shared with other organizations, so that these community outreach lessons against COVID-19 could be promoted and so that others could access the plants that exist in their own chakras, communities or the jungle. Another one of my thoughts was even to share this manual with the mestizo and urban community as a prevention aid to the same disease. What I hope



Figure 10.3 Indira Vargas preparing an educational session with community members at Unión Base. Source: © Bryan Garcés.

is that the systematization and exchange of this knowledge can be expanded as a form of resistance and resilience for Indigenous communities. This manual is part of our long-term resistance in the face of the state's obsolete and inadequate health system for Indigenous peoples.

She continued:

Since I have a lot of knowledge in plants, it was not difficult to recognize them. Plants are part of our territories. Our grandmothers have taught us how to cultivate and care for them. All the plants in this book are plants that we can find in the jungle. I was also able to systematize the information without difficulties. I was able to find the scientific names in books by other authors. Beyond that, the book contains the lived experience during the pandemic, including the photos I captured when our elders prepared recipes to prevent the coronavirus including: one macerate (or infusion) recipe for prevention of COVID-19 or muscle pain and fever; one warm syrup for patients with COVID-19 to alleviate diarrhea and belly pain; and one vaporization to improve breathing.

The recipes and instructions in the *Plantas medicinales* manual are written in the voices of the women who shared them. For example, the plant *ilex guayusa*, commonly called *guayusa*, is described as sacred and offered for its precise bodily effects: 'The leaves have been consumed as an infusion for more than a thousand years by our grandmothers and grandfathers for their energetic, antioxidant and anti-inflammatory properties.' Other plants, such as *ayahuaska*, are discussed as healing to the spirit: 'Named, mother, teacher and doctor, mother because she guides, teacher because she teaches and doctor because she heals the spirit, gives power and purification to the spirit, weaves a human and spirit bond showing the world the *ayas*, guiding them either with her spirit or an ancestor.' A section of the manual is dedicated to 'Preparations to combat COVID-19' and contains the three recipes mentioned by Vargas above, for a maceration (infusion), a warm syrup and a vaporization treatment. Photographs of the plants were taken by Vargas' colleague, Bryan Garcés, who uses both a professional camera and a cell phone camera. Plants were located in the chakras of the women of Unión Base and in the surrounding environments of communities.

During the pandemic and with the support of multiple organizations and cooperatives, Vargas was able to print 500 copies of the manual

to distribute in Indigenous nationality communities in Ecuador. This outreach had a positive effect as an initiative to create material resources for communities, the first of its kind in this region. In addition, 100 copies were delivered to a training school for community health promoters at the Simón Bolívar Andean University in Ecuador's capital city, Quito, and the manual was also given to several Indigenous organizations as an example of communal efforts in fighting the disease. For example, the manual was used by the Zanja Arajuno Ecological Center in Santa Clara, Pastaza to further their efforts to cultivate plants in communal nurseries and family chakras in Amazonian tropical rainforests. The members of Zanja Arajuno used the manual to recognize plants, cultivate them and create their own garden of medicinal plants (see [Figure 10.4](#)).

The long struggle

As the biomedical world became more aware of COVID-19 cases in which symptoms persisted long past both diagnosis and the conclusion of medical treatment (Crook et al. [2021](#)), we asked whether 'long COVID'



Figure 10.4 Rita, a wise woman of Unión Base, teaching a group of younger women how to harvest *chuchuwazo* bark, which is used as a tonic and anti-inflammatory agent. Source: © Bryan Garcés.

was a problem in Unión Base. Are members of the community showing sequelae typical of this disease such as decreased physical fitness, memory loss and anxiety? Vargas' reply points to the critical gaps and erasures of 'chronicity' literatures:

Well, the long-term effects, the ones we are most aware of, are not the individual symptoms but the way Covid allowed oppressive and harmful messages in our communities from people who claim to help. In one very negative situation during the pandemic, the evangelical religion (missionaries) imposed itself very strongly, indoctrinating the women and children of the community, violating their rights, holding Eucharistic meetings day and night with fasting, forcing children to pray and cry for the people. They claimed that this illness was a punishment from God. In my small community during the pandemic three religious groups were implanted: Catholic, [Protestant] Christian and evangelical, all teaching that COVID-19 was a punishment from God. Despite this division created by these religious actors, it has been possible to maintain our community cohesiveness, our language and our traditions.

Vargas continued, explaining that

... the struggle of IP [Indigenous peoples] communities and organizations to address long-term health in a way that aligns with their self-determined ways of life is a perpetual concern and an ongoing challenge. After centuries of marginalization and the irreparable effects of the territory destruction, including harms to their habitat by the pandemic extractivism, COVID-19 is just the most recent threat to the continuity of our way of life as Amazonian peoples. This is especially true for smaller population groups such as those in many sectors of the north, center and south of the Amazon.

Being under COVID-19 taught us to reconnect with the ancestral knowledge of our grandfathers and grandmothers. Young people had been forgetting this knowledge, so another positive situation has been the solidarity and strengthening of community life in the unit that occurred under COVID-19. I learned to value our ancestral knowledge and that it can complement everyone's health and build bridges of knowledge between our own and Western knowledge. I think this builds a true intercultural society. This pandemic has taught me that Indigenous peoples' knowledge has been in the background, devalued in every way. So I have felt

this urgency to work together as young Indigenous professionals, and generate these spaces for debate and inclusion in health, education, economics and politics. We cannot continue to step aside while others appropriate our knowledge to generate wealth. The medicinal plants manual may have to improve, but that is a challenge to continue improving any initiative to generate more information about material and cultural appropriation.

Combating the chronic and epistemic violence of capitalist and biomedical hegemonies is, in turn, a threefold vulnerability for Indigenous women. We must face in our daily lives the triple condition of exploitation for being women, for being poor, and for being Indigenous. This vulnerability is a constant challenge. The situation we experienced during the pandemic, with the high infection rates in some of our communities and without access to the high-technology, biomedical care, we the women of Unión Base came together to ensure that as many members of our community as possible had access to traditional plant knowledge. We Indigenous women play a primary role in the care of community, and this was clear during the pandemic. It has always been the case and will continue to be true.

Life-long characteristics of susceptibility, identity and constitution have little place in biomedicine's categories of disease (Smith-Morris 2010; Manderson and Wahlberg 2020); so too there has been little acknowledgement of inter-generational characteristics like ethnic trauma, racism in health care and ontological prejudice against communal or anti-capitalist lifeways as disease-causing agents (Smith-Morris et al. 2021). In the contemporary global economy and diaspora, where chronic suffering is increasingly mundane and invisible, the hegemonic force of the 'chronic' designation loses much of its power (Smith-Morris 2015). The response by Indigenous women of Unión Base illustrates the chronicity of COVID-19 as just one of many contemporary chronicities through which Indigenous communities suffer inequitably, often in isolation.

As scientific experts have begun to grapple with distinctions between chronic and acute COVID-19, the limits of both the biomedical perspectives on illness and of representational democracies (that is, one-person-one-vote or majority rule) become apparent. Structural inequities created by colonial era violence have yet to be repaired, and the once majority Indigenous populations now suffer continuing, chronic harms in the form of inter-generational vulnerabilities. In other words, by distinguishing the difference between acute, infectious COVID-19

and the long-term harm to already vulnerable communities, a powerful conceptual dichotomy is weakened. Each new infection can be viewed as a symptom of the communities' larger vulnerability, drawing our attention to systems of inequity rather than (simply) infection control.

Although whole communities share a vulnerability to COVID-19, we rarely see communal responses to this disease or to its chronic potentialities. The Indigenous community we have discussed responded to both the immediate threat and to their community's need for collective resilience. Vargas and other women leaders of Unión Base not only learned more about medicinal plants and healing practices but also dedicated themselves to disseminating this knowledge across their community: in printed manuals, live demonstrations, rituals and lessons and via Indigenous community radio programming (which reached well beyond Unión Base). In these ways, print media and radio act as extensions of an established communalist practice, allowing these women to exercise moral commitments to the collective wellbeing of groups, both within and well beyond community boundaries (see Simpson, Tapia and Smith-Morris 2024).

In this light, 'chronicity' demands a broad interpretation. In describing Covid's impact on Indigenous community, 'chronicity' offers a framework much more compatible with Indigenous experience and ontology, in that it is compatible with cyclical time frames, the long duration of families through generations and the focus on the co-existence of people and the planet (Smith-Morris 2020). The steady progression toward endemicity of a number of chronic conditions – including diabetes, heart disease and, perhaps, long COVID – is an indication of the chronicity of modernity itself (Wiedman 2010). In particular, when new health care policies and dollars are funneled through existing bio-medico-centric structures, rather than through community-nourishing strategies like the ones we've discussed here, neo-colonial and unexamined harms occur (Manderson and Smith-Morris, 2010; Team and Manderson, 2020).

A principal concern of this chapter was to expose how the availability and forms of treatment define the temporality of the disease, and therefore whether it is 'chronic' or 'acute'. As Smith-Morris has argued, 'chronicity is no longer defined by the natural course of disease (for example, the "slow killers"), but by the availability of biotechnical strategies to address them' (2010, 21). When 'whole communities share diagnoses, or significant risk for certain diagnoses, particularly in the development context ... the temporal, chronic-acute distinction no longer explains disease in terms that are meaningful' (Smith-Morris

2010, 23). Instead, the lack of commitment to health equity of federal and global health care systems causes these epidemics. This is visible in the location-specific containment of Ebola (Smith-Morris 2017) and in the evolution toward the endemicity of diabetes (Smith-Morris 2006). A crucial alternative, and one expressed by the women of Unión Base in the manual Vargas describes here, was to de-fragment the life course of human experience as a series of pre- and post-disease windows, toward more holistic, relational and contextualized systems of health care. Long Covid will continue and thrive because market-based solutions are designed to serve fragmented and individualistic lives. Meanwhile, long-term and decolonial solutions that protect smaller communities, such as the community-wide efforts of Vargas and the women of Unión Base, are devalued as unscalable, and therefore are unsupported.

Were the temporality of disease conceptualized as a continuum, rather than through a chronic-acute dichotomy, we might better be able to address bodily and societal experiences of disease across a lifespan and across generations. Such a conceptualization might incorporate not just those conditions that are biomedically defined, but also the lived conditions of rural life, ethnic cohesion and survival, and planetary respect. The struggle of communities and Indigenous organizations to address long-term health in ways that align with their self-determined ways of life is an ongoing effort. After centuries of marginalization and the irreparable effects of the destruction of their habitat by extractivist colonialism, COVID-19 is seen as just another threat to the continuity of the way of life of the Amazonian peoples. The epistemic violence of capitalist and biomedical hegemony is chronic here.

Combating this violence is, in turn, a particular challenge for Indigenous women who in their daily lives must face the triple condition of exploitation: through being women, because they are poor and because they are Indigenous. Women's chronic vulnerabilities leave them with constant barriers at the margins of society. The situation experienced during the pandemic, and the way that Vargas and this collective of Kichwa women responded, via communal wisdom and relational support, stands in stark contrast to the best strategies of biomedicine for COVID-19. Yet the strengths of biomedicine, such as vaccine development, falter at the distribution and equitable impacts of its science. The collective work of Indigenous collectives, such as the one described here, is inherently long-lasting and, therefore, infinitely better designed for combating chronic maladies.

The medicinal manual created by Indira Vargas and the Kichwa women of the Unión Base is an unscalable solution. As a remedy for

a public health problem, however, it is both scalable and replicable. Local solutions are inherently sustainable and culturally and linguistically relevant. Local solutions also engage the community in its own protections and healing, thus offering a better chance to stabilize gains in the long term. For Indigenous communities, these gains may also engage inter-generational wisdom, rooting potential remedies in the ontological core and values from which they take their identity. This is the goal of which Vargas speaks above, to contribute to the integral health of the communities. As a communal solution, the manual is not just for acute remedies; it also provides healing to redress the chronicities of Covid.

Conclusion

The COVID-19 pandemic exacerbated an already chronic state of neglect for Indigenous peoples. Our discussion of one woman leader's remedy to Covid's chronicities speaks to the medicinal, the ancestral, the female and the planetary aspects of healing. Covid's chronicities demand such breadth.

In this chapter, we have considered the chronic vulnerability of Indigenous peoples as a result of their marginalization from dominant society. The case study of one community of Kichwa women coming together, not only to learn about ancestral medicinal practices but to ensure that such knowledge reached more members of their community, highlights two important elements in the study of 'chronicity'. The first, the heightened need for ancestral knowledge to prevent and treat symptoms of COVID-19 because local and state-sponsored biomedical health resources were so scarce or untrusted, was a sign of the chronic vulnerability of Unión Base and other Indigenous communities in Ecuador. 'Long COVID' was not a meaningful construct in this community because COVID symptoms were just one of many ailments that went unattended. Ancestral medicines did not distinguish long from shorter forms of COVID because those temporal markers were not the concern of a healer. Instead, emphasis was placed on expressions of care, alleviation of symptoms and respectful acknowledgement of the ancestral source of knowledge. The second element is how the women of Unión Base responded to the need with a communal and relational effort, not an individualist one. Their broader effort reached more members and strengthened bonds across a community which has faced many similar crises together.

Future healing for long COVID, or for the next planetary illness, will demand that the multiple layers of community and human

inter-generational ties be taken into account. *Plantas medicinales*, as just one manual of ancestral medicines from the Kichwa women of Unión Base, offers us a model. Whether and how we use their model to improve not only health systems but community health will reveal much about our evolving attitudes toward de-colonizing health care.

Postscript

Asked if she had any concerns about ‘intellectual property’ with regard to *Plantas medicinales ancestrales para el COVID*, Indira Vargas provided a realistic response:

It is really worrying to publish ancestral knowledge and especially about plants, since for centuries this knowledge has been stolen for marketing and commercialization purposes for personal gain. Although this manual mentions that its use for commercial purposes is prohibited, this cannot be controlled once the manual has been uploaded to the internet. I would very much like to deal with this knowledge. It is very important to continue safeguarding this knowledge. But this book is a resource that can be told, found and shared. It connects us with the history we lived during the coronavirus pandemic, and this will allow generations to read and know the plants that could help alleviate the ailments caused by this disease.

Notes

- 1 The Confederation of Indigenous Nationalities of the Ecuadorian Amazon (CONFENIAE) has its headquarters in Unión Base, in the province of Pastaza, Ecuador along with its Indigenous communal radio station, La Voz de la CONFENIAE. Author Andrés Tapia is an elected leader and Communications Director with CONFENIAE and manages the radio station.
- 2 More information on chakras agriculture in Ecuador can be found at <https://www.equatorinitiative.org/2017/06/12/chakra-agroforestry-and-sustainable-agriculture/>. Accessed 16 October 2024.
- 3 *Minga* is a kichwa term for a collaborative effort, often involving the whole community.
- 4 Digital Lancers is a digital and radio media organization, part of La Voz de la CONFENIA of which author Andrés Tapia is the director.
- 5 Vargas, Indira. 2021. *Plantas medicinales ancestrales para el COVID* [Ancestral medicinal plants for COVID]. Published 23 May 2021 on [issuu.com](https://issuu.com/visualcafe/docs/plantascovid). Accessed 15 October 2024. <https://issuu.com/visualcafe/docs/plantascovid>.
- 6 *Herbal Guide to Collective Protection and Healing during COVID-19: Plan stores from Lakota and Dakota territory*. Accessed 16 October 2024. <https://dakotaplants.wordpress.com/wp-content/uploads/2020/03/herbal-resilience-guide.pdf>.

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Echoes of the past: epidemics and resilience among Indigenous peoples of the Upper Rio Negro, Brazil

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for Américo Socot, in memoriam

Indigenous communities living in the Upper Rio Negro region, Amazonas, along the border of Brazil and Colombia, face systemic vulnerabilities and obstacles. Here, Indigeneity intersects with heightened susceptibility to disease, environmental degradation and geopolitical complexities. Confronted with COVID-19, both their structural vulnerabilities and lack of access to health care were magnified. This was particularly true for the Hupd'äh and Yuhupdëh peoples, two of the most excluded and marginalized groups living in some of the most remote areas of Upper Rio Negro. In this chapter, we explore their community-led strategies during previous epidemics and in response to COVID-19. By examining their resilience and adaptability, we aim to offer insights into effective strategies for confronting future health crises. We start with a description of the severity of the Covid pandemic among Indigenous populations in Brazil and the approach we took to assess local responses and engagement with health services. We then provide historical context to situate the Hupd'äh and Yuhupdëh within the colonial and neo-colonial past and present. We follow with a description of what we learned and provide recommendations based on these findings.

COVID-19, epidemics and recollections of survival

Brazil was one of the countries most affected in the world by COVID-19. As of late February 2024, over 38,452 million cases and more than

709,900 deaths have been reported in the country (Hallal and Victora 2021; Portal do COVID-19 Ministério da Saúde, Brasil n.d.).

COVID-19 hit Brazil under Jair Bolsonaro's extreme right-wing presidency. The government's denial of the pandemic, alongside the uncoordinated actions and inconsistent messages between the various levels of governance, exacerbated the crisis (APIB 2022). Moreover, the highly conservative government and its supporters led anti-science campaigns that included antivaccine propaganda and the promotion of the inefficacious 'kit COVID-19' – a combination of anti-parasitic drugs, vitamins and steroids (Idrovo et al. 2021). In 2020, during one of the most severe pandemic waves in the country, alarming reports emerged regarding official health teams in diverse health districts procuring and distributing substantial quantities of these ineffective COVID-19 treatment combinations to Indigenous communities. Researchers and jurists have labeled these actions as an 'institutional strategy for the propagation of the virus' among these vulnerable groups (Zuker and Pedro 2022).

Indigenous populations in Brazil, including the Hupd'äh and Yuhupdëh, were disproportionately impacted by the pandemic (Santos et al. 2020). Despite under-reporting of cases among these communities, the incidence and mortality rates among Indigenous peoples were higher than among any other population groups in the country – in 2020 these rates were 136 per cent and 110 per cent respectively higher among Indigenous people compared with the national average (Fellows et al. 2021; Charlier and Varison 2020). These alarming statistics are closely linked with pre-existing vulnerabilities including poverty, infectious diseases and chronic lack of access to health care. The pandemic not only exposed these vulnerabilities but also exacerbated them, underscoring the urgent need for targeted interventions and culturally appropriate health care delivery systems. It highlighted the systemic inequities that Indigenous communities face, and the urgent need for transformative action (Guajajara 2022; Jardim et al. 2020; Rocha et al. 2021). Moreover, during the pandemic, data collection and surveillance activities were interrupted among Indigenous communities, jeopardizing accurate statistics and evidence to support advocacy efforts. On August 5, 2020, the Brazilian Supreme Federal Court officially recognized the failure of Bolsonaro's government to adequately address the effects of the pandemic among Indigenous communities (Álvares 2020; *Washington Post* 2020).

Since colonial times, the history of Indigenous peoples has been punctuated by recurring outbreaks of deadly infectious diseases, such as

measles, flu and smallpox. As Brazilian anthropologist Carlos Fausto reflected, ‘from the beginning of colonization, native peoples have had to learn within their bodies what an epidemic is’ (2020, 1; Santos et al. 2020). The pandemic reawakened collective memories and fears from previous epidemics.

In the Upper Rio Negro region, the novel coronavirus encountered a collapsing, fragile health system and triggered an alarm. In this context, in May 2020, a coalition of anthropologists and Indigenous leaders, concerned with the lack of a coherent intercultural communication strategy for local responses to infection, convened to create the Rio Negro Indigenous Health Forum (FSIRN). FSIRN utilized virtual platforms (WhatsApp and Google Meet) to engage key stakeholders. These include Local Indigenous Health District (DSEI) managers, representatives from FUNAI (Fundação Nacional dos Povos Indígenas [National Indigenous People Foundation]), the governmental agency responsible for Indigenous populations, and anthropologists, communication experts and NGOs representatives, to ensure a coordinated emergency response.

The FSIRN, acting as an agency providing technical advice, played a key role in mobilizing emergency funds and medical supplies through international networks. Considering the cultural characteristics and social vulnerabilities of the Hupd’äh, Yuhupdëh, Dâw and Nadëb peoples, the group advocated for compliance with Joint Ordinance 4.094 by the DSEI. This ordinance, issued by the Ministry of Health and FUNAI in December 2018, mandates specialized, multidisciplinary health care actions for Isolated and Recently Contacted Peoples – PIIRC (Brazil, Ministério da Saúde 2020). In recognizing PIIRC’s unique social structures, livelihoods and heightened vulnerability to epidemics, it was guided by a Contingency Plan for Outbreaks and Epidemics (Rodrigues 2014). The FSIRN’s initial efforts included the formulation of protocols for COVID-19 management, emphasizing the importance of respecting Indigenous medicinal practices and decision-making, thus enhancing the cultural sensitivity of the health emergency response.

In a collaborative effort, three FSIRN members (the authors of this chapter) worked together to create a digital platform to facilitate transparent, multi-directional information exchange, through the network of the Federation of Indigenous Organizations of Alto Rio Negro (FIORN) and including a local social accountability framework. Simultaneously, the FSIRN endorsed a community-led strategy adopted by Indigenous people to shield their territories from urban visitors. However, before we consider the relationship between leadership,

traditional medicine and the Hupd'äh and Yuhupdëh-led responses and approaches to monitoring health services in the Upper Rio Negro it is necessary to provide some background.

The Upper Rio Negro is inhabited by various ethnic groups belonging to the Arawak, Eastern Tukano, Naduhup and Yanomami linguistic families. The groups are characterized by distinct hierarchical and linguistic structures, and particular approaches to traditional medicine, shamanic practices, marriage and livelihoods such as cassava farming, fishing, hunting and arts (Cabalzar and Ricardo 1998; Wright 1992). Among these groups, the Yanomami became especially well known through ethnographic monographs and films (Chagnon 1968).

In this microcosm of diversity, the populations were characterized in ways aimed to capture the regional distinct linguistic groups, marriage practices and subsistence orientation. Eastern Tukano and Arawak people were grouped as the 'River People', and the Nadahup peoples as the 'Forest People'. The River People have historically possessed a socially dominant position, and this continues to translate into more direct control and power in contexts of interaction (Epps and Stenzel 2013).

To better understand the complexities of Upper Rio Negro today, a look into its historical context and cultural transformations can provide valuable insights. The first contact with Portuguese and other colonial troops dates back to the late 1700s when Indigenous people were forced into plantation labor and into gathering forest products for distribution throughout the colonial territory. In the late nineteenth and early twentieth centuries contact with non-Indigenous groups intensified with the arrival of Christian missionaries, military forces and traders (Eloy and Lasmar 2011). During this period, the exploitative commercial trading of rubber inflicted severe hardships on Indigenous peoples in the region, including through forced labor and violence (Cabalzar and Ricardo 1998). During the second half of the twentieth century, due to strategic geopolitical location of the region, several development and military projects were undertaken, including gold mining and the construction of roads, airstrips, dams and military buildings. Such initiatives led to extensive deforestation and attracted waves of labor migrants from other parts of Brazil and neighboring countries, posing additional challenges to Indigenous territory, livelihoods and cultural practices. The region's growth and unplanned urbanization widened socioeconomic inequalities among Indigenous and non-Indigenous peoples, particularly among groups such as the Hupd'äh and Yuhupdëh, who had been historically excluded from development (Cabalzar and Ricardo 1998; Eloy and Lasmar 2011).

São Gabriel da Cachoeira, the ‘capital city’ of Upper Rio Negro, is located on the remote northern shore of the Rio Negro and is the northernmost city of the Brazilian state of Amazonas. Approximately 90 per cent of its 46,000 inhabitants identify as Indigenous (IBGE 2020). They have consistently lived in areas of poor sanitation and environmental degradation, finding employment in illegal mining, and are subject to discrimination, stigma, poverty, socioeconomic inequalities and conflict, mostly with non-Indigenous peoples.

Indigenous populations in the Upper Rio Negro have historically organized themselves to resist and address this oppression, violence and abuse, especially from the second half of the twentieth century. Their activism catalyzed the creation of various Indigenous associations in the region (Peres 2018). FOIRN (Federação das Organizações Indígenas do Rio Negro) is the largest regional organization and plays a key role in advocating for Indigenous rights. However, groups such as the Hupd’äh and Yuhupdëh are under-represented in these organizations and other local decision-making forums. Such lack of representation stems from the legacy of colonialism and complex interethnic dynamics, resulting in power imbalances between different Indigenous populations and in relation to the state. Understanding these challenges is crucial to building inclusive policies regionally.

The Hupd’äh and Yuhupdëh inhabit the dense forest along the interfluvial and riverbanks of the Upper Rio Negro, deliberately avoiding contact with ‘outsiders’ and non-Indigenous peoples (Athias 1995). Current demographic data estimates the Hupd’äh population at a total of 2,634 individuals, while the Yuhupdëh population is approximately 1,058 individuals (FOIRN 2019; Lolli 2021). Their languages belong to the Naduhup family, which includes Hup, Yuhup, Dâw and Nadëb languages.

Distinct from the dominant Tukano and Arawak groups, the Hupd’äh and Yuhupdëh practice linguistic endogamy and clan exogamy in their marriage system. Preferential marriage takes place between bilateral cross-cousins in the same generation and seeks to respect balance and hierarchy between clans (Reid 1979; Athias 1995). Their subsistence relies primarily on gathering, short-cycle farming and hunting. Because of their hunting skills, ethnographers have characterized them as ‘professional hunters’ (Reid 1979). They also possess intense mobility patterns, preferring to travel on foot rather than by canoe (Pozzobon 2018).

These traits bring the Hupd’äh and the Yuhupdëh closer to groups like the Nadëb, Dâw, Kákwa and Nukák, earning them the designation of ‘Maku’. The term *maku*, adopted by ethnographers, is borrowed from

the Arawak, and means ‘one who has no speech’ or ‘he who does not have our speech’ (*ma* = private prefix, *aku* = speech), hence associating them with ‘savage Forest People’, as opposed to ‘River People’ like the Tukano and Arawak (Epps and Stenzel 2013; Epps and Bolaños 2017).

Relationships between Hup and Tukano families are often based on seasonal labor, food exchanges (for example, game meat and fruit are exchanged for cassava and fish) and other goods such as baskets and tools crafted by different Indigenous groups. For short periods, Hupd’äh relocate close to Tukano villages for work. During periods of work, Hupd’äh are expected to demonstrate respect and silence in the presence of Tukano, leading researchers to describe the relationships of Tukano and Hupd’äh as boss/client, hierarchical/asymmetric, or as ‘symbiotic’ or ‘intelligent parasitism’ (Ramos et al. 1980; Marques 2009; Marques, Ribeiro and Ramos 2009).

Missionary impact on the Hupd’äh and Yuhupdëh

The Salesian missionaries, belonging to the Catholic Society of Saint Francis de Sales, dominated the political landscape in the Upper Rio Negro from the late nineteenth to the late twentieth centuries. The core objective of the Salesian missionaries was ‘the regeneration of the impoverished savages ... under the beneficial influence of civilization and faith’ (Costa 2011, 2; Cabalzar and Ricardo 1998). From 1915, Salesian missionaries established the first mission villages and boarding schools along the Rio Negro, disrupting social dynamics and cultural practices. Missionary action included the imposition of Catholicism and the Portuguese language in a multi-cultural context, with the prohibition of traditional languages, rituals and shamanic practices, and the disruption of traditional territorial organization by the imposition of concentrated settlement of Indigenous groups around mission villages and boarding schools. As a result, there was higher exposure to infectious diseases, at times resulting in epidemics of measles, influenza and malaria, as well as increased prevalence of infections from poor sanitation (Cabalzar and Ricardo 1998; Athias 1995; Cabrera Becerra 2012).

Increased contact with missionaries intensified Indigenous communities’ exposure to infectious diseases, and the combination of immunologically susceptible individuals and high population density in mission centers and boarding schools created a fertile environment for epidemics, with devastating effects on mortality and morbidity. Historical missionary reports mention recurring epidemics of influenza, measles,

whooping cough and malaria in the mission centers and their surroundings (Athias 1998; Athias and Machado 2001). In March 1936, for instance, over a period of one month, a deadly measles epidemic started in two mission boarding schools and quickly spread to neighboring villages. People most affected by the epidemic abandoned their villages, as was common practice, but still there was a high fatality rate in these communities (Buchillet 2018).

During the 1960s and 1970s, missionaries intensified their endeavor to evangelize and educate Indigenous populations, and as their influence grew there was a steady establishment of the Hupd'äh and Yuhupdëh villages. However, members of these two groups were often relegated to the status of slaves, servants or outcasts from the point of view of other Indigenous people, missionaries, merchants and plantation owners (Lolli 2021; Pozzobon 2018).

In the 1970s, Tukano people who had been converted to become Salesian priests and nuns started to collaborate with non-Indigenous missionaries to establish the first mission village among the Hupd'äh. They aimed to attract Hupd'äh to areas closer to the Tiquié river, a tributary of the Rio Negro, so to facilitate access to the communities to evangelize. Simultaneously, mission boarding schools redoubled their efforts to recruit and institutionalize Hupd'äh and Yuhupdëh children. However, these children resisted conforming to new cultural norms, and their deep knowledge of the forest and its pathways helped them to escape back to their families. This reinforced their characterization as savages and outcasts, contributing to their exclusion and stigma.

Chronicity, vulnerability and resistance: Hupd'äh and Yuhupdëh responses

The field of health communication recognizes that linguistic and cultural diversity, along with processes of illness and healing and therapeutic practices, are cross-cutting and fundamental dimensions for quality of life, trust, bonding, listening and ethics in health care (Ramos 2007). Intercultural health communication includes recognizing 'intermedicality' (Follér 2004), acknowledging that both Indigenous medical knowledge and biomedicine are shaped through intercultural relations and embody power dynamics over the domain of bodies, language and cultural life.

With the COVID-19 pandemic, action research, Community Score Cards (CSC) and the Community Monitoring Platform for Indigenous Health Quality (CMP-IHQ) were deployed to identify the main barriers

to effective communication between state-provided health services and Indigenous communities of the region. The findings from these tools enabled the development of intercultural communication strategies, ensuring access to reliable COVID-19 prevention and treatment information, trust and cooperation between communities and health professionals for contact tracing and referrals, and enhanced response monitoring and reinforcing of social accountability. With remote team support, Indigenous researchers Américo Socot (Hupd'äh), Domingos Barreto (Tukano) and Marcelino Massa (Desano) conducted fieldwork in 14 villages, following strict sanitary protocols to mitigate contagion.

The São José II Polo Base was strategically selected for this research because it serves the largest Hupd'äh and Yuhupdêh communities in the Upper Rio Negro, mostly along the interfluvial areas located deep in the forest (Ferreira, Ramos and Shankland 2019). A polo base is the village health centre which provided health care and sanitation services for the Indigenous population resident locally and within the territory of the DSEI (Local Indigenous Health District). The São José II Polo Base pioneered the implementation of participatory evaluation initiatives when the Community Score Card (CSC) was first introduced during malaria outbreaks in 2016 and 2018. The CSC findings enabled monitoring health care quality pre and post COVID-19. Through community-led workshops, Indigenous groups crafted indicators to evaluate health care improvements and persistent challenges throughout the pandemic. This participatory approach not only provided reliable COVID-19 information, but also fostered collaborative bonds between Indigenous communities and medical teams, and empowered local oversight of service delivery during the crisis.

Protagonists of resistance

A total of seven Hupd'äh and/or Yuhupdêh villages were included in the action research. Taracua Igarapé village is home to 48 families from the Hupd'äh, Yuhupdêh, Dâw and Tukano ethnic groups, with a total population of over 200 people. The research team engaged with key representatives to gain insights about the community's response to COVID-19. They were: Indigenous Community Health Worker (ICHW) Jovino Socot, local teacher Tereza Socot and animator Samuel Monteiro, who is elected by the community and plays a crucial role in assisting and organizing community festivities and events, and provides support for extracurricular activities within Indigenous schools.

The pandemic emerged as the community continued to battle against malaria and diarrhea outbreaks. Tereza Socot recounts that, at the beginning of the pandemic, COVID-19 was seen as a ‘white man’s disease, and therefore, would not “catch” on Indigenous people’. When cases began to occur among local Indigenous people, the main precautions they took included the burning of *breu branco* (a white tree bark resin used for cleansing and shamanic rituals), staying in the village and avoiding trips to the city, since that was the focal point of contagion. However, Tereza Socot reported that residents in the city introduced the virus when they returned to villages with the aim to protect themselves. According to Jovino Socot, COVID-19 arrived in the village even before residents knew about the disease: ‘the disease had already filled the village, and no one knew about it’. The ICHW also mentioned that communication with other Indigenous communities via radio was key to exchanging traditional blessings and recipes for natural remedies to address COVID-19: ‘At the time, the VHF radio worked in the community; we received information through other Indigenous groups from Auari River about what natural remedies worked against COVID, such as *Saracura* and other medicinal herbs’ (Jovino P. Socot, 16 July 2021). The community animator, Samuel Brasil Monteiro, pointed out the challenges faced by the EMSI (Multidisciplinary Indigenous Health Teams) in responding to COVID-19, and emphasized that communication was a barrier in access to health care during the pandemic:

From the community’s perspective, COVID came from the big city. Perhaps it’s always difficult for the health teams to come to the villages. Within the team, they do not understand the Hupd’äh language, but there is always someone speaking Tukano to do the translation. (Samuel B. Monteiro, 16 July 2021)

While the EMSI provided guidance on COVID-19 prevention, it did not provide tools for the community to deal with the pandemic:

Then more guidelines arrived, but they did not give specific recommendations about what to do. They did [give tips] to wash our hands and keep a distance using a mask. It was distancing because nobody had masks at home. ... But they left neither masks nor medicines. (Tereza Socot, 16 July 2021)

The village of Santa Rosa, located on Samaúma Stream, a tributary of the Tiquié River, is home to six families of the Jaguar clan of the

Yuhupdëh. On 22 July 2021, the team of interviewers spoke with village leader Francisco Barbosa Vila, who told them how COVID-19 emerged and the blessings to cure it. In his view, its emergence was due to *paricás*, an inhaled powder used for shamanism and prepared by the first ancestors. During ancient times, ancestors prepared various types of *paricá*, including *paricá* of *ipadu* (coca leaves) mixed with dried snakeskin. According to him, the powder of the *paricás* of the ancestors made people sick with COVID-19, but at the same time, it was used by healers to cure infected people:

The powder of these *paricás*, as it is fine, it rises with the little wind and fills the person's, the human's breath. Then, this cough starts. It is through this that blessings are made for the COVID cough. (Francisco Barbosa Vila, village leader, 22 July 2021)

The *paricá* powder, as he explained it, descended to the south but later returned to the region, making communities sick with COVID-19.

In São Felipe on the Castanho River, the village leader emerged as a shaman, blesser and connoisseur of medicinal plants effective against COVID-19. The research team interviewed IHCW Geraldo Amaral Barbosa and local health advisor Pedro Ramos Marques. Both emphasized the importance of traditional medicine in mitigating contagion and providing treatment in the village. Interviewees explained that COVID-19 originated from the world of non-Indigenous people; it began with bats and spread across the globe, infecting everyone. As Geraldo Barbosa said, 'When it arrives, we no longer choose; it affects the old man, the old woman ... it attacks everything'. He expressed concern about the uncertainty of non-Indigenous people regarding the disease's origin and their lack of knowledge about treatments. Pedro Marques revealed that he had learned about COVID-19 from the technician installing the VHF radio in the village; thereafter, community members had started taking traditional remedies. In São Felipe, four blessers and a shaman guided the residents and performed rituals with *breu branco* and tobacco, with the smoke encircling and so protecting the village:

The knowledgeable ones provided protection, the blessing with *breu branco*. It also originates from the trees. *Breu branco* is what healers use to burn, bless, and provide that protection. Burning is done within and around the village to protect its residents. They are also protected with invisible masks. Yes, this part is so important. (Geraldo Barbosa, 20 July 2021).

Breu branco was burned around the community, creating barriers to protect families and invisible masks to cover faces. In addition to shamanic practices, people covered their faces with T-shirts when visiting neighboring communities. The main traditional remedies used were *carapanaúba*, *saracura*, *cashew bark* and *vine*. Geraldo explained that all these remedies are bitter, which is why they were effective in treating COVID-19.

Empowerment, resilience and the Community Score Card

Out of the seven Hupd'äh and Yuhupdëh villages included in the initiative, four responded to the Community Score Card (CSC): Taracúá Igarapé, Santa Rosa do Castanho, São Felipe and São Joaquim. Through the CSC, they evaluated the health care provided by the EMSI 'before and during the COVID-19 pandemic – measured by 21 health quality indicators co-designed with communities. Most interviewees revealed that during the pandemic both the frequency and quality of health team visits significantly decreased. Although the EMSI's rationale for decreasing frequency of visits was to mitigate contagion, this measure was perceived by Indigenous people as a sign of neglect.

The scorecards and interviews also indicated challenges in intercultural communication that jeopardized Indigenous access to preventive and management information about COVID-19. Interviewees emphasized the importance of participatory strategies for effective pandemic response, such as the inclusion of shamans, Indigenous remedies and medicinal plants. They also argued for community-led epidemiological surveillance, including the training and engagement of community leaders to detect suspected cases, report and be included in data collection and formal surveillance practices, as well as inter-community coordination to perform blessings.

The CSC analysis revealed a consistent discrepancy between the evaluations performed by communities located on the Castanho River (predominantly composed of Hupd'äh and Yuhupdëh families) and communities of the Tiquié River, where other ethnic groups, in a dominant position hierarchically, also live. The 'quality of care in communities' was rated poorer in the Castanho River area than among villages along the Tiquié River. Health personnel performance was also rated worse by the Castanho River communities and Taracúá Igarapé when compared with the regional average and the Tiquié River communities.

In the villages along the Castanho River, health indicators paint a picture of profound neglect, partly reflecting that access is more challenging during the dry season, when trips by canoes from one village to another can take several days. The communities of Santa Rosa, São Felipe and São Joaquim, along the Castanho River, stressed the need for more frequent EMSI visits. According to an ICHW from Castanho River, 'the health team rushes quickly. ... They don't pay attention even when spoken to'. The communities also reported that, often, neither a doctor or dentist participated in the visits, and that the team would bring only a limited variety of medicines and left very few with the ICHW, which negatively impacted health care for conditions other than COVID-19. The lack of support from EMSI teams was perceived by communities as a key factor in the limited efficacy of the ICHW.

CSC analysis also revealed the precarious access to clean water and sanitation, indicating that it was a serious problem for most communities while revealing the absence of response by local authorities. Open defecation and lack of clean water are standard in almost all communities, with negative impact on water-borne diseases such as diarrhea, vector-borne diseases and malnutrition, so also increasing the risk of impaired physical and cognitive development while trapping communities in poverty.

Communication with EMSI teams was identified as a major barrier to improving health care delivery. In these communities, dialogue with teams is significantly impaired by linguistic and intercultural challenges. In many communities along the Castanho River, such difficulties are exacerbated by the malfunctioning of radio communication, which hinders requests for help in case of emergency and limits people's knowledge of EMSI's plans and visit schedules. Respondents also identified intercultural tensions as hindering improvements in health care. According to a resident of Santa Rosa do Samaúma, there is little acknowledgement of interculturality and complementarity on the part of EMSI – the team 'does not even try to find out if there are traditional knowledge bearers in the village'. Despite the crucial role of *bi'id d'äh* (healers) and Indigenous medicine experts, intercultural dialogue with the EMSI is minimal.

Despite the recent prioritization of women, children and elderly health programs during EMSI visits, the CSC scores revealed the community's negative perception of these. Interviewees highlighted the need to improve the quality of women's health care, especially the need for more private spaces for gynecological care (tests and treatments are often conducted in the community center with no respect to

women's privacy). Communities also emphasized the importance of fostering trust and providing language translation in Hupd'äh and Yuhupdëh to bridge communication gaps, as many women are not fluent in either Portuguese or Tukano.

Moreover, Hupd'äh and Yuhupdëh communities face significant barriers in accessing the DSEI leadership teams. Obstacles to the exercise of accountability in health, according to interviewees, were related to the lack of support for councillors to perform their role (for example, no gasoline for boats or stipend provided for councillors to attend meetings in the city) and the lack of representation of Hupd'äh and Yuhupdëh in local governance and accountability bodies. Many villages do not even have a health councillor, and the few that cover Hupd'äh and Yuhupdëh areas are Indigenous Tukano, which limits dialogue and representation. In the words of a Yuhupdëh IHCW, 'every time, in the council, I make demands, but it seems they don't hear and don't pay attention'.

Discussion

Vulnerabilities unveiled

In this chapter, we have drawn attention to the vulnerabilities of the Hupd'äh and Yuhupdëh Indigenous communities in the Upper Rio Negro, Brazil. The historical and contemporary challenges these groups face are deeply rooted in systemic exclusion, colonization and complex interethnic dynamics. Currently they are exposed to multiple health threats, including COVID-19 but also malaria, tuberculosis, arboviruses, influenza, trachoma and suicide, as well as the harms of alcohol consumption (Souza and Orellana 2012; Hamdan 2023). These challenges prompted their leaders and partners to mobilize Joint Ordinance MS/FUNAI No. 4,094, and to denounce the state of health emergency before, during and after the Covid pandemic. The action research and community health monitoring strategies, described in this chapter, highlight the need for interculturality in health and specific strategies for health care delivery (FUNAI 2017).

Equity and resilience

As outlined in the recent Hupd'äh and Yuhupdëh Territorial and Environmental Management Plan, the establishment of a health district (DSEI) and/or polo base to specifically cater to these populations seems

crucial to overcome the current state of emergency and enhance health care delivery, tailored to their specific needs, but also to mitigate risks for future crises and health threats. Further, there is a need to invest in improved access to potable water and sanitation, as fundamental to enhancing the health and wellbeing of the Hupd'äh and Yuhupdëh communities. The close link between poor sanitation and disease perpetuates a vicious cycle, impacting not only physical health but also overall development of communities and their future generations' capacity to thrive.

As we have illustrated, traditional healers and Indigenous medicine practitioners played a major role in the community's pandemic response. Their expertise in ancestral treatments was considered instrumental in safeguarding and restoring health. To honor this legacy, the EMSI should embrace the knowledge of these custodians of Indigenous medical traditions, ensuring that the care provided to Hupd'äh and Yuhupdëh patients is culturally consonant and holistic. Such collaboration not only respects Indigenous therapeutic practices but also cultivates trust, enhancing treatment uptake and overall community wellbeing. In this context, a holistic approach that transcends biomedical paradigms and embraces interculturality is urgently needed to address the unique needs of these communities, and to respect their cultural diversity and autonomy.

Intercultural dialogue and collaboration between Indigenous and non-Indigenous health workers, researchers and authorities can foster mutual understanding and trust, and improve the quality and impact of health interventions. To bridge the communication gap identified in the community participatory research, health information needs to be translated into the Hupd'äh and Yuhupdëh languages. As IHCW Jovino Socot recounts, people 'hide the pain, because they cannot say that they feel pain'.

There is also a need for the increased presence of councillors in every village, to work with others in communities to advocate for active participation in co-designing and implementation of health initiatives, while ensuring their voices resonate at local Indigenous leadership forums. Community members also voiced an urgent need for the regular provision of medicines, supplies and equipment, and for advance notice of health team visits. Tailored training for Hupd'äh and Yuhupdëh ICHWs, including case studies and traditional practices, would enhance their effectiveness in resolving basic health care needs at the community level, even during the long periods when health teams are absent.

Conclusion

The COVID-19 pandemic disproportionately affected Indigenous groups in Brazil and has had profound effects on the Hupd'äh and Yuhupdëh peoples. Their struggles are rooted in their historical context, intercultural practices and overlapping elements of vulnerability. Community-led responses emerged as vital resources of organization and resistance, not only during COVID-19 but also in the face of previous epidemics that tested their resilience and adaptability and can provide a blueprint for empowerment and agency. The Hupd'äh and Yuhupdëh Indigenous communities stand at a critical crossroad of transformation and survival. Their journey is a testament to resilience in the face of adversity, built upon their vulnerabilities and strengths.¹

Note

- 1 We thank the team of Indigenous researchers formed by Américo Socot (deceased), Marcelino Massa and Domingos Barreto. In the context of the pandemic and the lack of health data in 2021, they carried out field research in Indigenous communities in the Middle Tiquié River. The entire analysis of community monitoring in Indigenous health reported in this article was based on data and interviews from this field research. The research project was approved by the National Research Ethics Council (CONEP) and duly authorized by FOIRN and each of the research interlocutors through Free and Informed Consent Terms (FICT) (FOIRN/SSL, 2023). All COVID-19 infection prevention protocols were respected. The action research and monitoring strategy that resulted in the creation of the platform was funded by the Covid Collective Project (UK Foreign Commonwealth Development Office), UKAID, Institute of Development Studies (IDS) and Saúde Sem Limites (Brazilian Health Unlimited). Further information about the community monitoring strategy for Indigenous health in Rio Negro see <https://ssl.org.br/plmcsi/>.

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Covid, postpartum mental health and the decolonization of Indigenous family services

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Indigenous people worldwide are at significant risk for postpartum depression and anxiety, yet little is understood about their experiences in general or in extenuating circumstances such as in the context of the COVID-19 pandemic (Leason [2021](#); Khoury et al. [2022](#); Owais et al. [2020](#)). We turn here to the mental health concerns of Indigenous people after giving birth during the recent pandemic, as told from the perspective of Indigenous community service providers working with families with newborns. They share how COVID-19 not only revealed long-standing inequities but gave deeper impetus for the decolonization of Indigenous family services. We conducted the research in early 2021 with providers working with 11 Tribal and urban Indigenous communities in Michigan, USA. Amidst challenging conditions, Indigenous community service providers persevered in delivering care, comfort and creative solutions to birthing people and their families (Kolahdooz et al. [2016](#)). The pandemic magnified structural, logistical, cultural and other factors which affected how Indigenous people accessed services, underscoring the need for the long-term development of equitable, community-based, culturally appropriate services (Begay, Godfrey and Ivanich [2023](#)). While the pandemic accentuated aspects of precarity and vulnerability, we show that it also brought into relief Indigenous community resiliencies and capabilities to support Indigenous birthing people exercising Indigenous sovereignty.

The importance of decolonizing services was a central theme emerging from the study, and highlights both the chronicity of coloniality and the 'survance' strategies of Indigenous communities. Survivance is a term coined by Anishinaabe writer, Gerald Vizenor, which combines

ideas of survival and resistance to capture simultaneously colonial oppression and its renunciation (Weaver 2022). The impacts of COVID-19 on Indigenous people of reproductive age are multiple and persistent. Before this pandemic, birthing Indigenous persons faced inequitable access to resources and services, structural racism and obstetric violence steeped in historical and ongoing colonialism (Theobald 2019). When understood as intersections of settler colonialism and gendered inequities, the harm of COVID-19 for Indigenous people is compounded and colonization is more dangerous (Howard-Bobiwash, Joe and Lobo 2021; Howard-Bobiwash 2022).

The existing disproportionate rates for Indigenous people of chronic disease, intergenerational trauma, child apprehension, sub-optimal nutrition, substance misuse and violence meant that fear of COVID-19 during pregnancy and postnatally increased adverse maternal outcomes (Kozhimannil 2020; Kozhimannil et al. 2020). Cascading consequences for physical, mental and social wellbeing ensue for Indigenous individuals and communities, and intensified under pandemic conditions (Power et al. 2020). We examine the discourse and actions of decolonization expressed on the frontlines of the pandemic, aimed at eradicating the chronicity of colonialism (Wiedman 2010). As everyday acts of survivance, these include articulations of independence from biomedical dominance and consumerism, Indigenization, reparation, reconciliation, the return of resources and the reconstruction of land-based cultures, the integration of life-cycle teachings and the humble balance of autonomous and collective needs within a non-linear community matrix with birthing people at the center.

Postpartum mental health and colonial chronicity

Indigenous women suffer untreated and undertreated postpartum depression and other perinatal mental health issues at a higher rate than their non-Indigenous counterparts (Baker et al. 2005; Black et al. 2019; Bowen et al. 2014). In the biomedical calculation of risk, Indigenous identity increases the risk of mood and anxiety disorders during pregnancy and postpartum by 62 per cent (Ward et al. 2022, 1). However, it is not being Indigenous that puts one at risk, but rather the low social support, low socioeconomic status, colonialism, lack of culturally appropriate screening tools, inconsistent perinatal care, need to travel for care, domestic violence, adverse childhood events and stressful life events (Heck 2018; Maxwell et al. 2019; Ness et al. 2017;

Walters and Simoni 2002). While studies of the postpartum mental health of Indigenous people is limited in North America and globally, historical and ongoing trauma, cultural barriers and philosophical differences in the conception of childbirth and the prenatal and postpartum periods are extensively reported and explain how mistrust of biomedical health care and service providers has been fostered among Indigenous women and their families (Meredith et al. 2023).

Hospitals are often seen by Indigenous people as places where providers do not understand their cultural needs; this is particularly true for birthing people throughout the perinatal period (Bruyere 2012). Provider biases can lead to negative experiences and health outcomes for Indigenous women and their newborns (Gausia et al. 2013). Traveling long distances to give birth in hospitals compounds cultural and social isolation for rural women, who often have to do this alone, and removal from their community settings perpetuates the damage to Indigenous knowledge authority and transmission historically caused by the forced movement of childbirth out of Indigenous communities and into hospitals (O'Driscoll et al. 2011; Theobald 2019). Connection to Indigenous homelands and places are central in childbirth practices and at the root of why moving perinatal care and childbirth into hospitals has been detrimental to community and cultural practices surrounding maternal care, childbirth and newborn care (Kornelsen et al. 2010; Brayboy and Morgan 1998).

Many Indigenous groups have expressed a desire for cultural safety and the option to receive care and give birth in their own communities (Smith et al. 2006) and to provide family-centered interventions (McCalman et al. 2017), including through participatory research and collaboration to construct effective and culturally relevant maternal and natal health programs (Wiebe et al. 2015). Indigenous paraprofessional and midwifery programs report high success rates, and many call for better education in cultural competency for health care providers, particularly nurses (Smith et al. 2006). However, training without structural change is insufficient. For example, Indigenous women have long been active in organizing for environmental justice alongside reproductive justice, because environmental pollution directly impacts maternal and natal health. Barriers to achieving environmental and reproductive justice relate to legal limitations and structural inequities in protective and advocacy action (Cook 2018; Gurr 2011; Theobald 2019) and highlight the limitations of Cultural Safety Training for service providers working with Indigenous birthing people under these circumstances.

The specific intersections of structural oppression experienced by Indigenous peoples shape the risk factors for postpartum mental health in ways that call for tailored rather than universal programs (Daoud et al. 2019). This may include framing approaches with local understandings of the impacts of colonization and therefore locally driven restorative models of healing. This might also include changing practices, ranging from adjusting screening tools to account for differently expressed symptoms to integrating collective, cultural and behavioral health systems (Owais et al. 2020). These considerations are urgent. Indigenous women in the United States are ‘dying at a rate 2 to 3 times higher than non-Hispanic white mothers nationally’ from maternity-related causes (Kozhimannil 2020, 1).

The chronicity of colonialism which shapes poor maternal health outcomes came to the fore during the COVID-19 pandemic and crystalized this urgency. In the United States, post pandemic, preferences shifted toward community-based maternal care, although with expectations that access to such care will continue to be limited (Gildner and Thayer 2021). The disruption of the pandemic also shifted views among maternity care providers toward a return to ‘humanistic practices of connection’ (Gutschow and Davis-Floyd 2022, 89; Davis-Floyd, Gutschow and Schwartz 2020). Decolonization is an important lens through which Indigenous community service providers are enacting humanistic practices of connection by recentering Indigenous community-defined cultural, holistic, land-based and sovereignty-supporting perspectives on reproductive health and wellbeing. This includes consideration for the historical context in which Indigenous protective factors have been destroyed, and with the divestment of resources needed to support the health and safety of Indigenous mothers, alongside integration of ‘traditional and cultural practices, Native language, strong social networks, and a connection to land and place’ (Advisory Committee on Infant and Maternal Mortality 2022, 9–15, 18). Practically, this may involve task shifting to ‘empower Indigenous paraprofessionals who are familiar with the spirituality, kinship patterns, language, and historical collective trauma to ... reduce depressive symptoms, improve mother–baby attachment, reinvigorate engagement with spirit and cultural practices, and promote overall wellbeing of Indigenous families’ (Ward et al. 2022, 7). As we detail below, these aspects of ‘culturally centered healing’ (Brown 2016, 120) both challenge and stretch the delivery of a range of services as these may impact postpartum mental health.

Prior to the COVID-19 pandemic, notwithstanding problems with the comprehensiveness of data, the prevalence rate of postpartum depression varied from 14 to 30 per cent higher for American Indian

and Alaska Native people than for all US women (Heck et al. 2022). In a study in Canada for the general population, half to nearly two-thirds of research participants reported depression from pregnancy to postpartum during the pandemic, compared to a global estimate of 14 per cent for postpartum depression before 2019 (Khoury et al. 2023; see also Liu, Wang and Wang 2022; Safi-Keykaleh et al. 2022; Yan, Ding and Wenbin 2020). Indigenous women already had twice the risk for postpartum depression compared to Canadian women, and the ‘emotional impacts of colonialism contributed to their emotional, relationship, and traumatic stress’ which increased their odds of postpartum depression (Leason 2021, 234). The COVID-19 pandemic compelled Indigenous community services providers across North America to mobilize their strengths in the shift to distanced and online contact with their constituencies, in which process women’s relational leadership played a significant role (Olson et al. 2022). They adapted quickly, maintaining engagement and working to ensure that families did not experience gaps in service, and continued to have access to healers, spiritual and cultural service providers through telehealth, online group and individual appointments (Howard-Bobiwash, Joe and Lobo 2021). In this chapter, we document how this shift prompted reflection and aligned action toward bolstering decolonizing strategies already broadly underway.

Community-based research during the COVID-19 pandemic

In partnership with the Inter-Tribal Council of Michigan (ITCM), we worked with Tribal communities to describe existing understanding and approaches to postpartum mental health and to develop long-term community-based strategies around this focus. ITCM, established in 1968, represents the 12 federally recognized tribes in Michigan, who are culturally Odawa, Ojibwe and Potawatomi and collectively referred to as the Anishinaabeg. Birth equity, maternal health and family wellbeing are major ITCM interests (ITCM n.d.-a, n.d.-c). The ITCM Home Visiting Program conducts family assessments, and provides referrals and support for pregnant women, postpartum women, children and other caregivers. ITCM had identified the ongoing need to ensure that effective methods for assessing and responding to postpartum mental health issues are integrated into its program protocols.

Officially, the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program is a federal program provided through

the Health Resources and Services Administration (HRSA 2023) that ‘supports pregnant people and parents with young children who live in communities that face greater risks and barriers to achieving positive maternal and child health outcomes’. It is voluntary and aims, among other things, to reduce child abuse and neglect, crime and domestic violence, promote expected child development milestones and readiness for school and connect families with support, resources and networks. Home visits may include activities that support and monitor healthy pregnancy and parenting, breastfeeding, safe sleep, nutrition, language development and goal setting (HRSA 2023). The Tribal Home Visiting Program is flexible to local adaptations, and the ITCM Home Visiting Program specifically focuses on emotional and mental health, strengthening early childhood systems and grounding in the cultural way of life of the communities served. Components include broad open enrollment, extension of services to age five, conducting assessments, developmental tracking, parent education and referrals for all children under five, and enhancing visits with a number of learning, cultural, nutritional and literacy curricula. This includes an Indigenous-modified Mothers and Babies supplement (ITCM n.d.-b; U.S. Department of Health and Human Services 2023).

Authors Gartner and Howard-Bobiwash first met October 2019 at a newly formed population health discussion group on the Michigan State University (MSU) campus. Drawing on our overlapping research experience in Indigenous women’s health, infant and early childhood health, mental health and community-based health care service delivery, we applied for and were awarded an internal grant to support this research at the end of February 2020. MSU went into lockdown on 11 March 2020, the day the World Health Organization (WHO) declared COVID-19 a pandemic. The first reported COVID-19 death in Michigan occurred on 18 March, and Michigan Governor Gretchen Whitmer issued a stay-at-home order on 23 March (EpiBayes Lab 2022). MSU remained under lockdown conditions through to mid 2021, when some limitations on travel for research were lifted. We delayed discussion with Indigenous community service providers of a research partnership until late 2020; in the interim, author Nash joined the project.

By April 2023, there had been 3.1 million confirmed and probable cases of COVID-19 among Michigan’s population of 10 million, and 42,667 deaths caused by the virus (Government of Michigan 2023). Data for Indigenous people are inaccurate (Gartner et al. 2023), but one source found that Indigenous people were one and a half times more likely than white people to have contracted COVID-19 in Michigan

(The Covid Tracking Project 2021). However, their death rate was lower than for the state population overall, and for Indigenous people in the United States (Leggat-Barr et al. 2021).

Numbers do not account well for the experiences and perceptions of COVID-19, nor for the ‘viral load’ which, as Gamlin, Gibbon and Calestani (2021, 108) argue, ‘tracks the fault lines of social and economic exclusions that give continuity to colonialism and its production and exploitation of racial hierarchies’. The importance of documenting these fault lines remained high for ITCM as the organization persevered to adapt home visiting to virtual encounters. Together, we designed a qualitative study centered on semi-structured interviews conducted online with Tribal Home Visiting Program staff, which expanded to include breastfeeding support providers, midwives and doulas, therapists and other Tribal organization staff recruited through snowball referrals, for a total of 23 interviewed. Our project resulted in presentations and a report for our community partners, and a series of infographics which have remained a highly utilized training resource for the ITCM Home Visiting Program.¹

Anishinaabekwe mental health after birth

The biomedical diagnostic label, postpartum depression, falls short of the expansive and holistic Anishinaabe understandings of the intersections of structural oppression, gender, relationality and mental health. It also imposes boundaries around what counts as relevant for service providers to identify as postpartum needs and limits how they can accommodate these needs. The broader concept of postpartum mental health in the Anishinaabe context captures both the diversity of experiences and concerns associated with new Indigenous parenthood and situates mental health (dissociation, suicidality, detachment) relationally to emotional health (anxiety, stigma, fear), social health (isolation, spirituality, supports, self-care) and physical health (nutrition, shelter, exercise and consideration of co-morbid conditions). This broader understanding of mental health balances these areas of deficit with the promotion and centering of positive individual and community strengths, identity and cultural practices that support wellbeing, and against the effects of historical and ongoing settler colonialism.

History matters. Its impacts reverberate through time. Indigenous mothers have personally and intergenerationally experienced harm from the medical profession including through coerced sterilization,

in boarding schools and in relation to child removal. The historical and ongoing denigration of Indigenous motherhood fundamental to boarding school and subsequent child welfare policies and interventions shaped the experience of Indigenous new mothers in important ways (for example, Ergün, Kaynak and Aydın 2022). Historical intergenerational trauma is a unifying vulnerability for postpartum depression and anxiety, explained as experienced by ancestors and carried through generations ‘in our DNA’, as one doula described it. Where connections to rituals, culture and language are disrupted by colonization, people fill this space with substance use or other coping behaviors. Fear of appearing vulnerable keeps Indigenous mothers who may be experiencing postpartum depression and anxiety from reaching out for help. As one home visitor related:

Out of our families, probably 10 per cent of them have a diagnosed mental health concern. But from me observing the symptoms, I feel like it’s much closer to a third to half of them, mostly just because they’re under so much stress.

Recognizing and understanding the application of these intersectional roots of postpartum depression and anxiety are foundational for establishing trust in health care and service providers, and for what is described as ‘being in good relation’, a term commonly used in North American Indigenous communities to convey the practices of responsibility and reciprocity that are grounded in kin-making. These are ‘generated and regenerated continually through embodied practice and within each family, community and generation of people’ and with the non-human world (Simpson 2014, 7). In contrast to transactional relations, being in good relation describes actions that ‘carry forth a value system to actively create the world in which we want to live’ (Denetdale 2020, 237). This manifests in diverse relational forms such as ‘becoming an auntie’, to ‘be their village’ and to ‘walk beside people’ in the words of ITCM-associated service providers. This approach produces practice-based evidence because service providers in good relation have a keen sense of who struggles with mental health issues and can contextualize the cues for official diagnoses of depression and anxiety in relation to what is ‘normal’ in the lives of those they serve. The trust established through acting as a good relation reduces barriers to identifying need and asking for help. As one home visitor related:

The great thing about doing a program like [this] was that we ... spend a lot of time with families and get to know them over months

and years. So, I would have clients who would say to me, 'I don't feel right. I feel really bad. I think this is postpartum depression, or I don't feel okay right now'. Or sometimes clients felt safe enough or vulnerable enough to cry, or really just talk about how hard things were. But sometimes I would just see a flat affect ... It wouldn't appear that they had a lot of interest in anything, including talking about things that I knew they cared about a lot, like their baby.

Service providers link aspects of the structural oppression experienced by Indigenous peoples to specific types of stress and fear that put new mothers at risk for postpartum depression. This allows for acknowledgement of these contexts (Daoud et al. 2019) and for the iterative adaptation of their standardized service goals to careful reads of individual needs and emotional disposition (Owais et al. 2020). Services are successful when trust is well established and maintained, and when information about postpartum mental health is communicated well in prenatal care. Stigma surrounding postpartum depression is also reduced with preemptive work to discuss the pressures and expectations of motherhood in a positive way ahead of birth.

Stigma persists, however, around seeking help for postpartum mental health suffering. Indigenous birth-givers are reluctant to engage with services for postpartum mental health, grounded in fears that their children will be removed if their mental health treatment is associated with being deemed incompetent as a parent (Denison et al. 2014; Maxwell et al. 2022; Heck et al. 2022). A persistent belief, especially if not the first child, is that mothers 'know' how to mother. In the context of the extreme criticism and denigration of Indigenous motherhood in the colonial perspective, it follows that sufferers fear that postpartum depression may be misperceived as an 'excuse' for not taking care of one's child or a deserved outcome of unhealthy behaviors during pregnancy. New mothers often resist asking for pharmaceutical treatments for mental illness because of the fear that this might increase a sense of loss of control, or that medications might interfere with breastfeeding. Hesitancy about taking prescription drugs is also tied to the lack of trust in prescribing providers caused by the inconsistency and lack of regular psychiatrists or nurse practitioners with whom relationships might be established. Bias of providers outside Tribal services, lack of assistance to navigate these services, and the multitude of health care appointments expected during the perinatal period, highlighted throughout the COVID-19 pandemic, remain significant challenges.

The survivance of service

The reach of the intersections of coloniality and patriarchy impact new mothers in birth processes in particular ways, which service providers regarded as vital to keep at the fore of their work as they persisted in providing comfort, care and creative solutions to the logistical and other challenges affecting people at the height of the COVID-19 pandemic. As one behavioral health services coordinator shared, their department saw a 40 per cent increase in need for services due to COVID-19, crisis calls were ‘astronomical’ and providers were dealing a lot with trauma. Suicidality behaviors increased in women, youth and children, and this coordinator was astonished – but proud – to be able to say that, at least in their service area, there had been no suicide completions nor fatal overdoses in nine years that included during the pandemic.

The separation and removal of children from mothers following birth, due to suspected COVID-19 infection, compounded fears and anxieties around child removal for Indigenous birthing people (Denison et al. 2014; Furlow 2020). This led to increased requests for birth workers to assist with homebirths. But, for example, one midwife related that she had stopped doing homebirths during the pandemic because her need to build a strong relationship with an expecting mother was impeded by social distancing requirements. In contrast, a doula had switched her services to an online practice, and found this approach thrived. An emerging Indigenous doula movement was already in motion before the pandemic (Cidro et al. 2018, 2020; Doenmez et al. 2022), and this doula explained how the pandemic set back the Indigenous birth equity movement because birth-givers

... lost some of their voice a little bit more. They were even more apt to C-sections and regulated birth because they wanted to have the babies quicker. So, I think we lost some ... I don't ever want to say it was that we lost something in a bad way, I think there was some step backwards that we have to kind of regain again because we were moving forward in a way that was seeing that birth was a normal, natural process again. But now women are in a very fearful mode, which is understandable. I'm not negating that whatsoever, because we still don't have all of the answers with Covid. Covid has exponentially affected birth in every way shape and form.

The fear of contracting coronavirus infection from home visiting service providers had knock-on effects. For example, one mother was afraid to

accept the help of a breastfeeding consultant, and ended up switching to formula to resolve challenges, then felt guilty and ashamed when she later learnt that breastfeeding could build immunity to COVID-19 for herself and her baby. But as one home visitor explained, ‘doing any type of breastfeeding [advice] over the phone or FaceTime [was] very hard when you’re trying to assist a new mom with trying to breastfeed’. Service providers considered, too, how historical factors might shape how breastfeeding assistance and other services may trigger postpartum mental health issues.

Isolation during the pandemic compounded to wear down Indigenous mothers with their newborn’s ‘constant need of being needed’. As one provider explained:

Covid really hit people hard. Understandably, being stuck at home if you have a new baby, baby’s not seeing anybody, you’re not getting any help, you’re stuck at home. And so I think just that constant need of being needed, it could be very wearing. Maybe due to worsening symptoms, or more awareness to general mental health concerns, the pandemic made some new mothers become more aware of the severity of their depression symptoms and [they] sought a referral for mental health services.

Feelings of loneliness and isolation are common for birth-givers even when surrounded by family and community support, in part because attention is centered on the newborn and the parent may feel left in the background. Home visitors encouraged new mothers to socialize and ask for help; however, this could also add stress that exacerbates experiences of poor postpartum mental health. Isolation imposed by COVID-19 allowed some mothers to have a break from the social expectations of receiving outside visitors, as one provider described:

They’re like, ‘everybody wants to come over but we’re in a pandemic. I don’t want them over’ [or] I’ve also heard ... young women, mothers, say, ‘I’m happy that I get to use Covid as an excuse ... Now I can be like, “Oh, the pandemic. We’re just not letting anyone see our baby”’. Which, if we weren’t in a pandemic, they felt like they didn’t have a choice but to open up their home and their child to guests and visitors.

That said, concerns about anxiety and mental health issues arising from isolation extended to family- and community-level uncertainties,

including the persistent fear of vulnerability to COVID-19. Attention also focused on potential developmental delays as a long-term consequence for children born during the pandemic (see also O’Keefe et al. 2021).

Remote visiting work made it difficult for service providers to observe aspects like changes in mannerisms, self-care issues or other signs which might indicate mental health concerns. Home visitors and other providers reflected on how the transition to remote visiting and appointments meant that they could miss making observations only possible in person, while in other ways switching to telehealth visits were beneficial (Collins et al. 2021; Howard-Bobiwash, Joe and Lobo 2021). For some homes with elevated risk for a variety of reasons, in-person visits continued; while they were less frequent, they were long enough sometimes for providers to assess how families were doing. However, quick ‘stop-bys’ to check in, common before the pandemic, were replaced with text and social media messaging. In some locations even this limited contact was hindered by long-standing policies that disallowed such communication. One home visitor insisted that new mothers send voice messages rather than texting because, as she put it, ‘I can hear emotion and tone and pick up on their energy just through their voice. I use a lot of voice messaging and make sure that they can do that back’. As another home visitor put it, ‘I’m grateful for [video] technology because we get to at least somewhat see the mom, but being in the home really makes a difference as far as looking at the whole picture, the big picture’. However, another remarked that virtual visits were much shorter as well because ‘people hit their attention/energy limit sooner’, and home visiting curriculum, activities and checklists were sometimes impeded or slower to complete.

Phone conversations helped to address power dynamics and lack of trust between providers and the people they serve, especially when the provider is non-Indigenous: ‘building our relationship just talking over the phone ... just seems more casual, and a lot less clinical’. This reflection extended to considerations of how the clinical space of health and family service offices reproduced and projected colonial power relations, even when provided by the Tribal community, prompting ideas for possible changes to address these spatial power dynamics. One therapist described how the office visit, curtailed by COVID-19, offered a refuge for some patients, ‘It’s been a lot more challenging for them to connect because they feel like they need that safe space of my therapy office. They need that break of coming in and being away from their kids for an hour and having some silence to work through some things’. Another mental health care provider found that telehealth appointments also had pros and cons,

I have quite a few clients with several kids, where it is so challenging for either of us to concentrate at all on the phone. A lot of times we have to hang up and they try to call me back in 10 or 15 minutes, or they can't, and we have to try again next week. But then again, those are clients that maybe wouldn't have showed up to their appointment at all because they didn't have a babysitter. So, I think there's barriers either way.

A different telehealth provider noted that families who did well with the switch to virtual care 'are the ones that already have it mostly together. The ones that need the most help are the ones that their phone is turned off or they don't answer it at the time'. Privacy influenced how much people could express themselves openly,

... when you're sitting in your small house and perhaps you're having a problem with members in your house that you want help troubleshooting. You can't exactly, on the phone, talk about that. It seems kind of censored to have a Zoom meeting or a phone call in your house, with other people around.

These factors emerged in addition to the basic pre-pandemic disparities in rural area access to a stable internet connection, which made virtual appointments out of reach for many in Tribal communities who lack access to broadband and rely on expensive cellular services. The plethora of pandemic-related grant opportunities created by federal and state governments generally did not allow for funds to be used to address this issue or to purchase devices for people to handle Zoom calls. In 2023, the Biden Administration's Infrastructure Law and Consolidated Appropriations Act included a Tribal broadband connectivity program, which will improve access for Tribes in Michigan in the longer term (U. S. Department of Commerce [2023](#)).

One home visitor summed up the lasting results of remote pandemic service providing this way:

COVID-19, the Zoom idea, I mean you and I are sitting here very easily as if we were sitting at a table, but for a lot of people, that's not comfortable, so a huge impact. I think we're going to see a lot of fallout.

When in-person home visits were allowed again, some families continued to keep outsiders out of their homes, and others were lost

to the program indefinitely. This led to shifts in the approach of the program to allow for more flexibility, fluidity and understanding for families to come in and out of home visiting enrollment, which may have longer term benefits, including permitting more people to enter the program.

Decolonization and durabilities

Where historical trauma is characterized as something ‘in our DNA’, some service providers highlight that ‘we also carry resilience’ and, as one doula stated, Indigenous communities in the region have been on a trajectory toward ‘seeing that birth was a normal, natural process again’. These perspectives reflect a resurgence of traditional knowledge surrounding childbirth and traditional approaches to breastfeeding, parenting and Indigenous foods, understood as foundational and protective from postpartum depression as part of a broader holistic health approach specific to Anishinaabe regional decolonization work (Barnes-Najor et al. [forthcoming](#); Clark 2022; Simpson 2014).

Few services address Indigenous experience with postpartum mental health specifically. In their absence, existing services provide ‘cultural coverage’ to help parents and families deal with postpartum mental health issues. For example, new mothers are included in access to traditional healers, traditional medicines, sweat lodges and talking circles, already offered through other programs. There they may also find referrals for help with placenta burying and naming ceremonies. Traditional healers are called upon to serve as mediators with mainstream health care providers when birthing people want cultural practices incorporated, such as smudging (using the smoke from burning sacred plants) in the hospital. Cultural teachings are incorporated into playgroups and breastfeeding assistance, and at annual baby celebrations organized by service providers in some communities (see also Cidro et al. 2018). Engagement of new mothers and families in group activities around making traditional items, in particular, *tikinagans* (cradleboards), offer direct opportunities for culturally informed approaches to support postpartum mental health; indirectly, making items such as moccasins and shawls, or engaging in language classes, has a similar supportive effect (Sydora et al. 2023).

There remains a lack of awareness about postpartum mental health among some Tribal cultural specialists. Many cultural programs follow a behavioral health model and become siloed from other services, raising questions about how culture might be approached within or between

different types of services. Many service providers who identify as non-Indigenous and work for Tribal services worry that they lack the knowledge or authority to appropriately convey the value of cultural services. Virtually no culturally informed services are available in mainstream mental health services (Gone 2004; Rainie et al. 2015). Moreover, racism in mainstream mental health services and insensitivities to Indigenous cultural and other experiences cause further harm to those suffering from postpartum mental health issues. Within Tribal services, there may be a mismatch in the cultural services available to accommodate the reality of multi-Tribal communities and diverse families. Urban Indigenous health services tend to provide cultural services informed by the majority Tribal identities in their region, although they may serve Indigenous people from all over the globe. Reservation-based health services serve members of other Tribes living in their communities. Healers and doulas are rare and circulate across many communities, rather than being part- or full-time staff in one community. This limits their availability and may increase wait-times for appointments.

Nutrition, especially traditional food and cultural teachings around food, needs greater integration with mental health services in general, and pregnancy, postpartum mental health and family wellbeing. Some services integrate cultural approaches with other types of help like non-specific meditation and relaxation or acupuncture, and make referrals to non-Indigenous postpartum depression clinics where available. However, as noted, there are limitations of doing this in the absence of Indigenous cultural safety in these clinics (Gopalkrishnan 2018).

Decolonization includes the process and state of being which allows healing from coloniality's chronicities (and chronic coloniality), in which Indigenous epistemologies shape everyday life and the organization of services, as a doula described: 'the mother and the baby are floating in the middle there with help and she's got every support and resource she needs so she feels supported in whatever she needs'. A non-linear community matrix centers around family, mother and baby, and generates confident mothers who are not questioning themselves, promotes engaged fatherhood and naturalizes community-wide gathering.

Independence from biomedical hegemony, particularly linked to birth trauma, was an important starting point towards this vision. As one person said, 'It's like we have normalized this medicalized way of controlling our bodies every step of the way, literally from the moment of birth, all the way up to the moment of our death. So, I think we just

need to really scene-clean the whole thing'. Birth support is an important protection from postpartum depression. This includes funding for home-births, supporting connection to culture, and helping people birth the way they want so they have a positive birth experience and avoid the traumas of biomedical birth. Building independence from the consumerist framework may help reverse pressures on people to 'think they have to have all kinds of stuff to be a good parent' and resist disposable diapers and other waste products are counter to Indigenous efforts toward sustainable ecologies.

The return of resources and reconnecting to land-based culture are central because this entails the daily use of traditional practices in sustainable and meaningful ways. The land back movement advocates for the return of Indigenous lands to Indigenous control on their terms and cultural framings, for example, positioning humans in reciprocal relationship with land rather than as extractive owners (Scobie, Finau and Hallenbeck 2021; Pieratos, Manning and Tilsen 2021). In this context, decolonization encompasses complete holistic, culture-based food and nutrition: meals are prepared collectively, for example, providing support to new mothers. The medicinal value of breastmilk and connection to sustainability are naturally promoted. A broad community-based shift integrates Anishinaabe teachings and principles; humility is one of the principal teachings which is central to balancing and meeting individual autonomous and collective needs (Barnes-Najor et al. [forthcoming](#)).

Centering Anishinaabe epistemics, such as coming-of-age teachings and the perspective of the role of midwifery in facilitating transitions across the life course, and expanding knowledge about postpartum cultural protocols illustrate how Anishinaabe teachings might frame services. The decolonization of care for Indigenous birthing people is a matter of praxis; making space for connection between women and families, especially if they share postpartum mental health issues, involves basic mutual aid and visiting. For example, simply coming around and making traditional foods or bringing traditional medicines and tea to the house provides support which can help diffuse and de-stigmatize postpartum mental health issues. One home visitor explained this as 'less talking and more practical support', and another reflected:

I think it would be a network of other like-minded women, Indigenous or not Indigenous, that would kind of go back to the traditional ways. Really coming into the woman's home, obviously invited ... providing them with soup, tea, maybe singing for them if that's something they'd enjoy, playing with their other children, taking some of the responsibilities, doing their laundry, doing their

dishes, sweeping their floor, opening their windows, taking their dogs for a walk, checking in with them and kind of just sitting with them and being with them in a way that it's helpful but it's not clinical and procedural.

Organizational, bureaucratic or structural barriers such as misrecognition of postpartum depression, structural racism, the legacy of trauma and insurance issues are important to eliminate. In decolonized services, care safety is the norm; all have confidence and freedom to ensure their care needs are known and met; they have a good fit with providers and capacity to change providers when not working; and they have the broader community matrix upon which to rely.

Conclusion

There are multiple layers to understanding Indigenous peoples' experiences with poor postpartum mental health. The causes of postpartum depression and anxiety are intersections of chronic colonialism, characterized by the deep, intergenerational and cascading reach of colonial institutions, structures and ideologies. These include capitalist, patriarchal and white supremacist structures which engage in continued extraction of Indigenous land and water and have attendant impacts of cultural knowledge loss about pregnancy and childbirth, generate stigma and fear and shape traumatic birth experiences. Social and biophysical factors linked to poor postpartum mental health include childhood trauma, domestic violence, lack of support, financial worries, change in identity, unrealistic expectations, loss of friends, poor sleep and diet and hormonal fluctuations. Consequences of poor postpartum mental health include impacts on relationships across the extended family and on self-esteem, leading to self-neglect, isolation and, sometimes, self-harm and suicide. This highlights the need to reposition time after giving birth as a period in which mental health can best be attended to in relational terms with physical, spiritual and emotional health balanced through individual, family and community support systems.

Pieratos, Manning and Tilsen (2021) describe the momentum in the landback movement during the COVID-19 pandemic. In a context in which epidemics are remembered as instruments of genocide, mistrust was steadily reinforced by policies of land dispossession, removal and containment, and perpetuate circumstances for more epidemics, poverty, malnutrition and ill health (Howard-Bobiwash, Joe and Lobo 2021).

Writing in the midst of the COVID-19 pandemic, Pieratos and colleagues implored:

As conditions worsen from the disproportionate effects of COVID-19 on our peoples, Indigenous leaders have to consider how to not only provide for the basic needs of our communities but also resource the social change work emerging from this moment in history. Obviously, Indian Country requires a complete paradigm shift in the way that society invests in Indigenous peoples and our self-determination. A confluence of factors both internal and external to Indigenous communities has made this shift within reach rather than a utopian dream. (2021, 47)

A doula who participated in this research summed up ideal postpartum mental health service development with this question, ‘What knowledge can we access that can be not only lifesaving and life-sustaining ... but [also] how can you help people get back to thriving?’ The story of service providers coping with the impacts of COVID-19 on postpartum mental health through the praxis of decolonization highlights how this paradigm shift is underway in Indigenous communities in Michigan.²

Notes

- 1 ‘Perinatal & mental health’. Inter-Tribal Council of Michigan, Inc. Accessed 19 October 2024. <https://www.itcmi.org/home/departments/maternal-and-early-childhood-services/perinatal-mental-health/>.
- 2 This chapter is based on a project reviewed by the Michigan State University Institutional Review Board, STUDY00005472, and a Commitment of Practice between MSU investigators and the Maternal and Early Childhood Services Department at the Inter-Tribal Council of Michigan, Inc. The research described in this chapter was funded by an award from the Science and Society @ State program aimed at promoting interdisciplinary scholarship from STEM, health sciences and social sciences at Michigan State University.

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Structured neglect and moral action: Punjabi and Hmong community- based organizations' pandemic response in California's San Joaquin Valley

Nancy J. Burke, Premjot K. Saroya
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Nancy's phone pinged as new photos appeared – beautiful smiling faces painted in intricate colorful designs. They were pictures of *promotoras de salud* (lay health workers) sent from the monthly pop-up COVID-19 vaccine event at the Merced County flea market which, since May 2021, we had been organizing with a local community-based organization and community clinic. The pop-ups were designed to make vaccines easily accessible to Spanish, Punjabi, Hmong and English speakers, many of them farm and factory workers who were wary of the paperwork required to receive the vaccine at pharmacies. It was October, so the *promotoras* were dressed up for Halloween. They often talked of the importance of making the pop-up clinics fun and welcoming, to encourage families and individuals to get their shots. This month they had invited someone to do face painting at the booth, and they laughed with those (fathers, mainly) who were reticent to get the vaccine. 'You'll need it to go dancing', they chided, eliciting laughter and knowing nods from the men.¹ Bilingual students from the University of California, Merced, many of whom had grown up in the region, were on hand to help interpret when necessary.

This scene is one of many in which community organization staff and volunteers took a leading role in vaccine and testing rollout in poor and marginalized neighborhoods and counties in California, a deeply divided and stratified state well before the COVID-19 pandemic. California has the fifth-strongest economy in the world and is characterized by

its beautiful coastline and politically progressive cities that serve as incubators for music, art, film, literature and culinary masterpieces. Silicon Valley, a geographically amorphous area known for its tech startups and 20-year-old millionaires, has transformed coastal cities such as San Francisco and Oakland, pushing housing prices out of range for middle class residents and inflating the rental market to new levels. The population of unhoused, including many working poor and families living in cars, exploded in response. In the five years preceding the pandemic, the San Francisco Bay Area had seen increasing out-migration to neighborhoods further inland, causing the highway connecting Central Valley towns to the Bay Area to become known as the country's most dangerous commute, and the individuals driving it as 'super commuters' (Baldassari 2019). As economic inequalities increased, so have stark differences in health across the state. Pre-pandemic, life expectancy was 74.8 years for Blacks, 80.5 for Whites and 82.5 for Latinos living in California (Schwandt et al. 2022). Between 2019 and 2021, the life expectancy for Latino Californians fell by almost six years, from 82.5 years to 76.8. In 2021, life expectancy had dropped to 78.6 years for Whites (by less than two years) and had decreased by nearly four years for Black Californians (from 74.8 years to 71), and by three years for Asian Californians (from 86.6 years to 83.5) (Schwandt et al. 2022). Before the pandemic, residents in the state's poorest 1 per cent of census tracts had a life expectancy of almost 76 years, about 11.5 fewer years than those in the richest 1 per cent of tracts. In 2021 that gap grew to 15.5 fewer years of life (Schwandt et al. 2022). The persistence in differences in the length and quality of certain lives compared to others points to structures that maintained the unequal worth of lives well before the pandemic took hold.

California is also a state of immigrants. One of the first 'minority/majority' states in the United States, with a population of over 39 million (Johnson et al. 2024), California has passed some of the most progressive immigrant policies in the country (ACLU 2023).² In October 2017, then Governor Jerry Brown signed State Bill 54 which created sanctuary for anyone living in the state without legal documentation. This law prevented state and local police officers from asking about an individual's immigration status and prohibited federal agencies from using local authorities to enforce federal immigration policies.

Less well known than the state's coastal cities, the San Joaquin Valley, an area encompassing eight counties within the Central Valley, is known as the country's breadbasket. It is intensely agricultural. Highly industrialized farming techniques have enabled the production of much of the country's vegetables, nuts and fruit, despite century-defining

droughts. The ground has been sinking slowly, as the water table has been drained to support production. Long periods of drought and lack of rain have also contributed to increases in forest fires throughout the region. Coupled with high levels of particulate matter (PM)_{2.5} from daily pesticide applications, the toxic air has led chronic asthma to become a normal part of childhood for the majority of the population living in the region. The San Joaquin Valley has its own page on the US Environmental Protection Agency's website which notes that it is home to 'some of the nation's worst air quality, high rates of childhood asthma, and contaminated drinking water' (EPA 2023). The 2023 'Measure of America' report found that no San Joaquin Valley counties scored 9 or above on the 10-point Human Development Index, a measure of wellbeing and access to opportunity made up of health, education and earnings. The 900,000 residents who did score above 9 (2.3 per cent of the state's population) live mostly in Bay Area counties including San Francisco, Alameda and Santa Clara Counties, and 'enjoy higher levels of wellbeing and greater access to opportunity than *almost anyone in the country* [emphasis added]' (SSRC 2023).

Statewide disparities in life expectancy are found in microcosm within the San Joaquin Valley. A policy institute at a state university in the region found that a child born in a wealthy neighborhood in the northern end of the city of Fresno is expected to live over 80 years, more than 10 years longer than a child born in a poor area in the city's southern end, and more than 20 years longer than a child born in a rural part of the San Joaquin Valley (Maxmen 2021).

Persistent intergenerational poverty, poor air quality, extreme heat and high rates of diabetes and hypertension within the San Joaquin Valley set the region's populations up for a harsh experience with COVID-19. This experience was exacerbated by the state's slow ramp-up to considering 'equity' in its distribution of COVID-19-related resources (for example, personal protective equipment [PPE], testing kits), including the COVID-19 vaccine, when it became available. These pre-existing stratifications continued through the pandemic and into the 'post'-pandemic setting, highlighting the chronicity of inequity, structural racism and structural urbanism in the state (Young and Crookes 2023; Probst, Eberth & Crouch 2019).

In this chapter we explore the role that community-based organization staff and volunteers played in the COVID-19 pandemic, with a focus on those organizations serving the large Punjabi and Hmong populations in the region. We focus especially on these groups because they comprise a significant proportion of the frontline and essential

workers prioritized in the pandemic response, and because they suffered from workplace and social exposures at high rates. Community-based organizations, as we will show, provided support that included increasing access to vaccines and testing, direct access to culturally and linguistically appropriate information and COVID-19 resources, and advocacy for labor rights and housing support. Staff in these organizations put themselves at risk of exposure and infection in order to ensure that people in their communities received the information they needed, in their own languages, to know their rights as workers and to access resources needed to protect themselves and their families.

Didier Fassin has written of the moral economy of life in the pandemic, posing the question, ‘whose lives are thus spared, and whose lives are neglected or even exposed to risk?’ (2021, 156–7). Fassin defines moral economy as ‘the production, circulation, distribution, and utilization of values and affects, obligations, and norms’ (2021, 157), drawing on Thompson’s use of the term in his work with the English working class (1968) ‘to refer to a traditional economy grounded on reciprocal obligations between the members of social groups’. In the context of the pandemic, the value granted certain lives over others (for example, food production workers versus those able to work at home), and the push to reopen businesses in order to save the economy, knowing that this would result in the loss of lives (but whose?) are questions of moral economy (Fassin 2021; Butler 2022). Fassin compares the impact of the pandemic in prisons in the United States and France to highlight the differential value granted individual lives and forms of life within the two systems. While prisoners in the United States died at higher rates from COVID-19 due to inadequate prevention and response, prisoners in France die from suicide at much higher rates than the United States. As he argues, ‘biological life threatened by the pandemic is undoubtedly much better preserved in French correctional facilities than US ones ... On the other hand, the disregard for other forms of life’, which he refers to as ‘biographical life’, ‘leads in France to another, much less visible, attack on biological life’ (2021, 168). COVID-19 isn’t killing prisoners in France; their treatment by the justice and prison system is. These calculations of worth communicated in institutional policies have clear trickle-down effects. At the same time, within institutions and communities there are moral actors, such as those described in this chapter, who engaged with a sense of urgency to ensure, or attempt to ensure, the protection of those most likely to be left out or neglected. This action, this relational engagement (Butler 2020, 2022) refuses the acceptance of loss and instead works against it.

The setting

The San Joaquin Valley is home to rural towns, unincorporated areas and small cities. Some towns are without potable water or a clinic. Hospitals have been closing in the region over the last decade, requiring residents to travel long distances for emergency and specialty care. The most recent closure, the Madera County Hospital, served inmates in some of the region's 22 mega-prisons. More than 4 million people live in the region, 41 per cent of whom are covered by MediCal, the state's Medicaid program.³ Out of California's 58 counties, Fresno, Kern, Madera and Tulare are ranked 52nd, 53rd, 49th and 50th, respectively, for health outcomes. The region also lacks adequate medical staffing. For every 100,000 residents, the Valley has 39 primary care physicians, which is 22 per cent less than the state average of 64, and has an even lower share of specialists.

The legacy of migrant labor, and the fight for workers' rights, marks the landscape. Housing built for migrant workers in the 1930s set the template for housing tracts that continue to dot rural roads. The United Farm Workers of America Union (UFWA), which gained strength in the 1960s with the Delano grape boycott, continues to have an active presence. In the midst of the pandemic the UFWA became actively involved in advocating for workers denied their rights to safe working conditions and compensation for missed work due to COVID-19 infection (see Madrigal et al., this volume). When food production facilities became hot spots for infection and workers were at a loss for information and direction, often because information on infection rates and options was provided only in English, the UFWA stepped in alongside community organizations.

The San Joaquin Valley counties have a combined foreign-born population of 900,000, over two-thirds of whom come from Oaxaca, Sinaloa and Guerrero (Kissam et al. 2019). There are between 600,000 and 700,000 farmworkers in California, and 850,000 to 900,000 farmworker dependents, or about 1.5 million members of farm working families in total (Gaxiola 2023). Of these, four out of ten workers are undocumented, and half have less than eight years of schooling. Two out of three speak little English, and eight per cent are of Indigenous origin (see Madrigal et al., this volume). A high proportion of these farmworkers lives below the poverty line. The average California farmworker makes US\$18,000 a year (Kasler, Tobias and Bizjak 2020). The high number of workers that lack legal residency means they have limited access to social services including unemployment and health care, despite paying

taxes. Recommendations made by the Centers for Disease Control (CDC) on social distancing were impossible for many of these workers to follow, as they were working and living in close quarters, including carpooling to worksites.

Alongside these immigrants, there are approximately 400,000 Sikhs – the majority from Punjab, in Northern India. Punjabi is the third most common language spoken in the region, following English and Spanish, and tenth most common in the state. The first Sikh temple (*gurdwara*) built in the United States, in 1912, was located in the city of Stockton, in the San Joaquin Valley, signaling the long history of migration to the region. A quarter of California's Punjabi population work in agriculture; others work in trucking and meatpacking (Singh et al. 2023). Almost 95,000 Hmong live in California (Cowan 2019), and the Central Valley is home to one of the largest concentrations of Hmong in the United States (Yang 2001, Pfeifer et al. 2012). Originally from highland agricultural areas of China, Vietnam, Laos and Thailand, the majority migrated after the US-Vietnam War and found their way to the San Joaquin Valley as a secondary migration site, one that afforded them the opportunity to return to farming (Thao et al. 2023). The social, cultural and linguistic challenges Hmong refugees experienced integrating into the Merced community were detailed in the lauded book *The Spirit Catches You and You Fall Down* (Fadiman 2012). Highlighted in this journalistic rendering were the many miscommunications and misunderstandings that undermined the care of a Hmong toddler suffering from seizures. While the book has been strongly criticized by Hmong Studies scholars (Chiu 2004), it provides some insights into the challenges Hmong refugees face interfacing with the US health care system.

Alongside meat and other food production factories, the 'logistics industry' – the large warehouses that support companies like Amazon and Walmart – is also taking hold in the region, displacing homes, gardens and small farms, and transforming landscapes (Cowan 2020). All of these workplaces were sites of COVID-19 outbreaks, and they are all dependent on largely immigrant workforces. These workers and their families were heavily affected by policies and rhetoric put forth by the Trump Administration. Then President Trump denigrated Mexicans as criminals and passed policies to increase deportations. Televised immigration raids planted fear throughout the population, leading immigrants to be wary of all government representatives, including public health workers. In February 2020 the Trump Administration was engaged in talks with the Lao government about relocating Hmong refugees to Laos (Mentzer 2020). These talks ceased once attention turned to managing the

SARS-CoV-2 (the virus causing COVID-19) outbreak, but the fear and exclusion fomented by their commencement lingered. The racialization of the coronavirus via slurs, including 'the China virus' and the 'kung flu', incited anti-Asian discrimination and violence throughout the state (Young and Hagan 2020; Venkatraman 2022).

The stark economic stratifications across California are reflected in regional differences in political affiliations. The coastal cities tend to be Democratic, while the inland valleys skew Republican. These political affiliations informed the ways San Joaquin Valley leaders responded to Covid policies put forth by the state's Democratic governor. California became the first state to issue a stay-at-home order to reduce the spread of COVID-19 in March 2020. The order was lifted in May, allowing each of the 58 counties to assess its own readiness without necessarily meeting state benchmarks (Largent et al. 2021). In the same month, Governor Gavin Newsom announced that he would send 'strike teams' to eight San Joaquin Valley counties and would ask the legislature to approve \$52 million to improve testing, tracing and isolation protocols in the counties (Lin, Gutierrez and Chabria 2020).⁴ 'This disease continues to grow in the state of California', he stated, from the Diamond Nuts plant in Stockton, 'It continues to spread, but not evenly. It's disproportionately impacting certain communities and certain parts of the state' (Lin, Gutierrez and Chabria 2020). The 'certain' communities were largely black and brown populations and 'parts' of the state the poorest counties, many in the San Joaquin Valley.

On 16 May 2020, days after the Governor's news conference, the Merced County Sheriff declared that he would not enforce public health measures imposed by the state government to slow the spread of COVID-19. 'The Sheriff's Office will continue to go after the criminals that are committing actual crimes. We will not be going after anyone gathering during the holidays', he wrote (FOX26 News 2020). His pronouncement, published on social media and followed by three similar statements from County Sheriffs in nearby Fresno and Stanislaus Counties, blamed the state's Democratic governor of taking advantage of the situation to abuse his power and impose lockdowns without adequate evidence. Governor Newsom's second reopening plan, issued in August 2020, was designed to address variation in coronavirus prevalence across counties. This was in response to the fact that census tracts with the worst measures of community wellbeing (education, income and health care access) accounted for 40 per cent of the state's COVID-19 cases (Largent et al. 2021). Newsom's Blueprint for a Safer Economy included an 'equity focus' that provided resources for San Joaquin Valley counties.

Despite the surge in cases in the region, many in the San Joaquin Valley shared the Merced County Sheriff's resistance to state-level mandates and fears about the economic fallout of lockdowns. The Sheriff likely reflected the opinion of many in the region when he stated, 'Nothing, nothing that they've come up with has ever come to fruition, and yet we're being killed slowly through our economic areas here especially in this county, and it's like it's going on deaf ears in Sacramento' (Sandrick 2020). Fears of economic devastation as small businesses closed their doors in rural towns combined with political conservatism and the ubiquitous effects of then President Trump's anti-immigrant rhetoric and policies to inform a city council declaration in Atwater, an agricultural town south of Merced. In June 2020 the city council passed Resolution 3148-20, declaring the city of Atwater 'a sanctuary for all businesses'.⁵ The cooptation of the phrase used in the context of creating safe living spaces for undocumented immigrants was strategic, particularly in a designated sanctuary state. The contradictions in the designation – in a town and region dependent upon immigrant labor – point to the complex economic, social and political machinations at play. In 2019 Atwater was ranked as the second most financially distressed city in the state, following Compton. In July 2020, the city had passed its first balanced budget in eight years. The resolution named local businesses as the catalysts for this recovery, noting that the pandemic closures had left them 'perilously on life support' (Bransen-Potts, 2020). The Merced County Sheriff is an Atwater resident.

Approach

At around the time the Merced County Sheriff made his pronouncement, our team had started working with a community-based organization serving farmworkers in the region, to both try to understand the impacts of the pandemic on their families and livelihoods and address informational and practical gaps in access to resources. Our work together took several forms, each developing out of ethnographic observations and the challenges people faced in completing what should have been straightforward Covid-related tasks.

A student working with our team, for example, observed an older Spanish-speaking couple in a drug store try to obtain the newly available COVID-19 vaccine. They were clearly in the age group prioritized at the time, and the drug store advertised available appointments. However, there was a sign at the pharmacy – in English – informing patrons that

they would need to scan the QR code on the sign and fill in the requested information on an online form on their smartphone. The older couple looked confused. When approached they asked why they couldn't just get the vaccine from the pharmacist. The student proceeded to help them fill out the information on her phone, but the appointment available was for the next day, requiring them to make an additional trip. In response to this and stories of people assuming they were not eligible for the vaccine because they did not have health insurance or did not hold legal immigration status, our team created a telephone help line staffed by students bilingual in English and Spanish, Punjabi or Hmong. As noted in the opening of this chapter, we worked with a local community-based organization to establish vaccine 'pop-ups' at the local flea market. This organization partnered with us in the creation of an 'I Test!' Instagram and Facebook campaign featuring local leaders. We conducted focus groups with Spanish-speaking families, in-depth longitudinal interviews with Hmong residents, and observed community events at Sikh temples. We also interviewed public health staff and *promotoras* about their experiences working through the pandemic. We conducted a population-based survey with 553 parents of children aged 0–18 years (English-, Spanish- and Punjabi-speakers) to gain insight into their decision-making around their children receiving the COVID-19 vaccine. After initial analysis, we conducted 20 interviews with parents in the same language groups to explore unclear trends in the survey results.

We draw on this broad experience to reflect on 'moments' in the pandemic in the San Joaquin Valley that illustrate the ways community-based organizations and their staff stepped in to fill gaps and meet needs that were not seen or deemed important by state and local government agencies. The invisibility of these needs is a legacy of the persistent structural racism and urbanism in the country's richest state.

The language of risk

Giggles erupted as Prem's phone was passed from hand to hand around the table, letting the TikTok video run. It depicted a young woman dressed as if she were a grandmother, shouting at another young woman and throwing a shoe at her head. The two characters were clearly Sikh, and the narrative was in Punjabi. It was an educational video that two students had created as part of their work with the Jakara Movement, a community-based organization that serves California Punjabi Sikhs, with a particular focus on providing leadership opportunities and ensuring

that young Punjabis learn about their heritage. Important for Prem, the group also focuses on gender equity, something she is particularly attuned to. The video was designed to comically address the importance of young people, as well as older adults, getting vaccinated. In it a granddaughter stands at the entryway of her house, while her grandmother sits in the adjacent living room. Her grandmother asks why the granddaughter would go out since they are under lockdown orders. As the granddaughter prepares to reply, the grandmother throws her shoe (*chappal*) at her (humorously, because having *chappals* thrown at you by elders is a common trope in the Punjabi community – usually accompanied by *chappal peni aa* ('you're about to get the *chappal*')). The granddaughter tells her grandmother that people can safely gather so long as they have their vaccine and that she is leaving to get her own vaccine. She then encourages her grandmother to do so as well. The fact that both characters are played by young people adds to the humor and playfulness in the video.

This is just one example of the creative ways the Jakara Movement used social media to communicate in Punjabi with the ever-changing information during the pandemic. Despite the high numbers of Punjabi Sikhs in California, little information about the pandemic, especially in the early phases, was available in languages other than English and Spanish.

Prem had gotten involved with the Jakara Movement COVID-19 response team mainly because she was concerned about her grandparents. They lived together in a multi-generational household in a neighborhood that had experienced a surge in infections, and she worried about the difficulty her grandparents experienced trying to understand what was happening, especially because there was little information in their language. She had been involved in health-related volunteerism previously – helping her younger sister to promote Narcan⁶ access in her high school's classrooms (another Jakara Movement effort) due to the common occurrence of fentanyl overdoses. Working to ensure relevant information was available to people like her grandparents in the midst of the pandemic enabled her to have a direct impact. She loved seeing how they shared information that she had brought to them with their friends at the *gurdwara* each week.

The Jakara Movement mobilized to help the large Punjabi food production workforce as well. Designated as essential workers in March 2020, many continued working throughout the early months of lockdown, incentivized by small salary raises and confused by changing information about masking and social distancing. Meat and poultry

production was already perilous and dangerous well before the onset of the pandemic, with an average of two amputations weekly from cubing machines, band saws and grinders (Wasley et al. 2018). Things worsened as supervisors sped up production lines to compensate for employees who were out sick. Once the virus started spreading within plants where workers stood shoulder to shoulder processing food, it was difficult to stop. The spread was exacerbated by the lack of PPE provided to workers; some were forced to pay for masks while others were given only two to reuse over the course of months (Philpott 2020; Perez-Lua, et al. 2023). Across the state, food and agricultural workers had a 39 per cent increased risk of dying during the pandemic, and rates increased to 59 per cent for Latinx food and agricultural workers (Chen et al. 2021).

The lack of safety and adequate protections in the poultry plant where many Punjabi worked came to a head in the summer of 2020, after a spate of outbreaks in regional food production facilities. In May 2020, for example, 174 employees of two frozen food plants in Tulare County were infected with COVID-19 (Sun-Gazette 2020). On 22 April a Hansford meat packing plant had reported 32 cases; the number had risen to 182 by mid-May. Another outbreak followed at a pistachio processing plant in Kern County, where workers reported being charged \$8 for each disposable mask (Kasler, Tobias and Bizjak 2020). On 1 September 2020, the Merced County Public Health Department forced the closure of the Foster Farm poultry plant in Livingston, a small town in the county of Merced, after 392 positive COVID-19 tests and nine employee deaths. The Health Department had undergone a number of personnel and leadership changes in the preceding years and had brought a local physician out of retirement to serve as the County Medical Officer during the pandemic. He visited the plant repeatedly and warned management multiple times that the plant would be shut down if it failed to make recommended changes to the work environment and break room to reduce interpersonal exposures and support recommended social distancing. The Health Department faced pressure to keep the Livingston Foster Farm's plant open, including a phone call from a federal official who argued that the plant 'must remain open because of Trump's executive order to keep meat-processing plants operational' (Maxmen 2021). Press releases detail the timeline; the health department requested these changes over a month before the first death occurred. Workers had reported they had been provided a \$1 raise at the beginning of the pandemic, but the raise was rescinded on 31 May 2020, just before this local outbreak began. The UFWA sued the Livingston plant in December 2020 on behalf of several employees due to

the company's failure 'to take the necessary safety precautions to prevent the spread of COVID-19' (Maxmen 2021).

In Fresno County, another Foster Farms poultry processing facility received different treatment. Following a Public Records Act request, the *Fresno Bee* reported 'that during the outbreak at the South Cherry Avenue plant that infected hundreds, health officials tipped off company executives about a Cal/OSHA (Occupational Safety and Health Administration) inspection, coordinated media talking points during the crisis, withheld information from the public and issued no corrective actions' (Tobias 2021). Unlike the Merced County Public Health Department, Fresno County Health Inspectors identified their role as 'ministerial' rather than regulatory. Five workers died in this outbreak.

Some argue that it should not be a surprise that these food production sites served as hot spots for the virus. Well before the pandemic, meat packing plants in the region had 'poor compliance' with health and safety standards. Nearly half of inspections in the state occur in the region, despite being home to only 13 per cent of the state's meat packing plants (Lin, Gutierrez and Chabria 2020). Outbreaks such as this were not only occurring in the San Joaquin Valley. Across the country up to 310,000 cases and 5,200 deaths were due to outbreaks starting in livestock plants that spread to surrounding communities (Saitone, Schaefer and Scheitrum 2021). There was little incentive for companies to make the necessary changes, as fines imposed for excessive outbreaks were minimal. Smithfield Farms, a pork production company, for example, received a fine of only \$13,393 for an outbreak in April 2020 that infected almost 1,300 workers and resulted in four deaths in Sioux Falls, South Dakota (Maxmen 2021).

Workers told family members and community organizers that inside the plants, most information on infection rates was provided in English, despite the fact that the majority of employees spoke Spanish, Punjabi or Hmong. Twenty per cent of Foster Farms workers are Punjabi. In support of these workers the Jakara Movement catalyzed bilingual students like Prem to inform workers of their rights. They used social media and set up information tables at regional *gurdwaras* to make sure that employees knew about SB95, the Senate Bill that offered workers 80 hours of supplemental paid sick leave between January and the end of September 2021. They interpreted at rapid testing sites, and organized vaccine clinics at *gurdwaras*. Jakara Movement staff canvased weekly in Punjabi neighborhoods in Fresno and Merced counties to promote upcoming vaccine clinics, to identify needs and to

provide support. In a few cases, Jakara staff organized transportation to vaccine clinics for elderly couples without anyone to drive them there. Staff and volunteers took advantage of the opportunity to talk to workers at the vaccine clinics, and handed out masks, gloves, face shields and hand sanitizer. In these conversations, workers described feeling unsafe approaching Human Resources representatives in their worksites, for fear of retaliation if they requested time off due to illness or recovery from receiving the COVID-19 vaccine; staff members were equipped with scripts that workers could use to safely approach their managers, and also staffed a bilingual call line for anyone seeking information on upcoming clinics or questions regarding resources. Jakara staff helped families of those who died in the plants to apply for benefits (Hall 2021).

While providing information about COVID-19 vaccination and worker's rights at a local *gurdwara*, Prem responded respectfully when she was questioned about her knowledge of Sikh history and 'tested' on her facility with the Punjabi language. She laughed as she described the older man approaching her table, assessing her responses before accepting the PPE she offered. 'It's not at all surprising', she said. 'Our elders are always testing us, especially us girls, to make sure we know our history'.

Farms and funerals

Vue⁷ looked slightly bewildered as he recounted his experiences providing logistical support to farmers in the early months of the pandemic, seeming to marvel that they made it through that time. Everyone was in a panic, he said, because the farmer's markets where they sold their produce had closed. They were afraid their crops would rot. He described how he turned to his boss – the two of them the only employees of their small community-based organization – and saw that he was also at a loss. Then he had an idea. What if he reached out to the churches who were supporting food banks and asked them to use the produce? That way the farmers could get paid (once he found a way to pay them, which he did through a small grant from a local non-profit organization), and the food would make it into the community. He would manage the distribution as long as the churches could give him the space. It ended up working, and once the city became aware of the program, it invested over \$500,000 to allow the program to expand.

This was followed by work with farmers and small businesses to help them through the processes of applying for Economic Injury Disaster

Loan and the Paycheck Protection Program funds, offered by the federal government. These were complicated application processes for English speakers, and more so for monolingual Hmong farmers, the population with whom Vue worked most closely. Hmong farmers account for over 900 small scale farms in the region (Thao et al. 2023). The majority rent their land and are subject to challenges related to disappearing water and the high cost of fertilizer and other chemicals. A number have been displaced from their land when it was sold to accommodate the massive warehouses needed for the growing ‘logistics industry’. Well before the pandemic, Hmong farmers struggled as persistent droughts dried up their water sources. It became common for many to spend all night on their plots of land, waking up every three hours to turn the water pump on for different rows of crops because the water pressure was too low to water them all simultaneously (Castillo 2016). As temperatures have increased with climate change, farmers water in the middle of the night to let the moisture seep into the ground, rather than letting it quickly evaporate under the hot sun. Despite these challenges, farmers kept their crops going and sold their yield at farmers’ markets across the state – until the onset of lockdown.

An additional challenge farmers faced during the pandemic was the Creek Fire. Started in September 2020, this fire ravaged the Sierra Mountains and continued through December. It destroyed over 850 structures and burned over 379,000 acres. Heavy winds fueled the fire and blew huge clouds of ash tens of thousands of feet into the air, creating a pyrocumulonimbus cloud that the *Fresno Bee* compared to the aftermath of an atomic explosion (Price 2020). The poor air quality stemming from the fire lasted over a month, which made the physical labor required to maintain fields and crops more difficult, especially while wearing masks on hot days. As Vue reflected, it felt like it was all ‘against you’.

Community-based organizations with long histories of serving Hmong and other Asian populations in the region (including Laotian, Vietnamese, Chinese) came together early in 2020 to ensure that families were connected to housing support in the form of rental assistance, funds to cover utility bills and food distribution. There were so many agencies collaborating on Zoom calls, Vue told us he couldn’t remember how many different community-based organizations were involved: ‘When I think through all of that, I don’t know how many agents I met anymore. It’s just a lot of people, a lot of different CBOs’. He continued his work supporting small farmers and businesses, and, when he took a position at a different community-based organization with a health focus, he

worked with these networks to bring mobile vaccination clinics to housing units. He also worked to ensure that messaging reached Hmong elders, who are mainly monolingual, via radio and Facebook.⁸ One thing he had not anticipated was how much time he would spend talking to people about funerals.

As deaths started to pile up in the Hmong community, how to honor and adequately guide the souls of the dead to their resting place became a challenge. Pre pandemic, a Hmong funeral in the United States would last from Friday to Monday, with the funeral home open 24 hours a day during that time to accommodate the ritual. As deaths increased from COVID-19, some families had to wait months to honor their dead. Eventually funerals were condensed from four days to one and were scheduled mid-week. This truncation undermined the time needed to allow the deceased to cross into their spiritual resting place; many believe elders return to their homes in Laos when they die. Vue told us:

We believe that if you don't do the full ritual, the person cannot go and be reborn. They need to go meet with the ancestors and to be reborn. So because the whole ritual had to be cut, you cut out everything, all the ritual is more like observation. You go in to observe the body.

Similarly, his coworker Ahn reflected on the difficulty posed by the funeral home shift in policy regarding food preparation.

A major change was that because a lot of these funeral homes didn't allow families to cook and serve food, a lot of the family members had to take time away from the funeral home service and prep food at home, package it and deliver it at the funeral home so everyone can eat. Because in our culture you have to be a good host, so you always provide food, snacks and whatnot. So, a lot of the time during funerals, people, family members would have to step away from the funeral home to prep food, package it and deliver it.

These ritualized ceremonies are also highly communal and well attended by family members and relatives from near and far. Pre-pandemic funerals included upwards of 500 participants. During the height of the COVID-19 pandemic, the City of Fresno implemented lockdown regulations that limited indoor gatherings to a maximum of 10 people. This had a significant impact on the number of family members and

relatives who were able to pay their final respects to those who had passed away. Vue found himself on the phone with people throughout the San Joaquin Valley, using his own experience of physical weakness and fever when he had COVID-19 to try to convince them not to attend a funeral, or if in the position of needing to host a funeral, keeping it small to avoid exposure. These were complicated conversations with deep implications for family wellness. Many family members and relatives were distressed as they could not pay their final respects to their loved ones. Additionally, failure to support the transition of the soul to the spirit world was unthinkable for many.

The intense work that Vue engaged in was exhausting. And he had two small children at home. He had started in non-profit work only a few years prior to the pandemic, when he found himself out of work and spending his time helping his mother harvest bitter melons on her farm. When describing his experience in community-based organizations, he smiled and said that

work in non-profits is the work of God. Not to get religious here but it really truly is because when you choose to work a nonprofit, you choose to make a difference and it's not so much about 'I' anymore. It's about we, the community.

But the pandemic was a different experience entirely. Vue shared his difficulty remembering what happened in the first two years:

I forget about 2020, unless I go back and talk about each month of what I did. Because I remember I was doing so much every month for that whole 2020 and 2021. And I usually combine when I think about the pandemic, I think about 2020 and 2021 as one year. Because it didn't feel like ... It felt like forever, but now looking back, it was very short.

Conclusions

The San Joaquin Valley and its residents have been historically neglected by the rest of the state, despite the essential role they play in food production for the entire country. The impacts of this long-term neglect were evident in the course of the pandemic as resources and policies lagged in their inclusion of and attention to the region. Pre-pandemic dismantling of the public health infrastructure, nationally as well as

within the state, meant that county health departments were ill equipped to respond rapidly as case counts rose. The trend of rural hospital closures across the country and lack of sufficient health providers in the region undermined the need to identify adequate beds for severe COVID-19 cases. The economic fallout of lockdown measures was experienced differently across the state as well. In a region beset by severe droughts, disappearing water sources, toxic air and a low median income, the ability of small businesses and farms to withstand months of closure was nil.

And yet, there were people and organizations that stepped in, that anticipated their communities' exclusion from English-only information networks and application processes. The loans that Vue helped small businesses apply for were fleeting and often allocated to large corporations rather than the small organizations they were intended to support (Quinn 2021), yet he and his staff spent hours cold calling to make sure people were aware of the opportunity. Outreach workers and volunteers like Prem balanced their concerns about their own exposures and the possibility of spread to their family members with the need to provide information about COVID-19 vaccination and workers' rights. Information about the senate bill that mandated paid sick leave for those exposed to COVID-19 in the workplace was disseminated in English and Spanish. If not for the work of the Jakara Movement, monolingual Punjabi poultry-production workers would have had no idea that they could stay home when sick. Fear of job loss due to sickness in low-income households was a reality that these organizations, staffed by the children of factory workers, understood well.

The structures of neglect that these organizations worked within and against remain in place. At the national level, OSHA's poor response across the country to outbreaks in food production facilities was fostered by the gutting of the organization in the prior decade. Reduced to the lowest number of inspectors since its founding in 1971, OSHA does not have the staffing needed to conduct adequate inspections (Lerner 2020). It failed to protect this essential yet vulnerable workforce. At the state level, funds have not poured in to rebuild public health and health care infrastructures in underserved areas. Instead, it seems a form of forgetting has taken hold. Despite the recognition of the need to invest in and strengthen community resources and public health infrastructure to address seeming intransigent disparities that put certain population groups at higher risk of infection and death repeated in news outlets in the first years of the pandemic, local and state governments seem to be settling into pre-pandemic priorities. Different from the collapsing of time, the difficulty of remembering what happened what year as

described by Vue, this form of forgetting is the kind that emerges as the unique privilege of the powerful, a ‘willed forgetfulness’ that enables cruelty (Nietzsche 1918).

As many have noted, disparities in health and wellbeing, in the value that certain lives are granted over others, pre-dated the pandemic, yet the pandemic revealed and aggravated them (Manderson, Wahlberg and Burke 2021). These health disparities serve as the physical expression of structural violence, a form of violence that corresponds to inequality in the distribution of power (Galtung 1969; Fassin 2021) as manifest in political, social and health institutions. Detailed throughout this chapter are examples of structural violence in the form of racism, neglect and forgetting. Relying on episodically funded and understaffed community-based organizations to manage communication to the state’s linguistically diverse population beyond those who speak English and Spanish was a form of neglect, a devaluing of those lives. Failing to provide adequate protections to those who continued to work outside the home in food production facilities that kept the rest of the country in supply of meat and vegetables is a violent act. The global response to the pandemic has been charged as ‘the advent of biolegitimacy’, the recognition of life as supreme value, as evidenced in the willingness of governments around the world to shut down and sacrifice economic growth to save lives. The reality of the ways lives – plural – of those living in places like the San Joaquin Valley are treated ‘is a different beast’, however (Fassin 2021, 162, 165). The ‘moments’ of support and challenge that structure this chapter speak to this tension. They are points of interpersonal engagement and caring based in a mutual understanding and respect – a valuing of lives (Butler 2020) and a refusal to accept loss.⁹

Notes

- 1 The *promotoras* were referring to the need, at the time, to provide proof of vaccination to be allowed into dances.
- 2 On 28 September 2016, Governor Jerry Brown signed Assembly Bill (AB) 2792, known as the Transparent Review of Unjust Transfers and Holds (TRUTH) Act, into law. The Act imposes obligations on California law enforcement if they notify the Federal Immigration and Customs Enforcement (ICE) Agency of an inmate’s upcoming date and time of release. On 1 January 2014, the California TRUST Act that prohibits a law enforcement official from detaining an individual on the basis of an ICE hold after that individual becomes eligible for release from custody under state law became law. Accessed 21 October 2024. <https://cpoa.org/truth-act-trust-act-ice-detainers-california-law-enforcement/>.
- 3 Medi-Cal, California’s Medicaid program, is a public insurance health care program that provides health care services for low-income individuals and families who meet defined eligibility requirements.
- 4 This \$52 million would come from the \$499 million the state received from the US CDC.

- 5 Accessed 21 October 2024. <https://www.atwater.org/wp-content/uploads/2020/05/Resolution-3148-20.pdf>.
- 6 Narcan is the brand name for the nasal dose of the pharmaceutical naloxone, a medication used to reverse opioid overdose.
- 7 Pseudonym to protect participant's anonymity.
- 8 Accessed 21 October 2024. <https://www.facebook.com/HmongAE/posts/message-from-pao-yang-ceo-of-the-fresno-center-regarding-the-covid-19-outbreaktf/2912298002125606/>.
- 9 We would like to thank the *promotoras*, community health workers and community-based organization staff that worked so hard to ensure that their communities and families had access to all available resources throughout the course of the COVID-19 pandemic. We would also like to acknowledge the contributions that Andrea Lopez, Kesia Garibay, Luis Garay, Elizabeth Salvador Trinidad and Nhi Le made to the research and community engagement of the Health Equity Research Group at the University of California, Merced that informs this chapter. Portions of the research on which this chapter is based was funded by National Institutes of Health funded grants NIH/NHLBI - NIH/NHLBI CEAL grant #21-312-0217571-66106L, NIH/NIDA3R01DA036749-05S1; 3R01DA036749-05S2.

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Vaccine trials and the politics of extraction

Lenore Manderson and Susan Levine

COVID-19 researchers required massive financial and human investment to find a SARS-CoV-2 vaccine. But while the speed of response and the global scope of collaboration to develop vaccines were exceptional, it was never unimaginable: the work built on an already highly industrialized medical complex. In South Africa, involvement in the Phase 3 trial, known as the ENSEMBLE trial, was predicated on the need for an African arm to the study to test for different variants of infection and, arguably, because the single-dose vaccine was developed with such countries and populations in mind (Janssen Vaccines & Prevention B.V. 2020). The Johnson & Johnson (J&J) vaccine was the first authorized vaccine to require one dose instead of two, and it could be stored at regular refrigerator temperatures. These aspects made the vaccine appealing in resource-poor settings. Lead scientists of the J&J trial, including Dr. Katherine Gill and the Director of the Desmond Tutu Health Foundation (DTHF), Professor Linda-Gail Bekker, were hopeful that the trialist vaccine would prove a reliable alternative to more expensive vaccine options that required two doses and colder storage. Population recruitment and retention are central to vaccine trials at all levels, and a core component of infrastructure is an accessible population. To effect this in South Africa, established TB and HIV scientists were deployed to work on the J&J vaccine. In this chapter, we consider how participants were recruited and retained, how monitoring supported their engagement, and how unblinding returned them to endemic states of exclusion and marginalization. In the process, we highlight the chronicities of power and the inequalities of its distribution.

In his novel *The Constant Gardener*, John Le Carré (2001) writes of the unscrupulousness of global corporations and individuals as

they suppress adverse events during the trial of a new (fictitious) anti-tuberculosis drug. The novel and the film of the same title center on the murders of the two protagonists seeking to expose the deaths and halt the trial. The mystery is set in the context of an industry concerned with profit as much as with vaccine efficacy and effectiveness, and with how global capitalism and colonial politics are enmeshed. These themes re-emerged as trials for vaccines against SARS-CoV-2 were set in place in different economic settings, even as a politics of urgency overshadowed concerns regarding the chronicity of neo-colonialism shaping science practice and the ethics of working in African settings (Agoro 2020; Schipper 2020). Research infrastructure, health care resources, funding and ethics overview processes all influence where trials can be conducted. But population recruitment is central to the conduct of a trial. Below, we describe the social infrastructure that facilitated this in South Africa; in doing so, we revisit old ground set in Africa about the extractive, neocolonial and racist overtones of vaccine trials.

Clinical trials everywhere are designed to recruit willing participants to donate their time and bodies, while ensuring that participants understand the inherent risks in the trial of getting sick or acquiring lifelong affliction from iatrogenic aspects of previously untested chemicals. Trials now routinely specify the need for racial, ethnic and gender diversity, so to ensure equal access to experimental treatments and to establish evidence of the effectiveness and efficacy of treatment across groups (see Joseph and Dohan 2012). While the emphasis in protocol is on inclusion criteria, those running the trials must avoid coercion of potential participants and find ways to minimize risk through treatment protocols. They must also be able to intervene rapidly at the first indication of adverse reactions to the drug, or act with speed with the development of illness either because the drug was ineffective or because the patient was given a placebo. The ideal is that people will participate through altruism not pecuniary gain – they participate in the trial for the public good – and, accordingly, any compensation is intended to cover immediate, modest out-of-pocket expenses. But this is not so simple, as an examination of the relationships between pharmaceutical companies, government scientists and trial participants suggest. In South Africa, in the study setting that we describe, the willingness of people to participate in the clinical trial was facilitated for the most part by population and household levels of vulnerability and poverty, extreme levels of unemployment, and the impact of this on care for immediate and extended family (Cammack 2020).

Deplorable economic inequalities continue to inform everyday life in black townships and rural settings across South Africa. Without underplaying this, here we trouble anthropological and historical narratives that offer reductionist colonial readings of bodily extraction in clinical trials. While there can be no doubt that bodily material, which we refer to as body capital, is drawn primarily from those who are most vulnerable to economic and social exploitation, we frame a specific trial site in the Western Cape within an older anthropological idea that accounts for the agential force of gift exchange, reciprocity and medical science as a stage for social good. We argue that the powerful ethnographic work of medical anthropologists who describe the uneven flow of body parts from brown bodies to white bodies, from southern bodies to northern bodies and from poor bodies to wealthy bodies, sheds light on hidden histories of organ harvesting (Cohen 1999; Scheper-Hughes 2007). It is possible and accurate to situate Covid science in South Africa within this critical medical anthropology framework. But in doing so, we erase the everyday forms of pride among the volunteer trialists, and the immense forms of care and energy provided by clinical staff on the frontlines of the Covid pandemic. In this chapter, we offer an abbreviated history of an intimate nature, in which we argue that reliable access to bodies and the politics of injection and extraction exist in parallel with strong traces of reciprocal social relations, including material benefits, kindness, medical care, citizen science and scientific discovery. The use of the term extraction, in this case, is literal and figurative: in the first instance, drawing attention to the physical extraction of blood and saliva for regular testing during the trial period and to the extractive economy of the trial itself, which depends on people's time, energy and adherence to the clinical protocols that are detailed in the chapter. These tensions echo the enduring gift of Marcel Mauss (1925), and here we imagine how the J&J trials were rooted in complex forms of gift exchange and reciprocity, what Lochlann Jain refers to as a "Maussian gift" (2013: 14). Jain's meaning is that cancer is entangled in the full depths of social worlds and processes of living and dying; it is everything all at once. So too with Covid entanglements.

In this chapter, we bring this entangled set of social relationships to the fore about the conduct of one clinical trial in South Africa, a node of a large multinational trial to test the efficacy and safety of the single shot J&J (Johnson & Johnson) vaccine for COVID-19. The trial was referred to as ENSEMBLE, so gesturing to the multiple partners and participants worldwide that allowed the work. The trial

was hosted by the Desmond Tutu Health Foundation and HIV/AIDS clinic in Masiphumele Township, which offers maternal care, HIV/AIDS testing and counselling while also housing clinical trials for HIV/AIDS and TB. For many people – mostly women – the offer from the research scientists to clinical trial participants of material and medical support ensured adequate numbers of trialists. Susan Levine participated in the double-blind trial for its 24-month duration, contracted COVID-19 twice in this period, and upon the unblinding phase of the trial when subjects and scientists learned whether placebo or vaccine had been injected, found that she had received the placebo. Given the urgency of the trial during the global pandemic, ethical clearance both for the trial itself and for our fieldwork was fast tracked by the Faculty of Health Sciences at The University of Cape Town (UCT). In addition to the fieldwork, we draw on our sustained involvement in Covid research and policy over four years (2020–2024). This includes our engagement as anthropological experts in media outreach, community education and analysis and report writing for government (Manderson et al. 2023), and through her involvement as a trial participant, Susan Levine’s interactions with medical research scientists and clinical staff; we draw too on her direct observation of provider–patient and patient–patient interactions, and discussions with trial participants. Over this period, we also continuously drew on and wrote about the pandemic: much data were and are publicly available. Our ongoing analysis draws on anthropological theory that helps us to make sense of history in the making (for example, Levine and Manderson 2021, 2023, forthcoming; Manderson and Levine 2020a, 2020b, 2021). For many participants, the clinic was already a familiar and hospitable space, notable for its decorative murals of Desmond Tutu, the former Archbishop of South Africa and proponent of HIV/AIDS science. The clinic is surrounded by manicured gardens, with sculptures and a central water fountain, and has generous amounts of space for gatherings and workshops. During Susan Levine’s time as a trial participant, she noted the effort that nurses, clinical staff and scientists made to build a sense of community solidarity. With the levels of fear surrounding the pandemic and the saturation of the news with reports of COVID deaths globally, participation in this clinical trial fostered a distinct sense of belonging to a collective actively contributing to the advancement of medical knowledge and the potential development of a COVID-19 vaccine. COVID-19 reactivated older solidarities forged by the national struggle to support HIV science, the stories of which are well documented by scholars Steven Epstein (1996) and Steven Robins (2008) among others.

The research setting: The Desmond Tutu Health Foundation

The Desmond Tutu Health Foundation (DTHF) was founded in the early 1990s as the HIV Research Unit at Somerset Hospital in Cape Town, under the leadership of Professor Robin Wood, to raise awareness about HIV and to provide the first anti-retroviral therapy for those living with HIV. In 2003, The Desmond Tutu Tuberculosis Centre (DTTC) was established at Stellenbosch University in response to the high rates of TB in the Western Cape, which were compounded by HIV. Desmond Tutu had been Archbishop of Johannesburg and then Cape Town, and was a deeply respected activist against apartheid and Nobel Peace Laureate. He became patron of both HIV and TB centers, so enabling its scientists to draw on a Christian ethos of goodwill and the specific reverence afforded him personally. Reflecting and capitalizing on his patronage, the center was named the Desmond Tutu HIV Centre in 2005, the year following the move of the DTHF to its present location at UCT under the leadership of Professor Linda-Gail Bekker, as director of DTHF and the center. She is a public intellectual and vocal spokesperson for LGBTQ health care and an activist for free access to ARV treatment and HIV care in South Africa.

DTHF is notable for bridging cutting-edge academic research with community development programs and collaborates primarily with those in under-resourced communities who struggle with access to medical interventions. The center underscores the prevention and treatment of HIV and related infections and DTHF researchers are widely respected for embracing critical perspectives from public health, the health humanities and medical anthropology. While the center is based at the Tygerberg Hospital, multiple clinics enable community engagement and education, testing and treating community members, and so provide the capacity and credibility to participate in the trial. Clinical trials in this politically progressive and community-based foundation are informed by an ethos of care rather than colonial logics, even as the meta context of South Africa is class, race and gender inequality. Indeed, who lives and who dies from infectious disease on the continent is informed by a necropolitics of scale (Mbembe 2003, 2019).

Masiphumelele is one of the under-resourced areas in the Western Cape where people are at high risk of HIV infection, and one of several similarly poor areas where DTHF established its clinical research site. With the cooperation of community leaders, clinical staff from DTHF work to realize the center's mission to provide opportunities for under-resourced residents to assist in research studies, including 'a range of

HIV prevention modalities, vaccine candidates, treatment delivery and adherence, clinical trials, ground breaking new drugs, and innovative technologies to address tuberculosis transmission' (DTHF 2023). Framed as opportunity rather than exploitation or extraction of vulnerable people, our challenge in this chapter is to traverse the contours of community activism, citizen science, gift exchange, science and historical forms of chronicity, to attend to whose bodies are rendered up for clinical medical science.

Masiphumelele is in the south peninsula of Cape Town, not far from the dramatic coastal landmark of Cape Point. A pioneer in HIV prevention, adolescent and LGBTQ research, the research site is recognized globally for its role in conducting clinical trials and epidemiological research, for more than 15 years. The primary urgency of this HIV research, as explained to Susan by Masiphumelele Director Dr. Katherine Gill, is that:

A staggering 1 in 4 adults living in the Masiphumelele township is HIV positive, and the number of new infections continue to rise year after year; most of those infected are women. The recently urbanized, overcrowded and under-served township is representative of many peri-urban communities in South Africa that are challenged by infection and disease. The Masiphumelele Research Site aims to understand and ultimately control the TB and HIV epidemic in the area by gathering data and researching HIV prevention methods. The site is a Division of AIDS-accredited center for HIV prevention studies, including microbicides, pre-exposure prophylaxis (PrEP) and vaccines (Interview, December 2020).

COVID-19 arrived at an already pandemic-saturated country. Its impact has deepened economic precarity, intensified the syndemic burden and derailed, for a time, core HIV/TB science.

Seeing both sides

In the context of the politics of the implementation of the trial and its impact on the program of the collaborating scientists (Levine and Manderson 2023, forthcoming), we argue that the production of clinical knowledge drew on a material archive of identifiable symptoms that make up the immensely complex set of biomarkers. Conscribed personnel working in global data centers housed in India, among other countries, profiled and indexed legions of data feeds from clinical

trials all over the world. These datasets of symptoms ranged from the technical aspects of illness identification including fever, bloodwork, elevated or irregular heart rate and reduced oxygen saturation to the more interpretive aspects of fatigue, changes in appetite and disturbed quality of sleep, among other variables sought after in clinical trials. The micro detailing of bodily responses to COVID, and to the placebo or the vaccine that was administered in this double-blinded clinical trial, required body capital. The success of the ENSEMBLE trial relied on people who dedicated time to keeping careful records about their health and afflictions over an intense and deeply troubling two-year period in world history. Participants' willingness to contribute such data enabled the swift passage of confirming the protective success of the J&J vaccine against the most severe risks of COVID infection.

Viewing the chronicity of body capital in African settings requires that we situate clinical trials within the deep history of colonialism, coloniality, colonial medicine and the racist overtones of western science. We ask, what is meant by willingness? Under what forms of economic need does willingness, altruism or a sense of national duty emerge? The gift of the body, and of time, reminds us of Marx's denunciation of capitalism's most pernicious aspect, that of alienating the body from the natural rhythms of life by turning embodied life into an object of a particular kind that can be sold and exchanged (Marx 1844). The 'thingification' (Césaire 1955/2000) of the human is striking in trial logics, but when we focus simultaneously on expressions of belonging, pride and commitment to the clinical endeavor, a rather more complex picture emerges. Participants were paid for the blood that they donated, for the pain of enduring swabs up the nose and for the saliva taken and tested for antibodies. They were also paid in cash and in kind for keeping detailed logs about their weekly bodily responses to the placebo, vaccine or, in some cases, to their COVID infection. In return they received R350 per visit, a cell phone to keep biweekly health records and transmit these records to the data center in India, assurance of medical care in the case of sickness, an oximeter, a fancy thermometer and the opportunity to belong to a global community of trialists. For the scientists and clinical staff, the gift of these frontline trialists was the reward of confirming the efficacy of the J&J vaccine to flatten the curve in populations. The uneven nature of this exchange does not take the form of negative reciprocity (Narotzky and Moreno 2002), as no harm was intended for trialists, but it does signal the need to chart rather carefully the uneven nature of the exchange itself, and to link our study with the chronicity of colonial medicine as it emerged across Africa. Hence our attention to the

complex interplay of excluding and integrating local populations who were displaced, enslaved or recruited into colonial projects.

Colonial chronicity in vaccine science

Vaccines were increasingly central to public health from the early twentieth century, although variolation against smallpox, using arm-to-arm transfer largely with children, had been introduced in colonies and imperial centers in the previous century (Manderson 1996, 46–7). The success of this approach presaged the development and mass administration of vaccines to infants and small children against various prevalent illnesses – tetanus, diphtheria, measles, rubella, mumps, polio – as the vaccines (DTP, MMR, IPV) were developed.

In British colonies, all kinds of public health interventions were rolled out soon after their introduction in Britain. Discoveries related to the biology of illness and diseases in microbiology, parasitology and other fields from the second half of the nineteenth century led to various methods of prevention and control. Water, sanitation and food safety regulations reduced the transmission of water-related diseases including cholera and typhoid; building regulations reduced tuberculosis transmission; environmental measures aimed to reduce insect breeding sites (Vaughan 1991; Manderson 1996). These and similar interventions to prevent transmission and reduce the incidence and severity of infection and disease, and to ensure survival to adulthood, were largely determined by the growing need for a healthy labor force in both colonial centers and their peripheries. For example, antenatal and postnatal care, clinic and hospital-based deliveries and infant health check-ups were introduced to reduce maternal and infant mortality, to increase the likelihood of infants reaching maturity and so to join the labor force (Davin 1978; Manderson 1996; Ram and Jolly 1998). In British Malaya, while people living on the periphery of the colonial economy were largely ignored, interventions to reduce malaria among rubber tappers and beri-beri among tin miners were rolled out explicitly because it was cheaper to prevent serious disease and death than to continually recruit laborers from southern India and China (Manderson 1996).

But who benefited varied according to the structure of colonial rule and the relationship between colonists and local populations. The discrepant distribution of clinical services in urban and rural areas, for example, reflected a primary motivation to provide care to colonial administrators, the military and the entrepreneurs and merchants with

whom they interacted most. In the latter part of the nineteenth century, for example, the registration of women as prostitutes, and their regular compulsory physical inspections and confinement if infected to Lock Hospitals, were intended to protect colonial troops and others. Women always, through twisted logic, were framed as vectors (Manderson 1996).

While the transmission of many potential lethal infections was interrupted with vaccines, vaccine development was elusive for most common infections with high mortality rates. The control of diarrheal diseases and acute respiratory infections through immunization rather than social structural and infrastructural measures has largely failed because these potentially fatal conditions are caused by multiple pathogens adept at genetic changes. HIV, TB and malaria also all proved inure to vaccination despite decades of research to this end. One of the unanticipated outcomes of the COVID-19 ENSEMBLE trial was hopefulness for an HIV vaccine. Set against over 35 years of a continuing history to develop an HIV vaccine (Esparza 2013), and the 60-year history of malaria research (El-Moamly and El-Sweify 2023), virologists were stupefied by the pace of work that saw COVID vaccines available in less than a year.

Most drugs ready for clinical trial are still developed in high income, high technology countries, with population trials taking place in a wide range of countries and conditions. Vast numbers of trials of drugs are underway at any given time. Nair and colleagues (2013) maintain that only around 1 per cent of clinical trials are conducted in North Africa and the Middle East, largely in Egypt, despite the perceived value of populations in this region for research on non-communicable diseases and rare genetic disorders. Few vaccine trials are conducted on the continent of Africa relative to the rest of the world, due to limited local expertise and resources, and lack of perceived markets for the drugs thus developed (Taylor-Robinson et al. 2021; Wiysonge et al. 2022). South Africa is an exception, and all major pharmaceutical companies are registered in Sub-Saharan Africa, so enabling the conduct of trials. In 2018/2019, prior to COVID-19 research programs, 377 clinical trials were registered in the region, predominantly for malaria and HIV (Ndwandwe et al. 2020).

While researchers regularly draw attention to persistent inequalities between global north and south research institutions, and emphasize the importance of redressing these (Nsanzimana et al. 2022), clinical trial funding and research capacity often maintain power imbalances. Clinical trials bring financial contributions to science infrastructure, funds to support the ongoing costs of consumables and new employment and

staff training opportunities. Many of these opportunities, once realized in terms of grants awarded, publications in ranked journals and citations, translate into revenue flows, depending on government funding models for the institutions where academic scientists are based. As Okwaro and Geissler (2015) describe, African scientists draw on multiple strategies to maximize collaborations to retain a qualified but flexible, non-permanent workforce and maintain prospective research populations to attract transnational clinical trials. This paid off as COVID-19 vaccine trials rolled out.

Researchers advocate that trials conducted on the continent are essential to ensure the effectiveness and efficacy of candidate vaccines in different settings, and to increase vaccines that are ‘tailor-made for the African context ... to find African solutions to the current infectious disease threats faced by the continent’ (Ndwandwe et al. 2020, 972, 977). This need for local solutions relates to the efficacy of different vaccines against diverse circulating strains of and drifts in viruses, the merits of one-off shots rather than sequential vaccinations where access to populations is problematic, differences in the site for and delivery of vaccines (as described by Sobia and Archary 2021) and the cost, stability and shelf life of vaccines (as for all pharmaceuticals). The availability and pliability of participant populations is rarely made explicit.

The perceived need for and advantages of trials on the continent reached a low point in 2020, at the beginning of the COVID-19 pandemic, before any candidate vaccine had been developed. Two French doctors discussed on television the ideal conditions to conduct COVID-19 vaccine trials in African countries, where there were ‘no masks, no treatment, no resuscitation’.¹ The debate caused public outrage and a forced apology. It was, Hellman and colleagues (2020) argued, a blatant example of moral imperialism and persistent colonialist thinking, including in terms of skepticism of the abilities of scientists in the Global South to undertake their own organized clinical studies (see also Egharevba and Atkinson 2016; Taylor-Robinson et al. 2021).

Vaccine development and clinical trials against COVID-19 were exceptional, not only in the speed of response and global commitment to rapidly develop and release effective vaccines but also in terms of the extensiveness of science collaboration around the world. With the goals of Operation Warp Speed as impetus (Levine and Manderson 2023), industries, governments and scientists worked together to bring in sufficient diverse study sites and willing populations. Spikes in stock markets at the start of phase III trials for vaccine candidates reflected the pace at which science and industry partners were working to contain the pandemic and restore economic life (while stimulating global pharma)

(Chan et al. 2022; Vural et al. 2023). In 2022, Wiysonge and colleagues (2022) identified 1,453 COVID-19 vaccine trials registered on the WHO International Clinical Trials Registry Platform. Of these, 108 trials were in African settings, including 90 trials evaluating candidate COVID-19 vaccines, 11 assessing vaccines already effective for other infections and 7 evaluating social and behavioral interventions to improve vaccination coverage. Over 50 per cent were being conducted in South Africa. This included the African arm of the ENSEMBLE trial, as described above.

While clinical research brings value to researchers, institutions, governments and economies, it also brings direct and indirect value to different publics. This includes studies with systems benefits: to establish suitable and effective ways to deliver drugs in different country contexts, while addressing diseases that are prevalent in poor populations (hence the important work of both TDR and DNDi²). At the same time, the trials bring immediate benefits, including employment for field staff in settings of high unemployment and underemployment. Trials also provide free health care for participants in settings where, usually, services are sparse and care perfunctory, despite that these benefits are temporary (that is, they cease when the study concludes) (Mabunda 2001; MacPhail et al. 2012).

Community members as citizen scientists

The Constant Gardener, John Le Carré's book, was based in part on the clinical trial of the antibiotic trovafloxacin (Trovan), conducted by Pfizer in 1996 in Kano, northern Nigeria, during an epidemic of meningococcal meningitis. Unreported side effects of the drug, including acute liver injury and deaths, were simply treated as inconvenient and unfortunate events to prove the effectiveness of the drug (Lenzer 2006). As the character Ham (Arthur Hammond) reflects in the film of the novel, 'there are no murders in Africa. Only regrettable deaths. And from those deaths we derive the benefits of civilization, benefits we can afford so easily ... because those lives were bought so cheaply' (Masemola and Makoe 2014; see also McGowan 2007).³

Outside the fictional and cinematic world, other trials, more recently, have continued to breach ethics requirements, including lack of transparency regarding the research and its risks; consent not always voluntary and informed; and difficulty in accessing financial compensation for physical harm because of a trial (Wemos 2017). There has been continuing concern about people's ability to comprehend clinical trials – routinely framed as 'low research literacy' – and their capacity to resist

pressure to participate. Dixon (2012) argues that in clinical research on tuberculosis, researchers and research participants interacted in ways that extended well beyond that specified in the protocol. In contrast, Akrong and colleagues (2019) argue that choices about participation in trials are made by people in the context of their experiences. Even when consent is informed, participants often agree because participation in a trial is a mechanism to access health care that is otherwise unavailable, of poor quality or unaffordable. Risk assessment requires that potential participants weigh up an intricate mix of biological, economic and social variables (Wassenaar and Bardorf 2007), and both poverty and the usual lack of access to services at community, household and individual levels are powerful motivators that frequently tip the balance in favor of participation in a trial. For example, Tengbeh and colleagues (2016; see also Richardson et al. 2016) highlight the pragmatic factors that influenced people to participate in scientific research during the first year of an Ebola vaccine trial in Sierra Leone, including specifically the availability and accessibility of health services.

Montgomery and Pool (2017) challenge the appropriateness of the idea of ‘community’ about clinical trials, as singular and static, and instead argue for deploying the idea of publics as multiple and emergent. In suggesting a conceptual shift from ‘trial community’ to ‘experimental publics’, using a case study of an HIV prevention trial, they emphasize that ‘experimental publics are situated at the intersection of various forms of inclusion and exclusion, both locally and globally’ (Montgomery and Pool 2017, 50). The site that they describe in Southern Province, Zambia, was set up specifically for the clinical trial, involving women (and explicitly not men) who had not previously been involved in research. The trial involved considerable interaction with women, including providing them with microbicidal gels, undertaking regular examinations and information gathering; mistrust and opposition were widespread, particularly from men. Engagement ceased with the conclusion of the trial. Because of the consequential controversies and occasional violence (of men towards women partners), Montgomery and Pool (2017, 60) concluded that researchers ‘should create long-term forms of participation in science, which transcend both the instrumental goals and the individual timelines of specific trials’.

In meeting the need for genuine informed consent in the context of COVID-19-related trials, Folayan and colleagues (2021) advocate for stakeholder engagement involving people from very different settings and standpoints to develop and implement policies to minimize trial-related physical, psychological, financial and/or social harms (see also

Ordóñez et al. 2023). Trust is developed through personal interactions – hence the importance of the everyday links between the outreach work of those employed in a trial and trial participants. Drawing on their work on developing prevention and treatment strategies for Ebola in Liberia, Kagan and colleagues (2021) see community outreach and engagement as critical in establishing trust.

Established institutions bring to research studies their long-established relations of trust with the communities in which they are embedded. In The Gambia, Fairhead and colleagues (2006) described parents who had long-term experience with the research institution, and their decision-making to enroll their child in a pneumococcal vaccine trial was largely shaped by the perceived benefits of their child's access to free medical care against other more distant benefits and perceived costs and risks. In South Africa, with unblinding and the conclusion of the ENSEMBLE study, participant populations returned to endemic states of exclusion and marginalization. However, because they were already part of a study community linked to the Desmond Tutu Clinic, they were and are always a ready population for drug trials.

The depth of unquestioned inequalities mostly prevents other ways of regarding individual stories on the ground, and yet part of the decolonial challenge in anthropology is to work against the narrow depiction of people as colonial subjects only and to name the forces of power that shaped, and continue to shape, everyday forms of agency, however entangled and overdetermined (Spivak 1988). This includes, for instance, how active health education, and the sharing of scientific knowledge about the technical aspects of the trial, created the space – however narrow – for what has come to be called 'citizen science'. Human dignity, as described by Fuh (2020), took shape in a unique historical moment with the formation of new publics, socialities and convivial forms of gifting and reciprocity (Nyamnjoh 2017). Reducing clinical trial participation to economic exchange, without including the range of convivial relations evident in the everyday fabric of the trial, leads to the erasure of human dignity and fails to acknowledge that local participants from Masiphumelele contributed in crucial ways to evaluating the safety and effectiveness of the trial vaccine.

The gift of knowledge

The Gift, written by Marcel Mauss and first published in 1925, explores the social and cultural implications of gift-giving and reciprocal exchange.

Analyzing a clinical trial setting using this framework opens corridors for thinking critically about the nature of reciprocity and patriation in clinical trials in an African setting. However uneven, participation in the clinical trial can be seen as a form of gift exchange between the researchers and the participants.

Mauss (1925) illustrates that the circulation of goods as gifts reinforces mutual social and material reciprocity. Gift-giving symbolically acknowledges the social relationships that underpin exchange and maintain their to-and-fro. Bodies, materials and knowledge all circulate. In the ENSEMBLE trial, as described above, people contributed their blood, saliva and daily bodily metrics including temperature, pulse and oxygen saturation. They kept diaries and answered lists of questions relating to sleep, fatigue, overall wellness or ailments. The questions were lengthy and needed to be answered on a biweekly basis. Trial participants welcomed fieldworkers into their homes and traveled to the research clinic regularly. All this effort was in exchange for medical care during the trial, the technologies that enabled them to collect their metrics and communicate with the scientists, as explained, and financial compensation for direct costs including clinical visits, airtime to transmit data and contact local trial nurses if needed, and the costs of their participation in training in the methods and purpose of the trial. These activities nurtured in participants a sense of care and engagement. They were covered in terms of their health – they were usually not – but they also enjoyed being part of a novel experiment that would flow on. Their sense of participation in the context of fear of infection, with their ‘Desmond Tutu Clinic’ T-shirts, their cell phones and oximeter, as well as the workshops that they attended, all contributed to ‘being there’ at the right place and time and participating in an historic global project. The logos, the training sessions and the technologies of participation helped create a sense of connection, belonging and community for participants, bolstering their engagement in the moral cause of the trial, at a time when South Africa (as elsewhere) was saturated with fear of infection, hospitalizations and death.

We can always argue that there are multiple, ongoing ways to think through engagement and to find some equilibrium through the give-and-take of field research. But we also need to see how the scale still tips because of chronic inequalities. Geissler (2011), drawing on Kenyan ethnographic research, notes how ‘reimbursement for transport’ masks the value to recipients of money given to them, and in doing so, masks the ‘discrepancy between bioethical discourse and materialities of survival’ (45); he argues that the rhetoric around gifting ideology obscures the

attraction of compensation in encouraging people to make available their body capital and time for research. Further, the needs of participants often far exceed those explicitly acknowledged by global economic funding for trials, though South African scientists are acutely aware of the political economy of class, race and gender after apartheid. Milford and colleagues (2021), for instance, describe how, in a trial on contraceptive options and HIV outcomes, although some people used compensation to buy luxury items and takeaway foods, others used the money to supplement income and cover basic living costs. This surely featured in the COVID-19 trials, as food and other household living costs escalated and income-generating opportunities plummeted (Khambule 2022). Further, the time given by those participating in trials is never measured or adequately compensated, since participating publics are often unemployed or survive on intermittent sessional work or are imagined as ‘doing nothing’. During the pandemic, women participating in the trial also had to manage precarious employment, household work, food preparation and the care of children and other householders, including elders, neighbors and friends; often, too, they needed to care for others infected with COVID-19 (Saloshni and Nithiseelan 2022). The emotional work and labor implicated in these multiple tasks were largely ignored and silenced by those designing and funding the field trials. They were not lost on frontline clinicians conducting trials, however, for their own lives were saturated with the realities of structural violence in South Africa.

Reciprocity in participation

Dwelling on the everyday forms of body capital at play in the ENSEMBLE trial, we argue that resident participation can be seen as a distinct form of gift exchange. Signing the informed consent document, which was discussed in detail with sisters from the Desmond Tutu Clinic, meant that all consenting adults were obligated to receive an injection with either the trial vaccine or a placebo. Participants would learn only during the unblinding phase of the trial whether they received the J&J vaccine trialist or the placebo (Levine and Manderson 2023), and over the 24-month trial period, some would develop COVID-19. Fortunately, nobody passed away from the virus during the trial period; given the high rates of severe morbidity and mortality in South Africa, this aspect alone suggests that built into the trial itself, was the gift – or promise – of life. As one participant said, ‘I did not enrol for the money but for the gift of life. I was so afraid of dying in my community that I would have

done anything to get onto that trial, like sitting for hours and waiting for my trial number'. From informal discussions with participants, most regarded their work as a unique contribution to virological science at the height of the COVID-19 global pandemic, akin perhaps, to giving a gift to society; this was evident in informal discussions and interactions with staff; it reflected, among other things, the heightened media cover of the pandemic and the vaccine trial, and the high level of Covid-literacy that this produced. The trialists' emphasis on the gift of life suggests the inherent tension in clinical trial recruitment. Enlisted trialists regarded the trial as an opportunity for access to life-saving treatment, but they were in the trial phase, which was explicitly experimental, not therapeutic. The caveat to this experiment is that all trialists were informed from the start that they would all be given the real J&J injection and six-month booster after the unblinding phase of the trial (assuming that the trial was successful). Susan Levine was one of the trialists who received the placebo, and within 30 minutes of learning this she was injected with the approved J&J candidate.

In enlisting in the trial, participants were assured by a caring team of nurses, some of whom came out of retirement to join the race for a vaccine, and were assured that all measures would be taken to provide high-quality medical care for the duration of the trial. Altruism and the gift of care were certainly entangled with the politics of race and poverty, and of course, the uneven roles of science, body capital and the chronicity of whose bodies appear on the frontlines. Participants could not have afforded the costs of private medical care, let alone paid for the style of home visits that were made to ensure the isolation of COVID-19-positive participants. After entering their regular biweekly symptoms, nurses from the clinic responded when one participant reported 'tiredness, headache, shortness of breath, fever and loss of smell and taste'. The quick response from the nurses included, one participant explained, 'home visits and the delivery of care, examination and a treatment plan. They took more drops of blood to check viral loads and any negative organ dysfunction done by the virus or the vaccination'. Emergency care was administered within hours of a positive symptomatology text message being sent to the clinical staff. It is critical to keep in mind that this was a double-blinded clinical trial, meaning that neither the researchers nor the participants knew whether participants would be harmed or protected by the vaccine or placebo. This is an implicit tension of all trials and the reason that body capital constellates a complex form of gift exchange.

Of course, the classic critique of altruism, as Mauss advanced, is that there is no such thing: there is always an expectation of return,

and the return ought to be of equal value to the original gift. We have offered a critique of experimental science and the implementation of clinical trials, in contexts of chronicity (for example, pre-existing and coterminous pandemics, persistent poverty, inequality, structural racism and violence). In doing so, we have focused on relationality, reciprocity and the social drivers that coalesce to make clinical trials meaningful social and scientific occasions. The scale of lockdown measures in South Africa, skyrocketing unemployment and increased anxiety in an already vulnerable country, meant that frontline trialists were keenly aware of their status as gift-givers. The symbolic value attached to participating in the trial, beyond monetary compensation, is an element of exchange often overlooked in discussions of clinical trials in Africa. In this sense, the act of participation gestures toward symbolic gifting by contributing to the broader project of reducing debility and death.

Conclusion

The expansion of research in African countries is frequently seen as a promising way to address endemic local health problems, and so remove poor health as a contributing factor to economic disparity. However, the perceived applicability of certain international randomized controlled trials in African countries has often been tenuous (Taylor-Robinson et al. 2021). Africa is increasingly positioned as a major marketplace for medicines and medical devices from the large pharmaceutical companies in the Global North, partly anticipating improved access to medical and surgical interventions (Kim et al. 2017). This is especially so in light of the growing prevalence of chronic conditions, both communicable and non-communicable. Even so, economic, technological and intellectual disparities globally still shape health care systems and the inequalities experienced by people seeking care.

South African scientists were caught up in the huge global research activity engendered by the pandemic and the challenges to its control. But their participation in global vaccine trials, including for the J&J vaccine, built on their prior work on TB and HIV, and the intellectual collaborations that supported this (Levine and Manderson 2023). This human capital, and attendant systems and infrastructure, was further capitalized in response to challenges to COVID-19's containment. Further, the South African scientists brought with them also their long-term community engagement and the trust that enabled the trial to proceed. Community members in turn provided both body and social capital: the former

through body matter, metrics and monitoring; the latter through their engagement in a project that was as much social and intellectual as biomedical. That is, with assurance the researchers would protect their health and wellbeing, they in turn gained status as civil society actors and citizen scientists. Through their participation in the trial, and their direct experience of the health care and support they consequently enjoyed, they strengthened the researchers' own standing in the community. This paid off. The same National Vaccine Roll-Out Team is now working on an mRNA-1273 boost, leveraging the clinical trial infrastructure developed and used for the ENSEMBLE study.

Foregrounding the long history of exploitation in African colonial medicine is critical, as is the ethnographic possibility to temper or offset a single story (Adichie 2009; Mkhwanazi 2016). The power dynamics involved in the distinct form of body capital in clinical trials provoke ethical concerns about paying individuals for scientific gain at the expense of bodily autonomy in already vulnerable social conditions. And yet, we have also argued that ideas about gift exchange can shed light on the political economy of clinical trials, which also include human capital and innovation, goodwill, and a sense of belonging to the work of making futures possible.

Notes

- 1 'French doctors suggest testing Covid-19 vaccine in Africa, slammed as racist'. *TRT World*, 2 April 2020. Accessed 22 October 2024. <https://www.youtube.com/watch?v=w2GzVKGn1W4>.
- 2 TDR, the Special Programme for Research and Training in Tropical Diseases, is a global program of scientific collaboration working to combat diseases of poverty and is co-sponsored by WHO, UNICEF, UNDP and the World Bank. DNDi (Drugs for Neglected Diseases Initiative) is an international non-profit organization which focuses on developing pharmaceutical products for neglected diseases of poverty.
- 3 See information on and quotes from *The Constant Gardener* [film] at <https://www.imdb.com/title/tt0387131/quotes/>. Accessed 22 October 2024. See also McGowan, 2007.

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‘We’re the health care in the town, pretty much’: rural community pharmacy and the chronicity of systemic precarity

Laura L. Heinemann and Ellen B. Rubinstein

I think the pharmacist role had a huge place here in a small town, especially during that time [when COVID-19 vaccines became available]. ... [A]t the time we didn’t even have a clinic open here in [town]. ... I mean, there’s a dental office in town, there’s physical therapy, and the nursing home. ... So as far as a health care professional standpoint in our town, I was it, pretty much, for someone who is actually doing the vaccinations and educating people [about COVID-19 vaccines]. (interview with Jordana, rural pharmacist/pharmacy owner)

In the early months of the COVID-19 pandemic in the United States, large pharmaceutical companies took center stage in the race to develop vaccines that promised a return to ‘normal life’. But scant attention was given to the role of pharmacy – as both a community locale (that is, pharmacies/drugstores) and the staff who work there, and as a field of health care practice – despite its capacity to bridge deep chasms in health care knowledge and access. In this chapter, we bring the perspectives of pharmacists in the rural US state of North Dakota into conversation with ongoing efforts to understand and address long-accumulating, poor and worsening US health outcomes exposed and exacerbated by the COVID-19 pandemic. Drawing together the concepts of chronicity and precarity, we frame these poor and worsening health outcomes as the products of long exposure to vulnerability compounded by systemic forces – what we call ‘the chronicity of systemic precarity’. By including the experiences and perspectives of rural community

pharmacists – a doubly overlooked segment of health care – we offer substantive examples of creative responses and new possibilities in the uneven topography of health and wellbeing in the United States.

The state of North Dakota is roughly trapezoidal, and as the population density decreases from east to west, both the geography and politics change. The iconic grasslands of the Great Plains become rolling hills leading into river-carved, rough-hewn layers of sandstone, siltstone and mudstone land formations known as the Badlands. While the east is more ideologically similar to other Midwestern states like Minnesota, Wisconsin and Iowa, many residents in the west consciously take their cues from a rough-and-tumble cowboy stereotype. The marks of white settler colonialism and segregation permeate both the state and region (see Howe and TallBear 2006). Owing to forced displacement from ancestral homelands and ongoing de facto segregation and erasure, Indigenous people and cultural communities are vastly underrepresented across regional identities, especially among health care providers ('About INMED' n.d.). The U.S. Census Bureau's 2022 data on racialized demographic categories show 86.6 per cent of North Dakota's 779,261 residents identifying as White, followed by 5.3 per cent American Indian and Alaska Native, 4.6 per cent Hispanic or Latino, 3.6 per cent Black or African American and 1.7 per cent Asian (only 2.6 per cent of the state claims two or more racialized identities); but none of the pharmacists with whom we spoke mentioned working directly with Native American patients. The confluence of resistance to public health interventions and a rightward shift in majority white, rural US politics comprises an important dimension of the landscape in which rural community pharmacy was operating during the COVID-19 pandemic.

Pharmacists were significant players from the pandemic's early days, even if they were rarely the subject of media reports about frontline workers. In early 2020, the US federal government's efforts to mitigate the pandemic began with mobilizing all sectors of health care, including pharmacy, through amendments to the Public Readiness and Emergency Preparedness (PREP) Act, which allows greater-than-usual flexibility in the scope of service for health care professionals during public health crises, providing immunity from federal and state liability and thus enabling the health care workforce to respond as needed without fear of litigation (Assistant Secretary for Preparedness and Response [ASPR] 2022). The 2020 PREP Act amendments allowed pharmacy staff – including pharmacists, technicians, interns and students – to provide new services, such as onsite COVID-19 testing and, later, vaccinations for an increasing number of demographic groups (ASPR 2021).

In February 2021, the federal government partnered with both public health agencies (the Centers for Disease Control and Prevention (CDC) and state, local and territorial public health units) and 21 national retail and supermarket pharmacy chains across the country to supply COVID-19 vaccines directly to pharmacies for public distribution through the Federal Retail Pharmacy Program (FRPP) for COVID-19 Vaccination (National Center for Immunization and Respiratory Diseases [NCIRD] 2021a). Criteria for participation in the FRPP considered ‘population served and community reach’ and ‘capacity to vaccinate (estimated daily number of doses each facility is able to administer)’ (NCIRD 2021b), effectively favoring distribution to large chains and community pharmacy networks. Because North Dakota still follows a 1963 state ownership law mandating pharmacies must be at least 51 per cent owned by a licensed pharmacist, only a few chain pharmacies (which predate the law’s passage) operate in the state (Wyckoff 2010). Independent and employee-owned community pharmacies remain the norm, which meant these pharmacies were excluded from the FRPP. Perhaps counterintuitively, this worked in North Dakota’s favor.

There was a pronounced initial clamor for vaccines, and pop-up mass vaccination sites in urban areas saw lines that stretched for multiple city blocks as people awaited their turn to receive first, and eventually second, doses. Rural communities likewise saw initially high demand for the vaccine, and even accommodated some of the ‘overflow’ from neighboring urban areas, where supply sometimes ran short. Only two US states relied primarily (in North Dakota) or exclusively (in West Virginia) on independent community pharmacies to distribute COVID-19 vaccines. Early in the vaccine rollout, they distributed over eighty per cent of their allotted doses compared to sixty per cent nationally. Local and national commentators alike attributed this success in part to the two states’ use of locally owned pharmacies with in-depth knowledge of their communities, rather than dependence on national retail chains (Mitchell 2021; Strickler and Cavazuti 2021; Turley 2021).

Pharmacy in North Dakota remains a close-knit community. In 2021, there were about 312,000 pharmacists in the United States (Mikulic 2022); roughly 1200 are licensed to practice in North Dakota (B. Maack, personal communication). With only one pharmacy school, most pharmacists who practice in North Dakota were trained in-state (D. Friesner, personal communication). In a place where people can trace personal and professional relations to a mere few degrees of separation, it can sometimes be easier to get things done, as early vaccine distribution demonstrated.

But as initial waves of Americans seeking vaccines receded, a new story emerged: one of vaccine hesitancy and outright refusal. At first brush, these developments were striking, even surprising, leading to questions about why so many would vehemently defend their decision to refuse what seemed a common-sense tool to protect themselves and loved ones (for example, Estep et al. 2022; Godfrey 2021; Hoffman 2021; Sobo and Drażkiewicz 2021). High mortality rates coupled with low vaccination rates in rural, politically conservative states like North Dakota soon gained national attention (for example, Godfrey 2021; Hoffman 2021). Less careful discourse often played on negative stereotypes of rural ignorance, rural resentment and other assumed cultural deficiencies long attached to rurality (see Janssen 2017). Such a limited view not only curtails accurate analysis of the poor health outcomes that pre-dated, were exacerbated by and persisted in the wake of the pandemic, but also fails to recognize locally-sourced, often less conspicuous, inroads toward meaningful solutions – such as the role played by rural community pharmacy.

As the quote with which we began this chapter demonstrates, pharmacists are often the most accessible – and sometimes the only – formally trained health care professionals in rural communities. They provide an important safety net for individuals who might not otherwise have access to biomedical resources, including accurate information about COVID-19 vaccines. Pharmacists are both ‘in’ and ‘of’ the communities where they work, enabling them to participate in public discourse as like-minded community members who are also bioscientifically trained. This positioning, further emphasized by their central role as small business owners in small towns, results in an ability to employ relational approaches to care in contexts deeply impacted by the chronicity of systemic precarity.

Politically situated vulnerability in a rural state

In this chapter, we bring together the concepts of precarity and chronicity to create a framework for understanding the amplified disparities in which rural community pharmacy is situated. This enables a richer, more process-oriented understanding of the systemic connections between politically situated vulnerability and the possibilities for human flourishing.

One initial common dimension of the global pandemic caused by the SARS-CoV-2 virus, which results in COVID-19, is that it laid bare the

vulnerability of human life. Yet this vulnerability was not experienced uniformly across contexts. In the United States, the COVID-19 pandemic initially sparked a self-perceived dislocation from global privilege that was perhaps only preceded in magnitude by the fallout following 11 September 2001 (see Butler 2004). But there were vast differences, for example, between middle- to high-income employees who could work from home and low-wage ‘essential workers’ who were required to attend the workplace. Such divergences spotlighted myriad pre-existing and unequally distributed vulnerabilities within the United States.

Deep inequities also materialized as disparate outcomes on measures of diabetes, obesity, chronic kidney disease, lung and heart conditions and other risk factors that long predated the pandemic and fed directly into more severe COVID-19 outcomes (Kompaniyets et al. 2021). Thus, those communities shouldering a disproportionate burden of illness prior to the pandemic soon were (and still are) grappling with the compounding effects of higher rates of hospitalization and death. Such disparities were amplified in rural areas (Mueller et al. 2021), as conditions in North Dakota demonstrate. As a largely rural, largely medically underserved state in which half the population lives in ‘nonmetropolitan’ areas (defined as areas with a population core under 49,999 people, according to criteria set by the federal Office of Management and Budget) (UND SMHS 2023, xviii), conditions in North Dakota are representative of other rural regions in the United States that must contend with depopulation, outmigration and limited access to health care services. North Dakota’s rural residents are ‘older, poorer, and have less or no insurance coverage than people in non-rural areas’ (UND SMHS 2023, xviii), which made them especially susceptible to the compounding effects of the pandemic.

Precarity

Precariousness, as Judith Butler describes, is a condition of vulnerability that comes with the existence of life, that is shared across all of humanity and which links humans and non-human animals – and which isn’t dependent on cognizance of that vulnerability (2009/2016, 34–5). ‘Lives are by definition precarious’, Butler notes; ‘they can be expunged at will or by accident; their persistence is in no sense guaranteed. In some sense, this is a feature of all life’ (2009/2016, 43). Precarity, on the other hand, points us toward questions of ‘whether the social conditions of persistence and flourishing are or are not possible’ (2009/2016, 39). Rather than an inevitable feature of life, precarity is a ‘politically

induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death [as well as] heightened risk of disease, poverty, starvation, displacement, and of exposure to violence without protection' (2009/2016, 43). Precarity, further, takes shape in the tensions between labor and capital (for example, Standing 2014, Alberti et al. 2018, Harris and Nowicki 2018, Coin 2018). It is situated at the intersections of local worlds and shredded social safety nets (for example, Heinemann 2016, 66), and thus it not only increases the odds of falling gravely ill but also complicates or altogether thwarts efforts to access medical care and caregiving.

North Dakota illustrates this. There is a dearth of health care providers, especially in the state's least populated areas, as current providers tend to congregate in the state's relatively populous, urbanized regions (UND SMHS 2023, xvii). Additionally, rural health care facilities operate under precarious conditions; 'the further [a health care] facility is from a metropolitan area, the more its operation is threatened by financial and other pressures, including staff recruitment and retention challenges' (UND SMHS 2023, 262). These realities are further inflected in profound racial and ethnic health inequities: In the Commonwealth Fund's 2021 *State Scorecard on Health System Performance*, the state achieved a score of 76/100 in performance for white patients, and a score of 3/100 in performance for American Indian/Alaska Native patients (Radley et al. 2021). The COVID-19 pandemic exacerbated these health precarities. As of March 2023, the state's rural hospitals were still struggling to refill staff positions, from custodial workers to geriatric nurses, that were vacated during the pandemic (Kwaw 2023). North Dakota ranks fourth in the country in percentage of the population over 85 years of age (UND SMHS 2023, xvii), and many of its nursing homes were decimated when COVID-19 swept through (Paulin 2020). Given the state's aging population, the current needs for comprehensive health care services are expected to increase in the coming years.

Chronicity

Over a decade ago, Lenore Manderson and Carolyn Smith-Morris (2010) problematized the binary paradigms that placed illness into the 'either/or' categories of chronic versus acute and communicable versus noncommunicable. In doing so, they invigorated a critical re-examination of the biomedical frameworks that had become hegemonic both in

practical and theoretical approaches to health. They emphasized instead more careful attention to the role of globalized socio-historical and political-economic contexts and forces. Specifically, Manderson and Smith-Morris's concept of chronicity draws our attention to the *temporal connective tissues* that link individual experience, identity and life course, to those of communities, regions and nations in a thoroughly globalized world. The authors write that by 'foregrounding the contexts of lifelong health status, so emphasizing chronicity in relation to context, we aim to instantiate the diversity of experience and to acknowledge the suffering of individuals and communities, institutions and states' (2010, 3).

The COVID-19 pandemic has painfully illustrated the limits of the acute-chronic binary: the existence of 'long COVID' offers just one example of how the lack of detectable viral infection does not necessarily mean illness is over. And the pandemic has exposed the hubris in assuming economic development produces a unidirectional 'health transition' (cf. Omran 1998). Industrialized and post-industrial nations were not spared the worst outcomes of this communicable disease. This was at least in part owing to the syndemic interaction of COVID-19 with non-communicable diseases, disproportionately borne by individuals and communities most harmed by the stratified political-economic conditions of life in industrial- and post-industrial contexts (see Weaver and Mendenhall 2014). Chronicity, in other words, offers a particularly apt lens for examining the accreted embodied vulnerabilities amplified by the pandemic and the unequal distribution of those vulnerabilities as a politically induced condition. And it does so in a way that accounts for the complex interconnections between the 'chronicity of life' (Smith-Morris 2010) and global systems where resources and power are unevenly shared. It is with these realities that rural community pharmacy already had been engaging prior to the pandemic, and with which it has remained throughout and since.

Although we tend to imagine 'rural' as a particular space or place, cultural historian Stacy Denton (2014) has argued rurality is not about a 'concrete geographical locale', but is applicable to 'anywhere on the rough edges of the landscape and economy' (Denton 2014, 123, citing Harkins 2004, 4). At the local level, rurality may offer a shorthand for a particular shared set of values (Sosin and Carpenter-Song 2020), yet at the national level, North Dakota and other states that comprise a large swath of the country's geography often are dismissed as filler between the East and West Coasts. The politicization of rurality became amplified throughout the pandemic, adding further complexity to the efforts of health professionals, as we describe below.

The evolution of community pharmacy

While the contemporary pharmacist's role of preparing and administering medicines has belonged to different actors throughout history (Zebroski 2016), pharmacy is grounded in the relationship between healer and sufferer, joined through the exchange of substances that act upon the body (van der Geest et al. 1996; Whyte et al. 2002).

There were no standardized educational and training requirements for US pharmacists until 1932, following a detailed study by University of Pittsburgh professor W. W. Charters, who believed 'the pharmacy profession had in many cases allowed itself to be overwhelmed by business concerns at the expense of patient care' (Zebroski 2016, 172). The 1975 Millis Commission report echoed this concern in a 'call for pharmacists to abandon their traditional focus on drug products and shift it to interacting with patients in terms of educating them about how to get the most from their drug therapies' (Zebroski 2016, 175).

This was the start of 'clinical pharmacy', with a shifting emphasis from drug products to patient relations, which pharmacist Charles Hepler developed in the 1980s as 'pharmaceutical care', a professional activity that was both practical and philosophical (Hepler 1996). As Hepler and his colleague Linda Strand defined it, pharmaceutical care 'is based on a covenant between the patient, who promises to grant authority to the provider and the provider, who promises competence and commitment (responsibility) to the patient' (Hepler and Strand 1990, 539). Despite its paternalistic bent, pharmaceutical care established a way for pharmacists to conceptualize their role in patient care to ensure the best possible outcomes from medication use. Although Hepler (1996) was clear that emotional attachment was not part of pharmaceutical care per se, other pharmacists have argued otherwise, introducing the concept of 'pharmaceutical caring' and encouraging their colleagues to develop 'caring relationships' with their patients (Murawski and Miederhoff 1994).

Much of the work pharmacists do, which we describe below as 'relational care', goes unrecognized. Pharmacists care for patients through the hidden labor of conversation rather than physical manipulation, rendering them 'a silent partner in health care', widely perceived as 'not contribut[ing] greatly to health outcomes' (Duffull et al. 2018, 309). Yet the scope of pharmacists' services has expanded over recent decades to encompass more clinical care related to, for example, diabetes management (Orabone et al. 2022), opioid use and naloxone education (Kosobuski et al. 2022), emergency contraception (Rafie et al. 2017)

and tobacco cessation (Newlon et al. 2022). However, payment and reimbursement for pharmacists' clinical care have lagged behind their increasing clinical role (Johns Hopkins Center for Health Security 2021).

Despite a lack of formal recognition, pharmacy is a crucial component of US health care. One study of Medicare beneficiaries in 2016 found that patients accessed community pharmacists at roughly twice the rate they accessed primary care physicians, particularly in rural areas (Berenbrok et al. 2020). Such accessibility proved especially important during the COVID-19 pandemic. As the pandemic continued, media reported on exhausted health care workers and overwhelmed health care systems, evinced in North Dakota by hospitals filled to capacity and the governor's announcement that COVID-19-positive nurses could continue working on COVID units (Turley 2020). These were dangerous circumstances for anyone in need of acute medical care. But as governments and publics became less able to rely on clinics and hospitals, space opened for community pharmacy to take on a more prominent role in addressing pandemic-related public health needs.

In 2021, the North Dakota Department of Health (now North Dakota Health and Human Services, NDHHS) funded multiple projects to improve the state's COVID-19 vaccination rate. One project involved pharmacists as COVID-19 immunizers. This was important, given North Dakota's unique pharmacy context of independent ownership, which meant most pharmacies' vaccine supply came through the state rather than the federal government.

According to internal figures from NDHHS, 105 community pharmacies originally registered to provide COVID-19 vaccines, 73 of which received their vaccine supply from the state. NDHHS oversaw the vaccine distribution process and required site visits, which were conducted by two university-employed registered pharmacists, to ensure compliance with CDC handling and storage regulations. Since some pharmacies stopped providing vaccines, a total of 52 pharmacies received site visits between September 2021 and February 2022. These visits provided a means to observe pharmacy practice during the pandemic and recruit pharmacists for follow-up interviews (see Skoy et al. 2023). Ellen Rubinstein and a graduate assistant independently telephoned and/or emailed the pharmacies' primary contacts and conducted interviews from January to April 2022 with 43 pharmacy staff, representing 42 unique pharmacies across the state. These interview data form the basis for our analysis below. All names are pseudonyms.

Pharmacists on the front lines

‘There isn’t other access to health care’

Pharmacists were not usually the referent when media touted the services and sacrifices of ‘frontline health care providers’, but pharmacists saw themselves as being on the front lines, especially in rural areas. The role of rural community pharmacy coalesced with much immediacy around staff members’ already close connectedness to their communities, which allowed them to offer meaningful reassurance and consistent presence even amid the fear and uncertainty of the earliest waves of US infection.

Cooper, for example, had been a practicing pharmacist for 23 years and had spent several years working at a ‘high-volume’ pharmacy (that is, filling and dispensing a relatively high number of prescriptions per day) before taking ownership of a rural community pharmacy in a small town. The pharmacy also serviced community members on surrounding farms and ranches, and Cooper found himself fielding questions and providing emotional support to community members when the pandemic first emerged:

There was always a phone call coming in. There was always a person coming into the pharmacy, just not knowing what we were seeing, what we were expecting, how we were handling it. ... There was no running and hiding from it, things still had to be done. People still had to be seen, prescriptions still had to be dispensed, illnesses treated. Just reassuring people that we were going to be here and that things were going to be okay.

Community members and pharmacists alike feared pharmacy closures, and it was important, particularly in medically underserved areas, to keep pharmacies open and pharmacists available. Multiple interviewees spoke about the need for accessibility to pharmacists in towns where other health care services were either limited or unavailable. ‘We’re the health care in the town, pretty much’, said Kayden, a practicing pharmacist for 14 years. The only other health care options in his small town, he said, were a local clinic open two mornings per week and a dentist’s office open four days per week.

Like Kayden, many pharmacists mentioned the importance of the health care access their pharmacies provided. Scott, for example, had been practicing since 1994. He managed two pharmacies and was a partial owner in six others, all in rural communities. He and his business partners focused exclusively on buying pharmacies in small towns as a

way of ‘keeping these rural communities going with health care access’. The pharmacies they bought were often the only ones in their respective towns, run by an elder pharmacist who was ready to retire. ‘In more than one case, the store was going to close if somebody didn’t buy it’, Scott explained, ‘... we bought it, and we’re remodeling those stores, getting young pharmacists in, and having them operating them’.

The consistent presence and deep community knowledge meant personal and professional lines often blurred as community members sought pharmacists’ health care expertise outside of regular business hours. As Cooper said:

I’ve had people show up in my driveway for non-pharmacy related things – their child wiped out on their bicycle and hit his head pretty hard. They just want your opinion because they know they can get to you faster than they can get into an ER [emergency room] somewhere.

He echoed Scott’s comments on the significance of maintaining pharmacies in rural communities:

One thing with the rural community is they just – There isn’t other access to health care. We’re fortunate here in [our town], we have a very strong medical community here, but there’s a lot of smaller towns that don’t. They may have a nurse practitioner and a pharmacy, and that’s the extent of it. Some don’t even have that. Some just have a pharmacy. So just having that presence in town is critical.

As the sole or primary health care professionals in their communities from the start of the pandemic, pharmacists faced the considerable task of attending to their everyday responsibilities while trying to keep their staff and customers safe. Some pharmacies had enough staff members to split into teams who worked separate shifts to avoid potential exposure, as Skye, practicing for seven years, explained:

Say one of our staff got COVID, and it wiped us all out, [and] we couldn’t work. Who would keep the pharmacy open? So then we had a process where half [of the] staff was on, half was off, and we were paying everybody regardless if they were working or not. But just essentially ensuring that, like, say Staff A got COVID, Staff B then would come on staff to keep the pharmacy open.

In pharmacies without extra staff members, pharmacists found ways to be ‘closed door, [but] not closed service’, according to Phyllis, a rural owner practicing for 37 years. She and her staff figured out low-touch and no-touch ways to continue operating. They installed a doorbell to alert them to customers’ arrivals – a practice they also implemented at local nursing homes so medication deliveries could continue – and placed purchased items into car trunks to ensure complete lack of contact. Phyllis’s husband helped custom design, frame and install Plexiglass dividers in the pharmacy to prevent close contact between customers and staff. Pharmacists like Phyllis went to such lengths not simply out of concern for their own health, but also to protect the health of their community, staff and customers alike.

Pharmacists and vaccine hesitancy

Especially in small towns, pharmacies are among the primary businesses located on Main Street, giving them both prominence of place and significant embeddedness in the community’s daily happenings. And owing to North Dakota’s 1963 ownership law, pharmacists who were also pharmacy owners occupied thoroughly hybrid positions, where health care, business and everyday community life came together.

As the initial demand for vaccines receded, pharmacists’ hybrid positioning became newly salient in the context of widespread vaccine hesitancy and refusal. Geoff, practicing for 15 years, opened a new rural pharmacy in 2014, rather than buying out a previous owner. He talked about the tension at the intersection of health care provision and business ownership, where the needs of community members as ‘patients’ sometimes tugged against the concern of tending to the ‘health’ of the business. Geoff’s pharmacy was in western North Dakota, a politically conservative region where people frequently downplayed or denied COVID-19’s effects, necessitating that he cater to customers who adhered to pandemic precautions and to others who did not:

Because as a business owner and health care professional, I feel like we walk a weird line of, you’re trying to take care of patients, but also just realizing that the health of your business has to be at the forefront of what you do.

Others likewise mentioned this tension. Norah, practicing for eight years, was not an owner but had become the pharmacist-in-charge at a rural pharmacy just as vaccines became available in December 2020.

She decided not to ask customers about their vaccination status because she worried about potential financial repercussions:

If they want it [a COVID-19 vaccine], I'm very willing to give it to them. And if they ask, I will tell them, 'Yes, you should'. But I'm not going to ask them out of nowhere if they've had it or not. I don't really feel that's appropriate on such a sensitive vaccine. Because I feel like they think we're judging them. I think North Dakota is hard because they're very opinionated people. I can't risk losing customers by pressuring them to get a vaccine that they don't believe in.

Running a business also left pharmacists with little time to stay updated on COVID-19. Although NDHHS held frequent virtual meetings for health care professionals, few business owners could attend. As Geoff noted, 'sometimes you don't have the time or ability to get on some of these hour, hour-and-a-half long conference calls to listen to what the new data is coming out from the state Health Department'. Sometimes patients heard new information through the media before pharmacists could be updated, as Tanya, another owner, commented:

That was very, very frustrating, where patients would call and say, 'Well, on the news, they're saying this', but we didn't get any type of information or anything to us before[hand] to be able to give them that education.

The media, whether mainstream or social, was a constant source of frustration for pharmacists who tried to combat information overload and widespread misinformation. Dolores had grown up in the rural community where she worked, had married locally and had worked as a pharmacy technician for over a decade before returning to pharmacy school, becoming a pharmacist, and eventually buying the pharmacy. Four years into her practice, with deep ties to her community, she could not overcome some people's insistent belief in inaccurate and misleading information:

I feel like there's so much, number one, misinformation as far as news media, and then the people aren't going to listen to what I say because they heard it on Fox News, or they heard it on the news last night. ... Sometimes they ask me, 'What do you think about this? Or what do you think about that?' Well, it doesn't matter [what

I think] because you heard it on the news, you're not going to take anything I say for – Even though I probably know more than the newscaster does.

The broader political context and the rapid spread of misinformation through mainstream and social media were factors that existed far beyond pharmacists' control. More germane to their circumstances were influential community members who were vocal with their anti-vaccination views. Pharmacists were particularly bothered by fellow health care professionals who spread anti-vaccine opinions, as these were supposed to be their allies against the pandemic. Nolan, a rural owner and practicing for 30 years, elaborated:

I do find a little bit of fault in some of our health care practitioners that come out to our areas that don't really explain the benefits [of the vaccines]. And I even heard reports of a nurse practitioner in our county that was telling people that they didn't need the COVID-19 vaccine, they're young and healthy. And they wouldn't do it [get vaccinated]. So, when I hear stories like that, it just kind of makes me cringe and think, you might have a personal opinion like that, but when you're practicing as a nurse practitioner in the only clinic in town and seeing patients that are coming to you for advice, you have to use the science. Again, you have to use the data, and you have to tell people the honest truth, not opinion.

Meredith, practicing for 12 years, managed a pharmacy in the state's largest long-term care facility, where some of the state's most vulnerable citizens resided. She had seen firsthand the dire consequences of vaccine refusal within health care settings. While residents' vaccination rates crested at 90 per cent, staff vaccination rates hovered around 40 per cent, forcing the facility to remain closed to visitors:

We still couldn't keep COVID out of the building. ... There was always, every single week, one to five or six positive cases. They haven't had the doors open to visitation in two and a half years for the most part.

To protect the residents, the long-term care facility took the unpopular but necessary step of implementing a vaccine mandate for staff. Meredith lost three employees who refused to receive vaccines after the mandate took effect. Her dealings with vaccine hesitancy were unique given her

pharmacy's location; while the outside world began to emerge from the pandemic's acute phase, the risks of the virus still loomed inside the facility. Given this, the reverberations of vaccine hesitancy and refusal, starkly illustrating the chronicity of systemic precarity, were never far from Meredith's mind: '[I just want people] to remember that for the elderly, it's not the same. And I don't know when it will be. But their lives are not the same'.

Pharmacists and relational approaches to care

Despite the difficult circumstances – the politics, the influence of social media, the widespread differences of opinions on the pandemic – pharmacists could still make inroads with some highly vaccine-hesitant or resistant community members. With much consistency across interviews, pharmacists underscored their accessibility and the public trust they maintained even as trust in science and expertise more generally frayed. This accessibility and trust were inextricable from pharmacies' situatedness within their communities, stemming from pharmacies' dual positioning as sites of health care *and* sites of retail, and from pharmacy staff holding both health expertise *and* local sensibilities. As such, they had learned to provide forms of locally grounded relational care, as the examples below illustrate.

One form of relational care, which aligned with North Dakota's libertarian politics, concerned knowing when to advocate for vaccines and when to lessen the pressure. Even the most ardently pro-vaccine pharmacists felt it was not in their purview to force vaccines on anyone. Sierra, an owner and practicing for 11 years, said:

Everybody has the right to choose and to do what they want. I will give info. I will help people make whatever decision they need to make, but I am not a pusher of vaccines because that's not my choice [to make for them]. ... I always joke that I'm not a very good used-car salesman.

Skye similarly felt it was her job only to provide good information that might encourage people to vaccinate:

I'm not about scare tactics or making people really nervous or stressed, like, 'If you don't get this vaccine, you could die'. I don't say stuff like that. I say stuff like, 'Well, what questions can I answer, or what makes you worried?' And then I give them the

information I have in front of me and then still make them decide for themselves.

Overall, pharmacists saw themselves in a position to educate, not coerce, which distinguished them from other health care professionals. Many people were more accustomed to receiving routine vaccinations from their primary care providers, which gave pharmacists flexibility in their approach to conversations about COVID-19 vaccines. Kylie, practicing for one year, preferred to make an emotional appeal that emphasized her feelings of care rather than her professional responsibilities:

They [patients] can come in here and feel safe getting it [the vaccine]. They also know that we're not going to push and fight them for it. Sometimes at the clinic, I think they feel that way with vaccinations because, I mean, that's a clinic's job. The nurses and the doctors are trying really hard to get people to think about their health care and things like that. By us being here and giving them almost an option, [it] opens things up a little bit more. Instead of being like, 'You need to get this', it's more of, 'We recommend it for you. We want to take care of you'.

In some cases, pharmacists shared their neighbors' political leanings, concerns about government overreach and/or initial hesitancy toward COVID-19 vaccines. Such pharmacists were able to speak to their patients from a place of shared values combined with their scientific expertise. Scott, who co-owned pharmacies in several rural communities, openly agreed with some patients' stated concerns about the federal government yet still saw himself as a source of 'unbiased' information about COVID-19 vaccines. He felt that sharing his patients' perspectives, coupled with the 'factual' vaccine information he provided, made him a particularly trustworthy source in the 'Wild West' of North Dakota:

They [patients] ask us [for our opinions] because we're very accessible. 'What do you think?' [they ask]. They trust us. So they're looking always for information. I think that was especially [true] in North Dakota, 'cause we're kind of the Wild West. ... I'm able to have those conversations with [people]. And they trust me. Because they don't trust government. People just don't. I mean, they don't, do they? If I can try to be some kind of an unbiased source, and if they want to complain about the system, and I agree with them on something, then they even trust me more. But I still need just to be

factual with them and say, ‘Just look, it’s your choice. You can do this. You don’t have to, but statistically, look at it’. So I think we [pharmacists] had a lot of influence. I had lots of conversations with patients, and some just said, ‘I don’t want to do it’. And I said, ‘I respect that, but just know you’re at a higher risk’.

Even when their politics did not align with their patients’ views, pharmacists approached conversations from a place of empathy. Many mentioned their own ambivalence when COVID-19 vaccines first became available. They drew on these personal experiences – overcoming their concerns, receiving their vaccines, and managing any unpleasant after-effects – to broach discussions with vaccine-hesitant patients. Tess, an owner and practicing for over 10 years, had changed her perspective on the vaccine in the months following initial distribution:

I can relate to the hesitancy, I’ll admit that. I did get [my vaccine] with the very first round when I was offered, but I was nervous. I’ll admit that, too. ... I use my own experience for people now that I know [more] ... So now I have definitely transitioned to where I educate people that I feel the benefit outweighs the risk, whereas at first I was definitely more neutral about it because I didn’t know.

Many pharmacists overcame differences by relying on the strong relationships they had cultivated over time. As Kayden said:

Oh, it takes years [to develop relationships with patients]. ... It takes a long time of talking to them and reassuring them and letting them know you’re knowledgeable about stuff and you’re willing to help.

Once those relationships had developed, pharmacists felt they were able to broach difficult subjects. Nolan, for example, described the many conversations he’d had with patients who were adamantly against receiving COVID-19 vaccines. Such conversations were possible because they rested on strong connections:

In a small town, we’re kind of lucky in that we know our patients very well. So we have more than just a passing relationship. We know them, we know their families, we know their kids, and it helps us feel more comfortable talking to them.

For Dolores, knowing her patients sometimes meant conversation was not necessary:

I know every single one of my patients, so that's the benefit of living in a small town. I know if they've had it [the COVID-19 vaccine], I know if they're absolutely not going to have it. You just, you know what their opinion is.

While pharmacists acknowledged that there were people whose vaccine beliefs would never change, their circumspection about the pandemic made them empathetic listeners for those with true questions or concerns. These small, local pharmacies could not reach the same volume of individuals as national retail chains, but they traded quantity for quality, banking on their deep knowledge of their patients and their communities to tailor their approaches. As Lisa, a rural owner and practicing for forty years, said:

So yeah, we were able to educate some people and get them vaccinated when it probably wouldn't have happened if they would've just gotten thinking they were going to a vaccine clinic where you just are in line and get your vaccine and away you go. I think we've been able to do a better job than that. I mean, not on the same scale, but we've been able to change some people's minds, I think.

Systemic emerging realities

Manderson and Wahlberg (2020) highlight the exacerbated challenges brought by the pandemic for people living with multiple chronic conditions. Even beyond the direct risk from the virus, the strains on the systems meant to support health have made 'chronic living' (living with one or more long-term health conditions) all the more precarious. As the authors note, the COVID-19 pandemic 'has come at a particularly delicate time for health care systems the world over' (2020, 434), and it is likely that an 'austerity pandemic' will follow in its wake as the public sector reckons with the financial costs of lockdowns and intensive medical care.

In many rural US communities, these observations and prognostications ring particularly true. Well before the pandemic, industrialized, corporatized farming practices had consolidated wealth largely outside of small rural communities, in turn offering predominantly

low-wage employment opportunities to local residents. Seeing diminished prospects, many young, educated professionals left while their parents and grandparents remained. Rural hospitals and clinics had already begun reducing their services or had closed altogether (Edelman 2021). These interconnected chronic realities in rural communities both produce and reproduce forms of precarity that are not merely structural – although they are indeed structured – but also systemic. That is, they are interdependent, dynamic, subject to change over time and prone to producing emergent realities (some of which might be by design, while others can be unanticipated). In this chapter, we have recounted some of the ways rural community pharmacy has been addressing these emergent realities – the chronicities of systemic precarity – revealed and exacerbated by the COVID-19 pandemic.

Specifically, by the time COVID-19 made its way into North Dakota, rural community pharmacists were already ‘on the front lines’ of health care in chronically underserved areas. Pharmacies already served as anchoring businesses and critical nodes of commerce in small towns. Pharmacy was already a career path that could allow young, educated professionals a pathway back toward well-paid work in rural communities. And, as integrally situated community members with high-level training in science, pharmacists were already uniquely important in connecting rural community members to the offerings of medicine through relational, accessible approaches.

Indeed, many pharmacists pointed out that anyone can talk to a pharmacist without an appointment and regardless of insurance status. One need only pick up the phone (as one pharmacist put it, ‘you call the pharmacy, you’re getting the health care provider right away. Like, I’m answering the phone’) or walk into the pharmacy (another pharmacist noting that people ‘can just walk in the door and ask for something and get it 10 minutes later’). Given the state’s pharmacy ownership law, most North Dakota pharmacies were small businesses with a close, interdependent relationship with their communities. Patrons were not asked to navigate smartphone apps or other technologized processes initially characterizing vaccine rollout at mass vaccination sites or national retail chains (Debré 2021). Instead, pharmacy staff recounted telephoning people on handwritten waitlists or posting vaccine supply updates on Facebook to help ensure vaccine access. Furthermore, pharmacists were available (sometimes outside of business hours) to help allay fears and provide guidance throughout the pandemic, as well as to bring vaccines to homebound community members. And as before, much of this relational care remained unrecognized and was not reimbursable.

The chronicities of systemic precarity that formed the backdrop for rural community pharmacy were amplified in the pandemic. Rural pharmacists worked harder to fill large and growing gaps in an over-stretched health system. Rural pharmacies adapted to new health and safety precautions so that they could be, as one pharmacist said, ‘closed door, [but] not closed service’, and provided stability to their communities amid uncertainty. And pharmacists’ ability to mediate between medical science and those increasingly distrustful of it was tested as misinformation and disinformation surrounding the pandemic ballooned.

In many ways, then, the story of rural community pharmacy throughout the COVID-19 pandemic is one of both continuity and rupture. It is a story of emergent realities. As we began writing this chapter, in mid-2023, the American Pharmacists Association (APhA) was advocating for legislation to recognize the expanded role of pharmacy on a more permanent basis, which would formally allow reimbursement for clinical services performed by pharmacists. Such developments open up further questions about whether and how the role of rural community pharmacy might continue to engage systemic precarity in rural areas. Will formal recognition of and remuneration for their capacities make it more possible for pharmacists to provide much-needed primary care in rural communities? Will new reimbursement structures introduce new barriers to those without health insurance? Might it diminish the trust they have cultivated through decades of relational care?

Just as COVID-19 revealed cracks in broadly intersecting systems, it also revealed what rural community pharmacy can do to offer health services and information, and to provide emotionally attuned labor and supportive care that is sensitive to community needs and residents’ positionality. Ongoing attention to the role of rural community pharmacy will be crucial in efforts by medical anthropologists and others to both understand and address the multilayered chronicities of systemic precarity in rural areas as they continue to ripple through and beyond the COVID-19 pandemic.^{1,2}

Notes

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‘But we want cassava, not COVID-19 vaccines’: the politics of vaccination in Uganda

Grace Akello

Early in 2020, Uganda’s local and national media began to cover news of COVID-19 deaths. While these deaths were occurring in distant places such as in China, Italy and the United States, television and print media showed that COVID-19 was dangerous and virulent. News broadcasts were frequently coupled with messages that Ugandans and people in other African nations must respond appropriately to the anticipated spread of the disease (Sirleaf [2021](#); Africa CDC [2020](#), [2021](#)).

The World Health Organization (WHO) declared COVID-19 a global pandemic on 11 March 2020. On 14 June 2020, the cases detected and reported on the African continent represented only 3 per cent of total cases worldwide (Morrison 2020). Uganda’s first case of COVID-19 was confirmed on 18 March 2020 – a traveler arriving at Entebbe International Airport. Thereafter, Points of Entry (PoEs) became hotspots for cases. These were mostly asymptomatic and mild (Kanyike et al. [2021](#); Bongomin et al. [2021b](#)), but, nevertheless, the state required all PCR¹-diagnosed positive cases of COVID-19 to quarantine for 14 days.

The president, Yoweri Museveni, led disease containment measures, assisted by a team of ministers and other politicians appointed to oversee activities that mirrored a globally standardized repertoire of containment measures: enhanced surveillance, laboratory testing and subtyping, risk communication and community engagement, logistics and supply chain management, infection prevention and control and case management. Lockdowns were the preferred method implemented to limit transmission (see Akello [2020](#)), and the country experienced two stringent lockdowns which, combined, extended from March to July 2020. People were under regular surveillance and punished when they breached lockdown measures; when they tested positive – even when

asymptomatic – they were quarantined or hospitalized, often forcibly, for 14 days. Schools, places of worship, bars and other places of entertainment were closed and public transport was restricted in a bid to halt the spread of the virus (Parker et al. 2020; Burt et al. 2021). By October 2021, Uganda had been through one of the longest lockdown periods globally.

On this basis, strict lockdown was already seen to have worked, and a major spread of infection had been averted. According to the Government of Uganda, by 30 September 2020, Uganda had seen a total of 8,129 COVID-19 cases with 4,260 recoveries and 75 deaths – hence a Case Fatality Rate (CFR) of less than 1 per cent of a population of slightly under 46 million (Margini et al. 2020). Kampala metropolitan area was most affected, with 2,735 total cases and 47 deaths. There were localized upcountry district outbreaks, with 104 of 107 districts reporting 87 cases between them and no deaths in September 2020. Nine months later, the vaccination program commenced.

As I illustrate below, the Ugandan state exerted excessive power and authority to enforce disease containment measures. When COVID-19 vaccines were introduced, in June 2021, many people hesitated to access them. The political environment and the authoritarian nature of the enforcement of pre-vaccination containment measures influenced people's distrust of vaccines. There was also, at that time, a need to promote vaccine equity from African actors such as Africa CDC. Donor agencies were pressing for vaccination targets. Actors' pressures overrode engagement with local epidemiologists and little attention was paid to emerging experiential evidence. This led to a disjuncture between government campaigns to increase vaccine uptake and local attitudes, including among people being urged to present for the vaccine, who viewed the disease as mild and failed to see the relevance of vaccination.

Field sites and methods

In this chapter, I analyze the government's endeavor to ensure population acceptance of COVID-19 vaccines. I describe state heavy-handedness in forcibly hospitalizing asymptomatic cases and enforcing prolonged lockdown and containment measures, all of which contributed to local people's resistance to control measures and the vaccine program. I analyse too how global health partners' focus on metrics had unforeseen negative consequences on vaccine uptake. I examine these issues following events in our study sites.

I draw on multi-sited ethnographic research conducted from June 2020 to September 2022 in the districts of Kasese, western Uganda; Gulu, northern Uganda; and Kampala and Wakiso districts in central Uganda. Below, I document the perspectives of frontline health workers working in urban and rural areas, and district officials in selected areas. To document the perspectives of national actors who led COVID-19 uptake campaigns, I participated in 17 national level meetings for COVID-19 containment, and I conducted over 450 interviews with officials working for the Ministry of Health (MOH), clinicians, members in the District, Hospital and Sub-County Task Force for COVID-19, National Emergency Operation Centre (NEOC) and National Task Force (NTF) members in Kampala. With consent, adults were interviewed about their experiences with COVID-19, how they interpreted containment measures, and whether they accepted vaccination. Handwritten and sometimes recorded interviews were later typed for coding, further classification and identification of recurring themes.

Containing asymptomatic COVID-19

National policy

Between March and September 2020, in his frequent nationwide addresses on epidemic preparedness and response measures, President Museveni stressed the need to isolate and hospitalize asymptomatic cases. Positive cases needed to be isolated to prevent the spread of disease; if people who tested positive did not adhere to these instructions, the army and the police would be called upon to ‘discipline’ them, with the threat of incarceration. Surveillance teams of the military, police and local authorities were deployed nationwide, particularly at PoEs (Parker et al. 2022). These teams were armed. They enforced lockdown and handwashing, and had ambulances to transport confirmed cases to designated points for disease management and hospital admission. The tone in presidential speeches was militaristic and authoritarian. COVID-19 was regarded as

... an invisible enemy, and people need to lie down, take cover, and listen, discover what the enemy is doing, how it is behaving. And this was the purpose of lockdown. But if the health teams discover that you have been attacked, and especially truck drivers need to cooperate, allow to be isolated and treated at designated health centers. Any resistance will be regarded as a case of indiscipline. (Museveni, 17 March 2020)

Surveillance teams of the military, police and local authorities were deployed nationwide, particularly at PoEs. These teams were armed. They enforced lockdown and handwashing, and commissioned ambulances to transport confirmed cases to designated points for disease management and hospital admission.

When patients were discharged from hospital, senior figures of public authority (including Resident District Commissioners) gave speeches exhorting them to 'keep their status negative' by adhering to preventive activities: maintaining a social distance of two meters, constantly sanitizing and wearing face masks. In this context, one respondent reflected on the contradictions of everyday containment activities, particularly when people were forced to stay at home:

It was during lockdown that we saw the highest number of clients – depositing large sums of money. The idea that COVID-19 existed and was killing many people was distant. We never heard or even saw a really sick person suffering from COVID-19 for all the eight months. Trust me, we were essential workers moving around everyday and watching how health teams conducted their business. (Interview, October 2020, Gulu).

Gulu

The designated COVID-19 treatment centre in Northern Uganda was in Gulu. All travelers, villagers and essential workers with positive PCR results were forcibly hospitalized at Gulu Regional Referral Hospital (GRRH hereon), even when asymptomatic or only mildly affected (Akello 2020). Typically, COVID-19 surveillance teams set up offices at PoEs and designated hospitals. Through routinized surveillance and testing, nasal swabs were taken from truck drivers, travelers and essential workers. Because PCR testing took 12–48 hours depending on 'client load' at laboratories, some truck drivers' results would be available only after they had traveled for more than 48 hours. Phone calls would then be made to surveillance teams stationed in districts where the traveler could have arrived, with instructions to immediately intercept and transport them to the nearest COVID treatment center. Three truck drivers who were arrested and detained had traveled a distance of over 500 km, and were subsequently admitted to GRRH for 14 days:

We were arrested at a trading center near Adjuman town. The COVID [-response] team found us about to set off for Juba [South

Sudan]. They surrounded us. They ordered us to leave everything and co-operate with them. They said we had corona and that we were being taken for treatment. When we told them we were not feeling any sickness and we wanted to go on with our business, they threatened us (with arrest at gunpoint). We could not argue more because the ambulance was already parked there. That is how we were ordered to board, brought here and have been here [GRRH] doing nothing. Sometimes the health workers would tell us to sing, to dance and to drink a lot of water (Group interview, July 2020).

In interviews conducted in June 2020, people consistently spoke of the inconvenience of their admission, and they experienced state representatives and disease containment measures as heavy-handed, oppressive and confusing. Surveillance teams forcibly arrested any confirmed case and transported people via ambulance to the nearest treatment center, and the military and police were deployed at treatment centers to prevent violence, resistance and escape of these patients. By July 2020, people in villages had started using the enforcement teams to arrest and detain ‘social deviants’ such as land grabbers, alleging that they were travelers and had COVID-19 symptoms (Akello 2020). Thus, with the securitization of COVID-19 containment efforts, there was a blurring between the experience of the disease and other complex social, economic and political matters.

Compulsory hospitalization had initially been advised by the WHO, but this changed rapidly to focus on the home management of mild cases. Observation and interviews from May to September 2020 with hospital task forces in different designated treatment centers confirmed all cases were asymptomatic. By August 2020, staff attending hospital management meetings at GRRH and other rural COVID-19 management centers were questioning mandatory hospitalization, and were advocating for a return to ‘traditional’ clinical practice, whereby only critically ill patients were to be hospitalized. They argued that hospitalizing asymptomatic cases was costly and required many clinicians, at a time when the hospital was understaffed. The minister had promised UGX80,000 (around GBP17.6) per day for each member of hospital taskforce teams, but payments were delayed and by October had ceased (‘UMA raises concern’ 2020; Ajuna 2021).

Asymptomatic COVID-19 patients also resisted containment measures and disease response activities, and found creative ways to escape from hospitals and quarantine centers. Typically, they requested permission to leave to buy water or food in the hospital neighborhood,

and never returned. Surveillance was subsequently heightened. Many patients resisted admission because they could not meet the proposed admission and quarantine costs. In September 2020, in acknowledging this and because hospitals were underfunded, clinicians increasingly declined to engage in non-traditional clinical care by admitting asymptomatic patients in regional and national referral hospitals. In response, the National Task Force proposed referring all asymptomatic patients to the National Centre at Namboole Stadium, established as a field hospital for people with COVID infections, with people charged for their stay.

One event documented in September 2020 involved 20 asymptomatic patients from Kitgum district in northern Uganda. Kitgum district hospital was not a government-approved centre for COVID-19 management and its clinicians avoided hospitalizing asymptomatic patients. Patients were therefore referred to neighboring GRRH for management. The GRRH Hospital Task Force had been directing its limited resources and 70 per cent of staff to care for positive COVID-19 cases, including those forcibly admitted. When another 20 asymptomatic cases arrived at GRRH, members of the task force and other clinicians referred them to the Namboole Stadium, where they were supposed to self-fund 14 days of quarantining and conservative management. Patients burnt down the bus 7 kms out of Gulu city. The police did not identify the cause of the fire and did not identify the patients who fled for safety.

Kasese

Uganda's PoEs, including Kasese district which borders the Democratic Republic of Congo in south Western Uganda, were portrayed as hotspots for COVID-19. In all hotspots, schools with hostel facilities, running water and electricity were approved by the government and guarded by the military to ensure that confirmed cases of COVID-19 and people with flu and cough were quarantined. Only senior officers, including district health officers, designated physicians and the Resident District Commissioner (the political representative) had access to these centers; researchers, journalists and relatives of forcibly quarantined people were prohibited. In September 2020, following interviews with administrators of schools where suspected cases were quarantined, it became apparent these were managed like detention centers, with containment an excuse to arrest and criminalize those who were perceived to be acting against the principle of lockdown in disease containment. One school administrator in Kasese put it thus:

The way I saw it, the people whom the COVID-19 response team brought here for quarantine were not sick at all. They were arrested at small border points or *panyas* [back roads] to DRC [Democratic Republic of Congo], carrying their goods, and trying to find markets in DRC. Some were known FDC [opposition party] supporters, and they were arrested arbitrarily. Some were having a walk, or [were] in their homes.

Cross-border traders who resisted state guidelines to ‘stay at home’ and isolate, and instead crossed into DRC to generate income, were arrested and detained at these quarantine centers, where they divided up cooking and cleaning duties, and spent entire days playing cards together and discussing how to escape. They often ‘escaped’ to conduct small-scale trade, and then returned to their quarantine centers until they were able to receive certificates of discharge. During an interview, a clinician in Kasese mentioned that ‘it was easier to discharge law-abiding citizens compared to (people who were) stubborn, resistant and people questioning authority’. Clinicians and political authorities deliberately detained defiant clients for a longer period of time.

As in Gulu, many villagers in Kasese perceived COVID-19 as a ‘disease of the radio’. For instance, one Village Health Team (VHT) community worker in Karambi sub-district observed:

In this village, we have not seen anyone suffering from COVID. We have seen many dying in far countries like China. In radio announcements, they keep talking about deaths due to COVID, in China and America. This is a disease of the radio and TV (February 2023).

And in a group discussion of seven villagers in Kisanga in February 2023, they asked:

Why has the government continued to announce lockdown, when we have not seen anyone with the disease here? For us this disease is only on radio. We hear it is killing people far away like China, but it has not reached here.

Introducing vaccines in Uganda

In March 2021, Uganda received its first batch of vaccines – 864,000 doses of Oxford-AstraZeneca – through the COVID-19 Vaccines Global

Access (COVAX), a global initiative aimed at the equitable access of COVID-19 vaccines. The Ugandan government announced priority groups to receive the vaccine: health care workers, security personnel, teachers, humanitarian and frontline health care workers and patients living with diabetes, heart disease and HIV/AIDS (Uganda 2020). By October 2021 Uganda had received 5.7 million doses, either through donations or by direct purchase. But from the outset, it was clear that most cases reported in Uganda were mild, and Ugandans were skeptical about the vaccine. People with higher levels of education, with a substantially higher level of knowledge about the vaccine, were more likely to accept it. Even so, many people, including 30.7 per cent of medical students, hesitated to access the vaccine (Bongomin et al. 2021b; Olum et al. 2020; Kanyike et al. 2021), influenced by negative information about the vaccine (53.5 per cent); fears that it might be unsafe (64.4 per cent); and concerns that it was not sufficiently efficacious to prevent disease (36.2 per cent) (Kanyike et al. 2021). Kanyike and colleagues (2021) also showed that around a third of medical students perceived only a slight risk of getting COVID-19, and were not worried about the disease. Other studies also linked low perceived risks associated with COVID-19 to vaccine hesitancy (Bongomin et al. 2021a; Sallam et al. 2021; Jain et al. 2021).

While national records indicate a 70 per cent uptake for vaccines, on 21 April 2021, Abet (2021) reported that more than 280,000 doses of the vaccine were likely to expire before being used, due to vaccine hesitancy and low uptake rates, particularly in upcountry districts where COVID infections were perceived as neither severe nor lethal. The demand for vaccines increased with the onset of the Delta variant in July 2021, mostly among elite groups in major cities like Kampala and Mbarara, by which time any vaccines available in the country had expired.

Again on September 23 ('67,000 Covid-19 vaccine doses' 2021), it was reported that 67,000 vaccine doses from a batch of 128,560 doses donated by Norway were likely to expire, 12,000 of which were in Kampala and 8,000 in Arua district in West Nile. At the time of their receipt by the Uganda Drug Authority, the vaccines had only 10 days left before expiry, and the receipt of drugs being delivered near expiry date diminished people's confidence in their efficacy and reduced their motivation to be vaccinated. This prompted the President to order District Resident Commissioners, District Health Officers and Chief Administrative Officers to carry out mass mobilization for vaccination for priority groups, on threat of dismissal if they failed to do so (President's Speech, Wednesday 22 September 2020) (Museveni 2020).

The President's threats to dismiss Resident District Commissioners and district authorities if vaccine acceptance remained low served to increase vaccine hesitancy and sparked fear among district authorities. In Kasese district, as a result, district leaders, backed by the police, instituted road blocks and forcibly vaccinated travelers and small-scale traders.

On 18 October 2021, Uganda's Minister of Health confirmed that most of the country's vaccines had expired (Kyeyune 2021). Although Uganda had received 5.7 million doses of vaccines through donations and direct procurement, only 2.4 million had been used, with the rest lying idle in storage. Of those doses administered, only 584,066 people out of the country's population of 46 million were fully vaccinated; 1.8 million had received a single dose of either AstraZeneca, Sinopharm or Johnson & Johnson vaccines. This was only 5 per cent of the population targeted to receive the vaccine by the end of September 2021 (Kanyike 2021); fewer than 15 per cent of targeted teachers, 34 per cent of targeted health workers and 19 per cent of targeted security personnel had been fully vaccinated. Kanyike (2021) concluded that Uganda had failed to reach the September 2021 target set by the WHO for countries to vaccinate at least 10 per cent of population priority groups.

In January 2022, local media reports showed that Uganda was set to destroy 400,000 doses of expired COVID-19 vaccines, when less than half of the targeted 22 million people had been vaccinated (Ojambo 2022). In June 2022, evaluating the campaign mode, the Minister of Health confirmed that the expired AstraZeneca and Moderna vaccines had been transported to northern Uganda but had not been used. Of the 500,000 doses of Moderna sent to northern Uganda, only 100,000 doses were used. In mid August 2022, it was projected that 1.2 million doses would have to be destroyed if not used by the end of the month (IntraHealth International 2022).

Rollout

Forcibly vaccinating travelers and small-scale traders ignited a general public outcry and threats of litigation of the state by affected citizens on radio talk shows. This prompted the state and global health partners such as the MOH-Uganda National Expanded Program on Immunisation (UNEPI) office in Uganda to draft guidelines to support a health promotion campaign to enhance vaccine uptake. In campaign mode, with legal backing, COVID-19 vaccines were extracted from routine vaccine supply chains, and people were asked to access vaccines outside health centers.

As described above, the Ministry of Health (MOH) in Uganda received its first donation of 864,000 doses of AstraZeneca COVID-19 vaccine, shipped via the COVAX facility, on 6 March 2021 (WHO 2021). To administer one vial of AstraZeneca, a minimum of 9 to 12 people had to visit a designated vaccine center, since an open vial could not be stored for future use. In June 2021, Uganda received a second batch of vaccines donated by the French government (Agaba 2021); other vaccine deliveries were donated by and acquired through bilateral purchases from China and India's Serum Institute. From receipt of the first batch of vaccines at the Ministry of Health headquarters in Kampala and in other cities like Gulu, Mbarara and Arua, the government's message was received with skepticism. The Ministry needed to use these supplies urgently, and it did this by issuing an order that all men in uniform, particularly in the Uganda People's Defence Forces, were to be vaccinated. Along with military personnel, those people whom one officer at the Ministry of Health called 'vaccine enthusiasts' (people who willingly accepted any vaccines as life-saving technologies) were vaccinated. But District Task Force staff in Gulu and Kasese, and National Task Force officials in Kampala, indicated that much of the first batch of COVID-19 vaccine had expired and had been reported to be withdrawn from health facilities and destroyed by the National Medical Stores; by August 2021, more than 5.6 million doses purchased through a World Bank had expired and were to be destroyed (Bamulanzeki 2021).

COVID-19 containment activities like lockdown shaped responses to vaccination, and as noted above, the roll out of the program was largely met with resistance, low uptake and suspicion. One officer told Ugandans:

If you have not yet been vaccinated, please make sure you do so while we still have some doses. In the coming months, no one will be allowed to cross PoEs, enter public offices and banks, unless you have proof for COVID-19 vaccination. (Interview, June 2021)

During a group interview (May 2022), villagers in Gulu said, and others agreed: 'For sure, let the government invest this money they are using on Covid to buy and distribute cassava instead'. An officer at the NEOC similarly stated: 'Give me cassava any day. It is because I am sure of its purpose, in feeding the hungry. But this Covid response thing has divided many people even here in NEOC' (Interview, May 2022).

Travelers at major airports globally needed to have proof of vaccination against COVID-19. In Uganda this was enforced at various

PoEs, including Kasese, where travelers received extra doses to the required two doses if they had left their vaccination cards at home or had not received a vaccine card when vaccinated. One 56-year-old man traveling from Kasese district reported:

In one week, I was vaccinated two times ... because I was traveling to Kampala yet I had no vaccine card. Instead of missing the business opportunity because I could not travel without the vaccine card, I [was] allowed to take another Johnson Johnson jab in order to be allowed to continue with my journey. (Interview, May 2022)

In Mpondwe and Karambi PoEs in Kasese district, many villagers were forcibly vaccinated at makeshift roadblocks. Research participants recalled: 'On that day, every bus was stopped and soldiers demanded to see all passengers' COVID-19 vaccine cards. Whoever did not have one was forcibly vaccinated before being allowed to proceed' (Interview, July 2022). Another interviewee added, 'the people at the roadblock were very tough and cruel. It was a waste of time to argue with them. Although I had only left my COVID card at home, I simply allowed [myself] to be re-vaccinated' (Interview, July 2022).

In the Kasese towns of Mpondwe, Bwera and Mobuku, many small-scale traders, travelers and frontline health workers reported they were vaccinated three or four times within a month. The military, supported by Uganda Red Cross, Baylor Uganda, WHO and CDC Africa, set up roadblocks at strategic points and prohibited people from traveling unless they showed proof of vaccination. Any individual who had lost, forgotten or not received a vaccination card in the prior COVID-19 vaccination exercise was vaccinated again before being allowed to proceed. In Kasese and Mpondwe POE, travelers who resisted or questioned why they needed to be vaccinated for COVID-19 were arrested and delayed in conducting their business:

By the end of the campaign mode, many people had been vaccinated multiple times with Johnson & Johnson vaccine. They were forced to take the vaccine again if they had forgotten their cards; they were punished and then vaccinated if they resisted and many *only* accepted to be vaccinated because in the previous receipt of COVID-19 vaccine, they were not given vaccine cards as proof. (Interview, May 2022)

Vaccine hesitancy among frontline health workers

Many frontline health workers questioned the vaccine rollout and were hesitant to be vaccinated themselves; to protect their jobs, some secured vaccination cards without actually getting vaccinated. In Karambi, Bwera and Katwe health centers in Kasese district, vaccines were administered to villagers by VHTs, who would typically sit in an isolated tent, waiting for clients to present for vaccination. Both potential clients and health care workers were keenly aware that the vaccines were at the point of expiry, leading to demotivation. VHTs would monitor the expiry dates closely and inform the District Taskforce when vaccine stocks were approaching expiry dates. In two interviews at Karambi and Katwe health centers, VHTs recalled how the Kasese DTF had instructed them to stop administering vaccines within one week of expiry. Additionally, the DTF in Kasese conducted radio talk shows indirectly encouraging people to access more reliable vaccines, entreating them to access *either* cholera or COVID-19 vaccines.

The cholera vaccine seemed much better since it had a longer expiry date of four years. But for COVID-19 vaccine, some had only one or two weeks to expiry date. Generally, clients who choose cholera vaccine should not take COVID-19 vaccines. (Interviews, May and September 2022)

Local authorities and local clinicians' perspectives about COVID-19 likely also affected uptake by people at risk. In several health centers in Kasese, Gulu and Wakiso, clients rejected the vaccine if the clinician they trusted or regularly interacted with in their local language had not been vaccinated. In a meeting to assess vaccine uptake after the campaign mode vaccination drive in Kampala, which I attended in June 2022, WHO representatives noted the inability of frontline health workers, ministry staff and the NEOC to vaccinate even the small target of 5 million Ugandans: 'What really needs to be done', one WHO official asked aloud, 'to attain this small figure?'

As noted, vaccine enforcement ignited outrage and suspicion. Nurses, midwives and other clinicians in Kasese, Gulu and Wakiso feared the vaccines were expired, others did not see their relevance, and still more perceived the vaccine rollout as a form of authoritarianism. Initial attempts to enhance the uptake of vaccines, mediated by militarization from May to August 2021, were met by public outcry. Many people wrote to newspaper editors raising questions of the forceful means to improve vaccine uptake

(Abet 2021; Monitor 2022). In response, the state, supported by donors, enacted and formulated legal guidelines to support their efforts.

Campaign mode, February–September 2022

The legal package and guidelines, which enabled COVID-19 vaccines to be delivered in ‘campaign mode’ or heightened health promotion, was launched in February 2022. This activity was led by the MOH-UNEPI program, with support by the WHO, CDC-Africa and other vaccine donors. Its main aim was to heighten and enhance uptake of COVID-19 vaccines in both rural and urban areas. Campaign mode activities strategically targeted distant and rural districts like Gulu and Kasese, which experienced the lowest COVID-19 mortality rates and case positivity in Uganda. The MOH-UNEPI teams, accompanied by loud music systems, following an itinerary of pre-organized meetings in upcountry centers, aiming to convince listeners of the importance of the vaccine. There were funds for this activity and many officers at the MOH traveled to villages with the aim of improving vaccine uptake. One officer at UNEPI mentioned: ‘The activity was important but it was [a] race against time, meeting global partner demands which was more important. Some vaccines were about to expire, or they were even expired. But people in many districts did not respond well’.

As already described, in campaign mode, the routine supply chain for vaccines was ignored. Typically, the guidelines enabled MOH colleagues to supply vaccines outside of clinical settings. District response teams commissioned original songs to be composed, suggesting that COVID-19 was a ‘killer disease’, and repeatedly played this in public settings. Vaccines were distributed at funerals, playgrounds, weddings and cultural ceremonies, and in playgrounds, schools and churches. At one funeral in Unyama subcounty, Gulu, a COVID-19 vaccine team erected a tent next to the burial ground, and repeatedly made announcements that mourners should go and get vaccinated. By observation, no one responded; people were grieving, laying wreaths and eulogizing the deceased. Apart from the villagers and frontline health workers who were forcibly vaccinated, few people responded to announcements by vaccine teams requesting that they leave funerals, weddings or other festivities to get vaccinated. One VHT member in Bardege hospital observed:

We know that the COVID-19 vaccines are expensive, and the government spent a lot of money to buy them. Some donors

have also brought for us many vaccines. But the people here do not listen. They think vaccines are only for diseases which can kill people. They say they have not seen anyone die of corona. (Interview, May 2022)

In Gulu, the campaign mode team invited one cultural leader to serve as a model; he agreed to be vaccinated in public. After campaign mode activities concluded in the districts, with low adult turnouts, the remaining vaccines were deposited in health centers and frontline health workers were instructed to administer them on request. By observation, in turn, in Karambi and GRRH, the frontline health workers shunted the responsibility for these activities once more to VHTs – local untrained volunteer healthworkers who usually perform only sensitization work and promote awareness in villages by distributing posters carrying health messages.

Kasese district is largely known for opposing initiatives of the current ruling party, and had historically been punished for it. Here, villagers argued that the vaccine rollout was another means by which the state could assert its authority, not necessarily to ensure population wellbeing. They questioned why the state, which frequently neglects their everyday health needs (by not providing malaria drugs, or facilities for admitting patients, for instance) was pushing vaccination against this ‘disease of the radio’. One leader at Kasese sub-county reflected:

I have never seen a disease which attracted as much government attention as COVID-19 in all my 10-year tenure, even when people in this area only know it through radio announcements ... the frequent jingles. The other day, the COVID-19 team wanted to interfere with a burial in the village, saying the death was due to COVID-19. Villagers became rowdy and wanted to fight the burial team. There was chaos until police came to resolve the situation and allow the villagers to conduct a normal burial.

Through observation and interviews with frontline health workers and clients alike at designated points, turnout was low from May and July 2022; on some days nobody came to be vaccinated. Over the course of a week-long observation in three health centers in May, only five teachers reported to Bwera hospital, and two villagers presented at Karambi for vaccination. At both these centers, when the VHT informed them that the vaccine was available but vaccination cards were not, people who presented then declined vaccination: it was apparent that their decision

to get vaccinated was not influenced by the need to protect themselves from infection, or any COVID variant, but by the need to protect their jobs.

The power of metrics and the logic of policy

The campaign mode for vaccine rollout was a legally backed approach to enhance COVID-19 vaccine uptake in Uganda. But while vaccination uptake dramatically reduced the mortality rate globally, COVID-19 had not been experienced as a killer disease in Uganda, even though it was known to cause deaths among people who were elderly or had comorbidities. Ugandans' experience of the disease was that severe infection and mortality were rare and the disease was never perceived as lethal. Certainly it was regarded as far more benign than other diseases like polio, measles and diphtheria, for which vaccination was traditionally rolled out in this same enhanced mode. However, the campaign mode was concerned with more than disease prevention. It was also concerned with a need to meet global health partner metrics; the state's assertion of power and authority; proof of response to an urgency by distributing this life-saving medical technology to vulnerable people; and dealing with vaccine hesitancy among poor people.

In the drive for vaccine equity, global health agencies pushed for the delivery of vaccines to Africa. Africa CDC also made this a priority. 'Partners' from these agencies operating in Uganda were under pressure to drive the vaccine equity agenda and improve vaccination rates to meet global targets; as one officer at UNEPI reflected: 'Each time we are invited for meetings by our partners, one of the items on the agenda is *how to improve vaccine uptake*. It is not even asked whether we need the vaccine such as COVID-19 vaccine or not' (June 2022).

I attended several meetings between November 2021 and June 2022 at MOH and NEOC and in District Task Force meetings in Gulu and Kasese and at the Public Health Emergency Operation center. In one meeting, a senior officer at the WHO angrily asked: 'How are we going to present this report to our global partners? What haven't we done right to only attain these low figures of less than five million people vaccinated?' He continued:

Why are even nurses not able to input data digitally to show the number of clients they have administered COVID-19 vaccines to? Don't forget that we have invested so much in the digital platform and trained these very nurses! I hear in many health centers, the

task has been left to unpaid, less technical VHTs. (Global hybrid and Zoom discussion at Uganda Low Vaccine Uptake, June 2022)

Over time, it became clear that the government's intentions were as much oriented towards fulfilling the expectations of recording high COVID-19 vaccine coverage metrics predetermined by global health partners, as they were towards protecting people against disease. The power of data and its importance to government and donor officials emerged as a key force driving action in Uganda. Further, deaths reported during the pandemic were more often caused by underlying diseases including malaria than COVID-19. Meanwhile, immunization clinic attendance declined. The number of children treated for pneumonia, diarrhoea and malaria also declined (Burt et al. 2021). Immunization against diseases like diphtheria, tetanus and pertussis (combined in the DTP3 vaccine) was lower in 2020 than in the two previous years (Burt et al. 2021). Neonatal mortality rose from 39 to 49 per 1,000 live births. Burt and colleagues (2021) have shown that antenatal attendance decreased and remained low during lockdown in Uganda, with an average reduction of 370 per 1,000 pregnant women reporting for routine antenatal care (between March 2020 and December 2020). This was likely partly due to the lack of availability of public transport during lockdown, but also because, apart from essential workers, at-risk people – including pregnant women – were prohibited from traveling.

Some WHO officers strategized to improve metrics for COVID-19 vaccine uptake, though repeatedly questioning NEOC and MOH officials and various task force members' efforts during online meetings. NEOC and MOH officials typically suggested discussing another item on the agenda. For instance, in June 2022, one agenda item was a report on low uptake of COVID-19 vaccines to global partners. Instead of presenting a grim picture, WHO participants suggested a positive spin, with emphasis on 'what went well about COVID-19 vaccines in Uganda'. The report emphasized 'positives', including that 'the president and cultural leaders were supportive'. For instance, in many districts like Gulu, Kasese and Kyenjojo, some cultural leaders agreed to openly take the COVID-19 vaccine. But not even these 'performances' motivated villagers to come out and take the vaccines. The NEOC report, drafted during the above stakeholders' meeting with MOH officials, reached certain conclusions, including that campaign mode had not improved vaccine uptake. Further, all efforts to enhance vaccine uptake yielded limited success.

In several interviews, even with senior officers at the MOH headquarters in Kampala, respondents wondered why state efforts in COVID-19

containment were not commensurate with how COVID-19 manifested. One senior officer at the pharmaceutical department, for example, argued:

Viruses are always with us, and the idea that they can shift from latent to virulent mode should be common knowledge to us. The only thing is that we should know that they can be controlled through basic approaches such as isolation, quarantine and conservative management. The best way to do this is to first make sure our health systems are efficient and equipped. Therefore, vaccines are not the best approach. For instance, this COVID-19 vaccine. How many variants are you going to deal with? What other variants are still in latent phase? Are you going to have resources to keep manufacturing vaccines for every virus? (Interviews, MOH, June 2022)

As this suggests, many people felt that vaccination was inappropriate, given COVID's manifestation as a mild disease in the majority of the population. Further, people questioned the prioritization of resources. For one government official, investment in strengthening general health systems (whereby hospitals were equipped with staff, clinicians and equipment to handle infectious diseases) seemed a more valuable use of time and resources. From his point of view, Uganda's experience of COVID-19 failed to justify vaccinating its entire population.

Resistance to containment methods also manifested at a national level, as this MOH officer suggested:

This COVID-19 has exposed many things among local and policy makers here at the MOH. Can you imagine, because there was some money received from donors, some officers were being co-opted and requested to go for admission at Mulago to try to indicate a burden of disease in order to receive some donor money? All this in order for [the] state to show other global actors that Uganda was also affected by COVID-19. (Interview at MOH, May and June 2022).

In short, Ugandan officials tried to respond to donor interests with a view to keeping funds flowing. Proportionate disease containment responses or tailored national responses proved impossible because of the need to report to funders, demonstrating outputs required by international partners. One officer at MOH-UNEPI argued:

This COVID-19 vaccine thing is dividing clinicians, politicians and responders. People in UNEPI are always invited to say Pfizer

and Sanofi Aventis for conferences abroad. And they come back with such powerful ideas to support their plans that what is left is to accept their ideas. The way I see it, they already know how COVID-19 was experienced here. They know that those who died in hospitals are mostly those with other conditions and they were neglected. They also know that Uganda has not really experienced the virulent form of the disease like the Europeans, Americans and Chinese. But since they have been facilitated financially, they will have to support the idea of vaccination even when it is not necessary. Just follow closely, there is no way those officers can ever decline the administration of any vaccines. ... I told you my story, there are many things which happened during COVID-19 lockdowns that made every officer here [at MOH] not trust anything about COVID-19. The responders, the money for admission, the admission and subsequent neglect, the yearning to increase the number of COVID-19 deaths, *in order to justify budget increase*. (Interview at MOH, May and June 2022).

As this indicates, some Ugandan officers believed in the value of a more context-sensitive approach to a vaccination campaign in Uganda, one attuned to local emerging epidemiological data and existential reality. Many officials interviewed, including the officer at MOH-UNEPI, were aware that donor funds were being directed to the country because of an assumption that COVID-19 would play out in Uganda as it had in other countries. Ugandan officials did not want this flow of funds to cease and so were keen to meet the expected outputs. Further, pharmaceutical companies were perceived to have vested interests in the vaccine push.

In one regional meeting hosted by MOH-Entebbe in April 2022 with representatives from the CDC, WHO and COVID-19 support partners like the European Union, the issue of rolling out the COVID-19 uptake in campaign mode was discussed extensively. One officer recounted that ‘even if the CDC discovered that the COVID-19 vaccine was not accepted by local people, and that people needed something else ... still the money for the COVID-19 vaccine had to be used for the COVID-19 vaccine’. He continued ‘I would rather take back the money, instead of giving it to the country to allocate it to other pressing health matters’ (Interview, April 2022).

As this participant highlighted, there was an emerging disconnection between local and global stakeholders in health, but also between MOH officials and global health partners’ actions, informed by their assessment of Ugandan health priorities and their objective of achieving

greater global vaccine equity. The officials, aware of COVID-19's mild manifestation in Uganda, had a different understanding of priorities to which donor funds might be allocated: strengthening health systems or responding to other infectious disease outbreaks, for example. But the need to preserve funding flows made it difficult for health officials to push back against the global agencies, whose representatives sat in on the national meetings. One junior officer at the MOH concluded an interview by speaking of the skewed nature of the vaccination effort and focus of the campaign mode. He perceived vested financial interests behind this widespread vaccination drive, since, in his view, it was evident that COVID-19 vaccination should not be a priority for Uganda:

At this stage we are all aware that the West was more affected by this disease. This made the pharmaceutical companies invest so much money to ensure that the disease is eradicated. Do you really think the investor in vaccines can just sit back and deal with losses? At least there must be ways for them to breakeven with these commodities. For instance, we have seen even World Bank, giving us a debt of 18 billion to ensure that this vaccine thing is rolled out. (Interview June 2022)

Summary observations

Four key observations emerge from the research I have presented. First, perceptions and observations of COVID-19 led villagers and others to resent forced quarantine, and to resist accepting the COVID-19 vaccine, even when distributed in campaign mode. Second, there was widespread ambivalence about accepting and distributing COVID-19 vaccines among frontline health workers, and health policymakers expressed disquiet about prioritizing the roll out of vaccines. This highlights a perceived disconnection between global priorities and discourses, and experiences and priorities at national and district levels. A third and closely connected observation is that the pressures to succumb to the policies and priorities of global partners was perceived to be intense. The endeavor to meet global health partners' agendas and maintain funding streams for other global health programs in Uganda underpinned the shift from static to campaign mode. This shift demonstrates how a global political economy shapes the policies and practices of national governments, as they seek to maintain a good image to global donors to pharmaceutical companies. Finally, state authoritarianism in

efforts to enforce first quarantine then vaccination sharpened distrust among target populations.

These findings broaden our understanding of vaccine preparedness and response. By foregrounding the perspectives of health officials and practitioners at national, district and sub-county levels, I demonstrate the multiple ways in which politics in both global and domestic spaces shaped endeavors to contain and manage COVID-19.

I see contradictions and disconnections between Uganda's local experience of COVID-19 and the global response. Officials questioned the necessity of investing in COVID-19 vaccination for all citizens, including young people. As well as analysing these contradictions, I also share ethnographic findings from a national health policy level, from districts and hospitals and among villagers in our study sites. Although here I follow the experience of COVID-19, elsewhere with others I have shown similar disjunctures characterizing approaches towards Ebola containment in northern and southwestern Uganda (Park and Akello 2017, Akello and Parker 2022). For instance, in Park and Akello (2017), we have shown how at-risk groups practiced caregiving in spite of their awareness of Ebola's virulence, yet local global health campaigns emphasized social distancing, mask wearing and referring affected people to designated points of treatment. To a great extent, at risk people go beyond standardized approaches to provide care in Uganda. This is, in part, a result of their awareness of challenges in the health system (Akello and Beisel 2019). Despite Uganda's experience with lethal epidemics like Ebola, and despite prior learnings that tackling one disease at a time is not only costly but also diverts attention from other priority health matters (Akello and Parker 2022), during the pandemic, again, Uganda focused only on COVID-19, a focus that had little impact on improving general wellbeing.

In *Pathologies of Power*, Paul Farmer (2004) explained how global and economic powers are entrenched in approaches to deal with diseases of poverty, including recommending appropriate technologies. If over 80 per cent of cases of COVID-19 in Uganda were experienced as mild or asymptomatic, then the current campaign mode to enhance uptake of COVID-19 vaccines is a classic example of how pathologies of power manifest among impoverished populations to enforce attempts to assert power and authority. Such heavy-handed state activities resonate with what Fisher and Anderson (2015) term securitization of development, whereby Uganda may evoke security threats to enforce its authoritarian agenda. Some of these authoritarian activities may be financed by other global agendas.

Ugandans have different priorities, including vaccinating children against killer diseases, fighting hunger and reducing mortality due to diseases like malaria, HIV and maternal mortality. As one respondent reflected: ‘You have brought the COVID vaccine, but we want cassava.’

The contradictions and disconnects were unprecedented during the COVID-19 pandemic. They confirm that there are no conventional standard interventions in global health, and that past experiences and the political atmosphere shape people’s participation in and adherence to global health interventions. To ensure better preparedness for disease epidemics in Uganda, there is an urgent need for decentralized systems of prioritization and decision making, and by extension, I argue, for a decolonizing of global health.^{2,3}

Notes

- 1 PCR (polymerase chain reaction) test used to diagnose people carrying the SARS-CoV-2 virus, which causes COVID-19.
- 2 I thank my colleagues, Professors Lenore Manderson, Nancy Burke, Melissa Parker and Hayley MacGregor for their constructive comments. The study was funded by Wellcome Trust (NH/17033).
- 3 Ethics approval was granted by the Uganda National Council of Science and Technology (SS4895).

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The chronicity of militarism: Sri Lanka's response to the COVID-19 pandemic

Priyanka Jayakodi

As I write this chapter, Sri Lanka faces its worst economic crisis since its independence from the British colonizers in 1948. It is a time characterized by constant state action to curb dissent, and consistent efforts to dismantle people's right to assemble and protest peacefully. For instance, the logic of 'national security' and draconian counterterrorism laws, such as the Prevention of Terrorism Act (PTA), have allowed arbitrary arrests and the policing and torture of minoritized groups, activists and journalists (Deane 2022; de Alwis 2022). The most salient characteristic of post-war Sri Lanka is the military's involvement in activities that are not traditionally under its purview, such as city beautification, farming and restoring Buddhist temples. There seems to be a general acceptance or consensus – at least within the dominant Sinhala Buddhist community – that the state's use of military forces to solve numerous sociopolitical problems is an effective use of the military in post-war Sri Lanka. Consequently, when the government used the military to enforce curfews, administer vaccines, contact trace and run quarantine centers during the COVID-19 pandemic, the attitude that the military can be or should be used to solve sociopolitical issues was reinforced.

The popular framing of the containment of COVID-19 in Sri Lanka as a war against the virus justified and legitimized the use of military forces in ways that infiltrated people's everyday life. In examining this, I describe how the military permeated and trafficked through different constituting parts of society – families, communities, public institutions, religion – that stand in nested relationships with the state. To this end, I use data generated through archival research (for example, mainstream media reports, images, social media posts, government

policy documents, media briefings related to COVID-19) and ethnographic interviews I conducted with Sri Lankans who experienced military oppression during the COVID-19 pandemic. As an analytical lens, I develop the concept ‘chronicity of militarism’ with an attunement to militarism’s temporal and structural dimensions and its material existence as militarization.

A working definition: chronicity of militarism

The term ‘chronic’ etymologically concerns time (Old French *chronique* or Latin *chronicus* both convey a temporal aspect¹); thus, chronicity is generally understood as a condition or a state of being ‘of long continuance’. In medical anthropology, ‘chronicity’ is often used in the sense of an illness category which is characterized by linearity and temporality (Kleinman 1988; Charmaz 1991; Estroff 1993). For instance, Sue Estroff defined chronicity as ‘the persistence in time of limitations and suffering and to the resulting disabilities as they are socially and culturally defined and lived’ (1993, 250). For her, ‘chronicity consists of a fusion of identity with diagnosis, a transformation of self to self and with others’ (251). In conceptualizing chronicity, typically, scholars focus on aspects such as the *time* (Frankenberg 1988) and *management* of chronic illnesses (Charmaz 1991; Naemiratch and Manderson 2008). However, Lenore Manderson and Carolyn Smith-Morris emphasize the need to reconstitute the ‘old temporal distinction’ of the acute/chronic illness binary and reconceptualize chronicity by heightening one’s ‘sensitivity to the structural factors that create, maintain, and produce fluidity and flux in disease patterns, their management, and outcome’ (2010, 1). Such a (re)conceptualization of chronicity allows an holistic analysis of disease processes which considers both individual experience and sociocultural context of an illness experience. This insight that chronicity needs to be understood beyond the linear understanding of time is crucial to conceptualizing ‘chronicity of militarism’.

According to Cynthia Enloe (2016), militarization is the ‘step-by-step social, political and psychological process by which any person, any group, or any society absorbs the ideas and resultant practices of militarism’ (12). Militarism is an ideology established through beliefs in and support of militarization as necessary and inevitable. In other words, when people (especially, dominant social groups) passively or actively accept this ideology, they support militarization as the most

logical and the best social control mechanism for the greater good of the nation-state and the safety of its subjects. As Roberto González and Hugh Gusterson claim,

militarism, like capitalism, is a lifeworld with its own escalatory logic that takes different local forms while displaying fundamental underlying unities ... rationalized and legitimated as defensive reactions to someone else's militarism from which they, therefore, differ in moral character. (2019, 22)

For Enloe, militarism is a 'complex package of ideas that, all together, foster military values in both military and civil life' (2016, 11). While these ideas that foster militarism are contextual, generally they include the belief that military personnel are the saviors/guardians/protectors of the country and that they deserve special praise and recognition for their service to the country; the belief that hierarchies of command are natural and necessary for a disciplined society; and that a strong military is intrinsically bound with the security of the nation-state. Such views 'justify military priorities and military influences in cultural, economic, and political affairs' (Enloe 2016, 11).

By coining the term 'chronicity of militarism', I draw attention to both the temporality of militarism (that is, continuance through various actions, institutions, thoughts and values) and its direct and indirect participation in perpetuating structural violence (Farmer 2004). Chronicity of militarism highlights that military oppression is historical and not equally felt or shared by communities across a nation-state. It demystifies the processes through which the state makes the military a mundane part of lived experience and the sociopolitical imaginary. Through the constant use of the military in everyday life, militarization becomes reified as a solution for everything. It becomes a central part of lived reality (almost becoming an object like a chair, a dumpster or a grocery store) so mundane that it ceases to be seen as an aberration or a threat, becoming an unquestioned part of 'the order of things' in civil society (Foucault 1966/1989). Chronicity of militarism attends to and disrupts this normalcy. In this chapter, I explain how militarism in Sri Lanka engenders social suffering in some communities more than others. To that end, I draw on Manderson's and Smith-Morris's (2010) radical conceptualization of 'chronicity' and provide substantial examples of how the Sri Lankan military meddled with people's everyday life during the COVID-19 pandemic.

Militarized responses to health emergencies and the war on COVID-19

The militarization of public health emergencies is not new. In *Discipline and Punish: The Birth of the Prison* (1975/1995), Foucault refers to an order found in Archives Militaires de Vincennes to describe the strict measures taken by the state when a plague appeared in a town at the end of the seventeenth century:

First, a strict spatial partitioning: the closing of the town and its outlying districts, a prohibition to leave the town on pain of death ... Each street is placed under the authority of a syndic, who keeps it under surveillance ... each individual is fixed in his place. And, if he moves, he does so at the risk of his life, contagion, or punishment. (1975, 195)

This is an example of biopower, where the governing or ruling body uses diverse technologies to achieve ‘the subjugation of bodies and the control of populations’ (Foucault 1978, 140). Foucault’s description of how strict surveillance and containment measures were implemented during the plague is akin to numerous steps taken by governments across the globe during the Ebola outbreak and, more recently, the COVID-19 pandemic. The modern military officer used by governments as a surveillance and punishment technology bears some resonance with the syndic of seventeenth-century France.

A growing body of literature describes how different pandemic governance technologies have been enacted in nation-states worldwide, and how these have been received. Danny Hoffman (2019), through his ethnographic research in Liberia, shows how the militarization of the Ebola outbreak provoked a civilian backlash. Similarly, referring to the Ebola crisis in West Africa, Adia Benton shows how domestic military forces secured ‘state interests by threatening violence against vulnerable citizens’ (2017, 26). During the COVID-19 pandemic, governments worldwide took various measures in the form of strict lockdowns, border closure, surveillance, quarantine and curfews to contain the virus (Gibson-Fall 2021; Giroux 2021), often involving the military to do so. The degree to which the military gets involved as a pandemic governance technology is entangled with its historico-political positioning in respective countries. For instance, in 2020, the French president mobilized the French army for *Operation Resilience* and declared war on COVID-19 (Opillard et al. 2020). In Brazil, under Jair

Bolsonaro's administration, framing the pandemic 'as an extra-territorial threat' legitimized and justified the deployment of the military in place of health care workers 'as an attempt to bring a sense of domestic peace and economic stability' (Pfrimer and Barbosa 2020, 140).

The reactions of the public to the military involvement in COVID-19 pandemic control were divided. For instance, Lenore Manderson and Susan Levine, referring to South Africa's militarized response to the COVID-19 pandemic, discuss how state-imposed curfews and surveillance strategies, although punitive and violent, were welcomed by some as a form of state care, although 'for the poor and dispossessed the COVID-19 pandemic was less of a rupture than a deepening of social fragility' (2021, 63). Similarly, Svetluša Surová shows how the securitization measures to contain COVID-19 'took place instead of right-based discourse and a humanitarian approach towards the most vulnerable and socially excluded, six marginalized Roma communities' (2022, 1033). Nation states might project military involvement in response to the COVID-19 pandemic as the most desirable, logical, efficient and practical solution; however, the consequences of such a response depend on historical and contemporary sociopolitical realities in any given setting. In many countries across the globe, the militarized responses to the pandemic intensified the already existing discrimination and violence against certain communities more than others (Manderson and Levine 2021). Similarly, different communities had varied understandings of and reactions to militarization depending on their historical, sociopolitical and economic backgrounds.

Using military metaphors to refer to different health conditions – those that are chronic, life-threatening or infectious – is pervasive not only in common parlance but also in scholarly writings in Sri Lanka as elsewhere (for example, battling cancer, the war against obesity, the war against tuberculosis, fighting HIV). Metaphorization or 'giving the thing a name that belongs to something else' (Sontag 1989, 58) can be harmful in the context of illness, as these metaphors can convey a moral meaning detrimental to people affected by an illness. For example, in *Illness as Metaphor*, Susan Sontag (1978) explains how illness becomes a cultural metaphor, and particular diseases like tuberculosis, cancer and leprosy can have compelling social meanings in specific contexts. The symbolic dimensions of illness often have unfavorable valuations and result in social stigma and ostracism. As Sontag states, '[n]othing is more punitive than to give a disease a meaning – that meaning being invariably a moralistic one' (1978, 58). It is therefore crucial to unpack and disrupt the normalcy of using military metaphors to understand illness and health emergencies.

Globally, in the case of COVID-19, military rhetoric implied the need for and urged the weaponization of disease and the diseased. The Secretary-General of the United Nations, António Guterres, claimed, 'We are at war with a virus. We need the logic and urgency of a war economy to boost the capacity of our weapons' (UNIFEED 2021). Similarly, in the UK, Elizabeth II intentionally evoked war memories in her speech on the pandemic when she said, 'We will meet again' (BBC 2020b), referencing the song made famous by Vera Lynn in the Second World War. The French president, Emmanuel Macron, stated that 'the country was at war with an invisible, elusive enemy' (BBC 2020a). In Sri Lanka, the containment of coronavirus was often portrayed by the government and (pro-government) media as a war against the virus. Newspaper headlines such as 'Special operation to trace unvaccinated people in Colombo' and 'War against COVID-19' were common (Fernandopulle 2021). At a media conference, Mahindananda Aluthgamage, a state minister, made a scathing statement that the Kuwaiti Government had knowingly sent back Sri Lankan immigrant workers who had contracted COVID-19 to Sri Lanka as 'human bombs' (*Colombo Times* 2020), invoking Islamophobia and evoking the memory of the Easter Sunday Bombings and suicide bombing during the civil war. Ignoring the violence of such language and the reproduction of ethnonationalist insecurities create conditions that dehumanize already marginalized people and perpetuate militarism.

An emerging body of literature examines the framing of COVID-19 as a war and a threat against national security in different countries (Cusato 2021; Pfrimer and Barbosa 2020; Gibson-Fall 2021). Exploring the normative implications of war metaphors and securitizing narratives as applied to the COVID-19 pandemic in international law, Cusato (2021) underscores the need (for the international legal community) to reject such narratives which oversimplify the reality, and to take responsibility for these problematic narratives. Similarly, Varma (2020) underscores that the military logic of the pandemic should be challenged, 'otherwise, we will remain tied to a world in which war is not only inevitable but also salvational' (377). One can argue that the war narratives which emerged during the COVID-19 pandemic gained people's attention to act in ways consistent with orders by health authorities to safeguard themselves (and others) against the virus. Nevertheless, such narratives, (re)circulated through newspapers, television, the internet and social media, have a wide impact on the larger society.

Beyond the war zone: Sri Lanka's military in the aftermath of war

In this section, I provide a brief background to the Sri Lankan military for readers unfamiliar with it. From 1983 to 2009, Sri Lanka experienced a civil war between the Sri Lanka tri-forces (the army, navy and air force) and the Liberation Tigers of Tamil Eelam (LTTE), who fought for an independent Tamil homeland in the north and northeastern parts of the country. On 19 May 2009, the Sri Lankan government, led by President Mahinda Rajapaksa, declared that the war was over (see Tambiah 1992; DeVotta 2004; Thiranagama 2011 on the civil war and what ignited ethnic tensions in Sri Lanka). In the aftermath of the military defeat of the LTTE, the Sri Lankan military, which had been active primarily in war zones in the north and east, was deployed countrywide, although still with a heavy concentration in the north and east, in infrastructure development, entrepreneurial business such as tourism (for example, operating lagoon cabanas, resorts and whale-watching vessels) and agricultural farms (Thiranagama 2022). In this post-war context, military presence (and violence) remained the default way of life in the Northern and Eastern Provinces while the military reach expanded to the South.

While economic development was initially emphasized as a top priority in post-independence Sri Lanka, the 1980s saw a shift, with 'national security' taking precedence, driven by escalating ethnic tensions (Tennekoon 1988). Political discourses began intertwining 'development' and 'national security', positioning the latter as a prerequisite for economic progress. With the defeat of the LTTE in 2009, the development agenda regained significance, although concerns about maintaining national security also continued (*Deccan Chronicle* 2015). During that time, Mahinda Rajapaksa appointed himself Minister of Defence and established the Urban Development Authority under his Ministry; he retained these roles until his defeat in 2015 (Amarasuriya and Spencer 2015). Meanwhile, he appointed his brother, Gotabaya Rajapaksa (then Defence Secretary), to oversee urban development as part of the national security agenda. One significant development project sponsored by the Urban Development Authority under Gotabaya was the Greater Colombo Development Project, in which army soldiers were consistently deployed on construction sites.² This raised concerns among human rights activists and scholars that the military was taking over jobs and public spaces from civilians (Thaheer 2014; Amarasuriya and Spencer 2015).

In the South, the Sinhalese majority which had largely ignored militarization in the North and East began to feel the presence of the

military, particularly when it was used to suppress protests against the government. This had tragic consequences. For instance, on 1 August 2013 the army opened fire at unarmed protestors, killing three people, including a 14-year-old, and injuring approximately 30 people during a protest against a factory that was polluting drinking water sources in Rathupaswala, Weliweriya, in the Western Province (Wipulasena 2013; Amarasuriya 2015). Using the military to hamper trade union actions was also common. In 2017, when fuel distribution was stopped by workers' unions of the Ceylon Petroleum Corporation (CPC), demanding the government to stop leasing oil tanks to India and China, the government deployed military troops to take over fuel distribution (Mallawarachi 2017). Referring to several protest mobilizations, Amarasuriya (2015) shows how post-war Sri Lankan society has been subject to greater state control through the military than during the war, and that this was backed particularly by groups supporting Sinhala Buddhist ethno-religious nationalist agendas.

Communal violence perpetuated by different ethno-religious groups in Sri Lanka has the intended or unintended consequence of reminding the masses that the consistent presence of the military is what keeps the country safe. On Easter Sunday 2019, a highly coordinated wave of terrorism was carried out by nine suicide bombers belonging to an Islamic extremist group.³ The bombing took place in three churches and four hotels, killing around 259 people and injuring many civilians (Imtiyaz 2019). That day, Sri Lankans felt that the threat of terrorism was unending, and the nation-state needed consistent military protection at any cost. In particular, the Sinhala Buddhist majority saw echoes of the civil war in this attack. The then opposition party, led by the Rajapaksas, argued that the tragedy resulted from the then government's neglect of national security. It emphasized that the government had incapacitated the Sri Lankan military. Hence, when he was a presidential candidate in 2019, Gotabaya Rajapaksa promised 'Priority to National Security' (Rajapaksa 2019). During this campaign, Asgiriya Anunayaka Thero, a high-ranking Buddhist monk, appealed to Gotabaya to be like 'Hitler' to ensure national security and the country's economic development (*Colombo Telegraph* 2018). Staying true to his mission, after coming into power, Gotabaya militarized many government institutions by assigning retired military officers to high-ranked administrative positions (DeVotta 2021). His appointment of a presidential task force, comprised exclusively of military and police members, to 'build a secure country, disciplined, virtuous and lawful society', provided further evidence of growing militarization (International Commission of Jurists 2020).

Different representations of the police and the military in Sri Lankan civil society help us to understand military involvement in COVID-19. The Sri Lanka Police Service is governed under the Ministry of Public Security. The Police Service maintains law and order, prevents crimes and anti-social activities, and controls vehicular traffic and the Sri Lanka military is governed by the Ministry of Defence, along with 39 other departments, and the President is the minister in charge.⁴ The institutional fabric or the composition of these institutions depends on the discretion of the Executive President. Most of the time, people respect and revere the military, not so much the police. Police officers are often criticized for colluding with politicians, and for corruption, incompetence and inefficiency. Hypermasculinity associated with the military is not so much associated with the police, and the police force is often portrayed as inadequate and incapable of managing large catastrophes. Sri Lanka's post-war militarization of civil life is justified through the discourses of courage, resilience, efficiency, professionalism and the absence of corruption in the military. In this context, by portraying the COVID-19 pandemic as a national threat which demanded an appropriate, disciplined, organized and efficient body to contain the virus and control people, the military expanded its reach into everyday life.

Militarization in Sri Lanka diverts public resources to the military from essential services such as education, health care and social welfare. For example, although the civil war had ended in 2009, the military budget continued to grow (Alphonsus 2021). In 2022, when the country was grappling with the COVID-19 pandemic, the highest approved budgetary allocation from the national budget was for the Ministry of Defence (Gunaseena 2021). This was counterintuitive to the expectation that the highest percentage of funds would be allocated to the Ministry of Health. Such confounding processes are integral to the logic-making that supports the extension of military reach into all levels of society. In the context of the well-planned unequal distribution of funds in the budget, the health ministry unofficially functioned under the military because the military was deployed to fulfill health care tasks.⁵

Militarizing the pandemic

On 10 March 2020, Governor Gretchen Whitmer issued Executive Order 2020–4 declaring a state of emergency in Michigan in response to the increasing number of people testing positive for COVID-19. At that time, I was working as a sales associate at a retail store in East Lansing.

As the number of people tested positive for COVID-19 started rising, many workplaces across the United States laid off employees; I was one of many who lost their jobs. During the lockdown in Michigan, I spent most of my time watching the news and following social media to see what was happening in the United States, Sri Lanka and elsewhere. Social media has always been crucial for me in staying connected with my family and close friends, and as a way to be in touch with sociopolitical and cultural changes in Sri Lanka.

On 27 January 2020, I woke up to the news that a tourist from China had tested positive for COVID-19 in Sri Lanka. She was the first COVID-19 patient reported. Social media was rife with anti-Chinese sentiments for two weeks, until the tourist tested negative for COVID-19. On the day she was discharged from hospital, a photo of Health Minister Pavithra Wanniarachchi kissing the 47-year-old Chinese woman on the forehead created another media frenzy (De Silva 2020). This provided comic relief until 11 March 2020, when a Sri Lankan tour guide tested positive for COVID-19. While the government and private TV channels reiterated that everything was under control, Facebook posts suggested that the entire country was panicking. Social media platforms were saturated with pictures of people hoarding provisions; posts called on the government to introduce mass testing and, most importantly, to incorporate the army in quarantine efforts. At the beginning of the pandemic, Sri Lanka's medical sector and the police played a significant role in containing the virus by enforcing lockdown rules, curfews and contact tracing. The police spokesman, Deputy Inspector General Ajith Rohana and then Director General of Health Services Anil Jasinghe frequently appeared on national news at COVID-19 media briefings, and soon gained social media attention. People started posting their pictures on social media, calling them 'heroes'. During the same time, the Sri Lankan government's media propaganda used COVID-19 morbidity and mortality data from the United States to heighten nationalist sentiments in Sri Lankans. News channels and social media celebrated nationalist pride and a sense of happiness by shaming the United States: the empire could not control the virus, but this small country had miraculously contained it.

However, as the number of people infected started to rise, the Sri Lankan government implemented a military-led response to the pandemic; this was encouraged and normalized through widely circulated social media posts that ridiculed the police and revered the military. The president and other political leaders in the government declared that the spread of the virus could not be contained because people were

‘undisciplined’ and that the military should work closely with the police until the virus was under control. The rhetoric around ‘discipline’ is significant here: the military is not only desirable but *necessary* because of citizens’ incapacity for self-control. This positions the military as a regulating force that responds to the inherent unruliness of people, as well as the uncontrollable virus itself: they represent this fantasy of being able to control otherwise uncontrollable aspects of society, bodies and disease. The impression that the police were incapable of enforcing lockdown rules was steadily reiterated at government media briefings, pro-government private media channels and on social media. In March 2020, the president, Gotabaya, established the National Operation Center for the Prevention of COVID-19 (NOCPC) under Shavendra Silva, then Chief of Defence and Commander of the Army. Consequently, the police and the Ministry of Health lost their decision-making power and Shavendra Silva and Gotabaya took center stage. I was shocked when Gotabaya declared a general election on 5 August 2020, dismissing health care workers’ concerns regarding the virus’s rapid spread and the limited capacity of health care facilities. I felt helpless and terrified for the lives of my family and friends back in Sri Lanka. Gotabaya allowed space for mass gatherings by intermittently lifting curfews, giving contradictory signals to the public about the significance of travel restrictions. Campaign rallies that Gotabaya attended were packed with people explicitly ignoring health regulations and concerns raised by medical personnel. After the general election, news media reported that the number of people testing positive for COVID-19 had spiked. The net result was the reimplementing of strict lockdowns. Military personnel transformed street corners into checkpoints.

As I continued to spend time on mainstream and social media, I saw how military heroism was evoked frequently, promoting the military particularly in government and pro-government private news channels. One morning, a friend shared an image on Facebook that was meant to evoke military heroism in relation to COVID-19 (Figure 17.1). In this widely circulated picture, the soldier is portrayed as someone (an invisible force) who works as a barrier to all life-threatening forces (arms, fire and the COVID-19 virus), enabling people to live peacefully without worry. This image conveys a well-established ideology that the military is willing to sacrifice their lives at any given moment to protect people. Such an ideology allows militarization as a solution for every crisis in at least two ways. First, it is the solution to controlling/containing bodies that might contaminate; second, it is represented as a necessary *precondition* for stabilized, ‘peaceful life’. This ideology normalizes the presence of army soldiers at almost every



Figure 17.1 A Facebook post appreciating the service of the military during the COVID-19 pandemic (Translation: ‘Let’s not be ungrateful and not forget ever ... war heroes, you are number one in our hearts’). Source: Facebook, 26 April 2020. <https://www.facebook.com/photo/?fbid=249904033042598&set=a.105866270779709>.

public place. Similarly, the above representation ignores that people make choices and take responsibility in everyday life. This representation of the military evades the fact that it is a part of the repressive state apparatus (Althusser 2014 [1971]). As Veena Das argues, ‘the stitching together of the state with the nation makes demands to men to exercise heroic virtues in war to protect the nation. Nevertheless, the individual experience of war might be remarkably different from the public celebration of the virtues associated with “civilized” men’ (2008, 286).

As images such as Figure 17.1 were rapidly circulated on social media, a consensus was generated that more oppressive rules (as in a time of war or terrorist attack) were required because the nation-state was under threat. The role of the military in safeguarding the country from the virus was regularly broadcasted through the media. But the contributions of the police were not shared with the same enthusiasm.

The Sri Lankan government used the military to perform tasks that the police could have performed as part of their general duties, such as informing people to maintain social distancing or enforcing traffic laws. However, the impression created was that the military was doing more than its job to safeguard the nation, and this was also linked to the legacy of war and the valorization of the military as defenders of the nation. Thus, when the military expands its reach to everyday life, obeying the hierarchical command of authority becomes a social norm, and people lose the space to question, negotiate, critique and dissent.

As the Sri Lankan Army website displayed, the military seemed especially active in performing various COVID-19-containment-related tasks in the Northern Province. For example, one news article on the army website was titled, 'Now, woman soldiers as special riders monitor spread of COVID-19 in Jaffna' (Sri Lanka Army 2021). The video and the images published under this news article show how military troops were dispatched to communicate rules and measures taken to contain the spread of the virus in public spaces. The video shows two women soldiers who have stopped a taxi driver (the only person in the vehicle) to inform him that people are required to maintain six feet distance from each other (SL Army Media 2021). While Sinhala Buddhists might find it better to have the military as a form of state care, already precarious ethnic minorities might not feel cared for by military presence in their everyday life. For Tamils in the north and east, the presence of the army would remind them of the war, the military defeat of the LTTE, and the loss of their loved ones, ancestral land and livelihoods. Using women soldiers in an area where most of the population is Tamil is symbolic of the demasculinization of Tamil men and a reminder of the authority of the Sinhala Buddhist nation-state. In addition to militarization, language policy and religious policy worked together to construct and consolidate the Sinhala Buddhist nation-state (Gajasinghe and Jayakodi 2022).

On 17 October, a news article was published about a complaint lodged against the unsafe quarantine processes of garment factory workers in Sri Lanka. The letter requested the Human Rights Commission of Sri Lanka (HRCSL) to inquire into the conduct of the respondents, Lieutenant General Shavendra Silva and the Sri Lankan military officers involved in escorting 98 garment factory workers to quarantine centers, treating them inhumanely. According to this letter, these workers were 'given mere minutes to pack their essentials, herded into buses, kept in undisclosed locations under poor hygienic conditions, not given proper food to eat and treated in a manner no human should be treated' (*Sri Lanka Brief* 2020). Women working in garment factories and as domestic

workers in the Middle East were highly stigmatized and accused for spreading the virus throughout the country. The following quote from a woman who worked at a garment factory early in the COVID-19 pandemic was cited in the complaint letter to the HRCSL:

The military came in the middle of the night and gave us only 10 minutes to pack our essentials and get onto the bus. The military told us not to delay them, because they had been having sleepless nights and were very tired. 'We have no time to check. We are overworked', they told us. I had just received my Negative PCR test 2 days ago, but I wasn't even given the chance to tell them this. They didn't allow anyone to speak! They just herded us into buses and took us away. (*Sri Lanka Brief* 2020)

The military is a granularly hierarchized patriarchal space where the execution of orders without complaint is the norm. The complaint that the soldiers were overworked sheds light on military use in Sri Lanka beyond the war zone. Similarly, the soldiers' complaint can be interpreted as a reminder of the soldier's 'incalculable' contribution to containing the COVID-19 virus. Their position as saviors of the nation-state was used to justify the ill-treatment of civilians and the disregard of human rights, especially of those who were marginalized because of their gender, ethnicity or socioeconomic status. Because of the reverence the military receives, one can hardly question the military's involvement in COVID-19-pandemic-related activities without being called unpatriotic. Therefore, there were no protests against militarization in Sri Lanka, except for individual and subtle resistance carried out by social activists, journalists and scholars.

In the field

My husband and I arrived in Sri Lanka on 25 May 2022. The politico-economic crisis was worsening, despite President Gotabaya's promise that the country would recover soon. Decades of feudal political dominance, corruption and mismanagement had led the nation-state to bankruptcy, and people were protesting, demanding Gotabaya to resign from the presidency. The public protests (*aragalaya movement*) were increasingly intense as people bore the brunt of prolonged power cuts, scarcity of fuel, medicine and food, and rising inflation. Even before I arrived in Sri Lanka, I knew that the summer break was not going to be

Later that summer, I met Himali. As I entered her garden through the wooden wicket gate, she walked hurriedly out of her house carrying two red plastic chairs, apologizing that she was unable to invite me in. Her house consisted of two rooms: a living room and a kitchen. The walls were unplastered. Monsoon rains had splattered a thick layer of mud on the walls, as if brown paint had been applied unevenly over the bottom layer of the cinder blocks. Himali explained that she felt compelled to return to Sri Lanka during the pandemic. She and many others lost their jobs and were forced to leave the Middle East; on arrival in Sri Lanka, she had been taken to an army quarantine center inside a military camp in Jaffna:

There's one thing I will never forget, the way the army took us from the airport and the way they brought us back. We got into the bus around 5.30 a.m. and it was around 6.00 p.m. in the evening when we reached the quarantine center. The buses didn't stop anywhere for us to eat; we were given just water bottles but no food. When someone wanted to use the bathroom, two army soldiers went out to check the selected wooded area and then they guarded us until we peed in the outdoor covered by vegetation. They didn't care whether it's a woman or a man. Everyone went out to the woods when they needed to use the toilet, even a pregnant woman. When we got down to go to the woods and when we got onto the bus, they counted us, as if we were criminals and we would run away.

As we sipped tea, Himali explained the rigidity of the rules at the billets (that is, the quarantine center):

At the billets, the rules were so rigid, we were given tea at 5.00 a.m., breakfast at 8.00 a.m., another tea at 10.00 a.m., lunch at 12.00 p.m., evening tea at 3.00 p.m. and dinner at 6.30 p.m. We were asked to switch off lights at 10.00 p.m., if the lights were switched on after 10, we got a call from the army guards to switch them off immediately.

Through Himali, I met Wasana, who had returned from Kuwait during the pandemic. She was furious over the unfairness of grouping people and sending them off to different quarantine facilities depending on their social and economic status:

You know, I paid relatively a larger amount which I could barely afford for the air ticket. When I asked why the tickets were expensive, the agent said that passengers should be seated according to social

distancing rules. When I boarded the plane, it was full! It took us some time to realize they had taken extra money for the quarantine as well. At the airport in Colombo, we spent hours waiting for immigration check-in and filling out multiple forms. Finally, a few soldiers came to us and asked us to wait to be taken to quarantine centers. While we were waiting for them to come back, one army personnel asked around 20 to 25 passengers who came on the same flight with us to accompany him. Later we got to know that they were taken to be quarantined in hotels – they must have been rich people or had connections with the army officers. They never came to our quarantine center in Jaffna. I heard they quarantined in hotels and Diyathalawa.

The days in quarantine facilities, Wasana explained, were strictly controlled, and she felt that army personnel always treated them with suspicion.

Nirosha had returned from Doha, Qatar during the pandemic, and had stayed 28 days in a quarantine center, away from her family, in the northern part of the country. I asked her why her quarantine had been 28 days:

After the 14 days, one person in our room got tested positive for COVID so we had to spend another two weeks there. Once that period was over, they loaded us all into a bus and drove us to our local police stations. A family member (guardian) was informed to come to the police station to fetch us home. At the police station they issued a certificate indicating that I completed the quarantine period of 28 days. I don't know why the army couldn't simply give over the information directly to the police or the public health officers in our areas without handing us over to the police station as if we were some criminals.

Despite the widespread valorization of the military as heroes during the pandemic, for these individuals, the experience of being 'assisted' or 'helped' by the military involved being subjected to a state of surveillance, carcerality and indignity made them feel criminalized and detained, highlighting the complex and uneasy intersection of military logics with health care.

The negative and dehumanizing experiences at quarantine centers located in these military camps located in the north of the country were quite different from those who were quarantined at Diyathalawa

army camp (popularly known as a VIP quarantine center) in the central highlands. As showcased on an English news program, individuals quarantined at Diyathalawa expressed gratitude to the military, praising them for their service, ‘for taking good care of them’ and ‘accommodating all their needs’ (Ada Derana 2020). These were people who spoke fluent English, marking their socioeconomic status as members of the upper class. Most had returned from countries such as the United States, the United Kingdom, Australia and Canada, where affluent Sri Lankans migrate to study, work or vacation.

Wahlberg, Manderson and Burke (2021) illustrate in *Viral Loads* how the COVID-19 pandemic has exposed ‘stratified livability’. Similarly, Judith Butler (2022), in *What World Is This?*, discusses how the pandemic exacerbated pre-existing crises of capital, care, race and climate. During the pandemic, Sri Lankan Muslims were highly stigmatized (labelled as a ‘threat’) and accused of spreading the virus to kill the Sinhala Buddhist majority. The pandemic reinforced the social and systemic production of health problems. Even those who were critical of the way the military handled them during the quarantine process tended to agree with the idea that without the military’s involvement, Sri Lanka could not have managed, because Sri Lankans are generally not ‘disciplined’ – demonstrating how politicians’ statements to this effect (quoted earlier) are absorbed and reiterated by people. For instance, Nirosha said:

I think it’s good that the army handled the quarantine processes. You know why, people are not disciplined in Sri Lanka. However, there were extreme things – the way they treated us, asking us to follow the same army theory – I think that wasn’t necessary, after all we were not criminals to be treated that way – the way they took us to quarantine centers in Jaffna from the airport was like we were caged animals. When we were in the quarantine center there were Tamils, and a Muslim family, and they rarely listened to anyone, and I felt it was good that they were under army rules.

On social media, numerous posts emerged that targeted Muslims, blaming them for the spread of COVID-19. For example, see Figure 17.3, where the team of construction workers are labelled as ‘the army, police and health officials’ and the cat that has ruined the newly cemented floor is labelled ‘Akurana Nana’ (the Muslim man from Akurana), with ‘nana’ a derogatory term used by non-Muslims to refer to Muslim men. Such racist posts went viral on Facebook during the pandemic.



Figure 17.3 A Facebook post insulting Muslims which implies that they were spreading COVID-19 (see explanation in main text). Source: Facebook, 1 April 2020. <https://www.facebook.com/photo.php?fbid=231652948213995&set=p.231652948213995&type=3>.

The stigmatization of Muslims was reinforced by the government’s policy of forced cremation of those deceased from COVID-19, which was rationalized as a scientific measure by Meththika Vithanage and Channa Jayasumana (*Daily Express* 2024). This policy was challenged by Muslims as a violation of their religious rights, but for several months their protest went unheeded, and the military, along with police and hospital staff, enacted laws enforced by the government.

Through a personal contact, I was able to meet Nisam, whose mother died from COVID-19 in December 2020. Nisam worked in a telephone repair shop and was the sole breadwinner of a family of five. We met on a Sunday at his house. Nisam told me how his mother had been sick for a couple of days when they hospitalized her; she died in the hospital. Only after her death were the family informed that she had died from COVID-19. Nisam described how, once the hospital staff confirmed

that she was COVID-19 positive, they had refused to release his mother's remains to the family to perform funeral rites:

I cried in front of the hospital staff and begged to see my mother's body and begged them not to cremate her. They never showed me or my father the dead body of my mother. They cremated the body and took me, my father, my sister, my wife with a 5-year-old child to different quarantine centers. For 14 days we were kept in separate quarantine centers around the country run by the army. Later, when we returned home, we were looked down upon by our neighbors ... as if we had committed a crime. When the *grama sevaka* (village officer) came to hand over the death certificate we didn't accept it. How can we accept it? I didn't get to complete funeral rites that our religion prescribes; she is not dead to me.

Nisam wiped away his tears. His father brought a photo of his wife and said, 'My wife is alive for me, for us she is alive. If she died, we should be able to do the funeral rites'. According to Islamic funeral rites, the deceased should be buried, never cremated. The compulsory cremation policy was based on the claim that the virus in human remains had the potential to contaminate underground water. Cremation enforced by the military, hospital staff and the police despite the objections and concerns made by religious leaders, local organizations and human rights organizations is merely one example of state violence inflicted on minoritized people in Sri Lanka (Centre for Policy Alternatives 2020). The denial of their death rights inflicted harm in multiple ways on both the dead and the living. With the amalgamation of the health care sector with the military and the police under the NOCPC, and the steady flow of resources to the military, this government policy was efficiently enforced depriving Muslims from properly honoring the dead with the infiltration of militarization into daily life (and death). In January 2021, UN human rights experts urged the government to withdraw the policy of forced cremation of those deceased due to COVID-19. In response to protests against the violation of religious/funeral rights, the government withdrew the policy the following month.

Concluding thoughts

In July 2022, three of my college friends and I were having lunch in a restaurant in Colombo. We were planning to visit the *aragalaya* protest

site at Galle Face. One friend, a human rights lawyer, observed that the military was everywhere in Colombo and there had been a rumor that trucks full of soldiers were heading towards the city. I told them that I have been thinking about militarization in Sri Lanka, reading work by Sharika Thiranagama and Neloufer de Mel to understand how militarization affects people's rights and democratic governance. Another friend, a physician, said 'I think as we don't have a war now, those soldiers should be put to work. There are thousands of them and what job do they really do now that we don't have a war? I think they could be a good labor force'. The other friend, a graduate student in the United States, objected: 'I think the military should be hidden, should not be put on display in every corner in Colombo, then they lose their respect, they become so ordinary, it's bad for the image of the military'. No one explicitly agreed or disagreed but we all nodded, as if we all understood that this was not a conversation that we could enjoy over lunch. However, the presence of the military at every street corner in Colombo and suburbs made it a topic that none of us could ignore.

The mundaneness of militarism was evident too in everyday bureaucratic processes and in people's desires and needs to have the military close to civil life or hidden away for later use, like a secret weapon. In a country where humanitarian disasters are common, military personnel are involved in rescue missions, even road accidents (*Newsfirst Sri Lanka* 2023). Through my ethnographic accounts I have intended to bring to attention how some people are prone to discrimination, dehumanization and harassment as a result of militarization, while for some, the military might be felt as a necessary protective force.

The COVID-19 pandemic is a moment in Sri Lankan history that opened up space for the militarization of the health care sector. While the government presented military involvement as crucial and the most logical and efficient solution, and the majority of Sinhala Buddhist community welcomed this without reservation, some people felt that the military had encroached on their personal life as never before. As described above, particularly for people from socioeconomically marginalized backgrounds such as Himali, Nirosha and Wasana who worked as domestic aids in the Middle East, and people from ethnically minoritized communities like Nisam, the militarization of the COVID-19 pandemic had unbearable consequences. Even people like Ruwan, with a middle class background, felt an inexplicable discomfort as he interacted with the military to get the vaccines.

Irrespective of socioeconomic status, people experienced militarization, but in different ways. The normalization and glorification

of military presence in everyday life converged with poverty and compounded the experiences of discrimination, suffering, oppression and vulnerabilities experienced by women, those who were socioeconomically underprivileged and ethnically minoritized groups. These structural inequalities converged to produce suffering, oppression and vulnerabilities, and in this, people were represented as the threatening illness for which the military was perceived as the ‘cure’ (or the solution). The government’s justification of the military’s involvement in containing the COVID-19 virus, and appealing to the public’s deference and loyalty to the military, contributed to increased investment in the military and the reinforcement of militarism.

As a dominant ideology in post-colonial Sri Lanka, militarism plays a significant role in silencing voices of dissent and limiting people from imagining greater freedom within the broader structures of democracy. A recent newspaper article reported that Sri Lanka is considering reducing the number of military personnel, given the current financial crisis in the country (Al Jazeera 2023). If this layoff of military is enacted, the decision will be based not on a sudden realization of the effects of militarization, but rather as a patchwork solution to the ongoing economic crisis and the IMF’s demand that the government cut down its expenses.

Etienne Balibar describes extreme violence as occurring not only in the ‘brutality and suddenness of traumatic events, catastrophes that bring death, displacement, (and) subjection to the power of a master’ but also in ‘the indefinite repetition of certain habitual dominations at the invisible or indiscernible limit of violence because, it seems, they are part of the very foundations of society or culture’ (Balibar 2009, 11). In Sri Lanka, during the pandemic, while some can perceive the apparent banality of the military encroaching on everyday life as a form of state care (Manderson and Levine 2021), for marginalized communities, it is a threat that affects their freedom and wellbeing. My focus has been to explain how well established militarism (as an ideology) in post-war Sri Lankan society paved the way for the military to easily become involved in civil society. The military is always present, sometimes invisible; it appears and disappears, consistently interacting with the everyday. The way that criminality is ascribed to those who have been exposed to or might be infected with the disease adds to the emerging discussions around the ways this pandemic intersected with other symbolic and cultural patterns of meaning-making, belonging, exclusion and violence.

The muted presence of threat in society justifies the visibility of the military. Building on these insights, I conceptualize ‘chronicity of

militarism’ as a fusion of militarism with intentional socioeconomic and political forces which result in social suffering across generations and communities. Chronicity of militarism can create a de-mystifying effect in understanding the interactions of illness and ongoing socioeconomic factors (social inequalities, vulnerabilities) and how militarization governs people’s ideas of life, livability, control and death. Militarization dismantles democracy, devalues other civil services, violates human rights and endangers minoritized groups. Rather than praising or taking the state’s employment of the military to contain a pandemic as natural or the most logical and efficient solution, it is critical to examine how the militarization of a health emergency and its effects on marginalized communities constitute a state of ‘chronicity of militarism’ with long-lasting impact on all levels of Sri Lankan society.⁶

Notes

- 1 According to <https://www.etymonline.com>.
- 2 Constructing jogging tracks in Colombo was part of these projects. See Atapattu, Prabhat, ‘Walking amidst the splendour of Nature’, 22 February 2021. Accessed 29 October 2024. https://www.defence.lk/Article/view_article/3066.
- 3 More recently, Gotabaya has been accused of extrajudicial killings after the war and planning the Easter Sunday Bombing (see *Sri Lanka’s Easter Bombings: Dispatches*, Channel 4 (UK), 2023. Available at <https://www.channel4.com/programmes/sri-lankas-easter-bombings-dispatches>).
- 4 See ‘The Subjects and Functions of the Ministry of Defence as published in the Gazette Notification No. 2281/41 dated May 27, 2022’. *Gazette Extraordinary*, 27 May 2022. Available from https://www.defence.lk/publication/gazette_notification.
- 5 In other countries also governments justify increased military expenses by drawing a connection between global issues such as climate change or global warming and distract the public from demanding more humane and democratic practices for addressing them. For example, in the United States, climate change is often framed as a threat to national security, promoting military approaches to addressing climate change and legitimizing increased expenditure on the military (Gilbert 2012). Referring to the national two-day military exercise in the United States that was titled ‘Climate change war game’, Marzec (2015) discusses issues that arise when the state extends the military into the arena of environmentalism in his book, *Militarizing the Environment: Climate Change and the Security State*.
- 6 The research on which this chapter is based was approved by the Office of Regulatory Affairs, Human Research Protection Program, Michigan State University, STUDY00007665. I would like to thank the participants for sharing their experiences which were hard and painful to reflect on. I am immensely grateful to the brilliant editorial feedback from Lenore Manderson and Nancy Burke, and close readings and provocations from Heather Howard, Caroline Doenmez, Vivek Vellanki, Hannah Grisham and Sasindu Patabendige. The views expressed, and any mistakes, are my own.

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Beyond COVID-19: caring by words in Long COVID discourses in Japan and Sweden

Claudia Merli

The pandemic broke out just after my return from a trip to Thailand and Japan between December 2019 and mid-January 2020. I sat glued to my computer screen, a rising sense of apprehension compelling me to check the situation in Sweden, my current residence, and Japan. In Sweden, many saw the rest of the world as being caught up in irrational panic, and my self-imposed isolation nurtured a growing sense of alienation from my immediate social surroundings. Everything was taken, I felt, too lightly by those around me – as if this were just another cold.

I had conducted fieldwork in Kagoshima prefecture in Japan in 2016 on volcanic ash risk and local health information on respiratory protection.¹ The COVID-19 pandemic provided another example to explore health communication. I researched how popular culture in Japan brought a pre-modern icon of epidemic back to the public stage, informing Japanese public health messaging and seeking to address social cohesion, even extending to become a global phenomenon (Merli 2020, 2022). The idea of making a comparison between Sweden and Japan was born out of similarities in approaches in the two countries, and declarations made by political leaders and public health authorities, at least in the beginning of the crisis. Befuddled, I watched as Japan and Sweden took diverging paths.²

These two countries, self-proclaimed as the most ‘modern’ in the world, distinguished themselves from almost all other industrialized and most low- and middle-income countries. In his comparative analysis of the place of community in response to COVID-19 in Sweden, Japan and Uruguay, sociologist Amitai Etzioni places the strategies along a continuum between authoritarian communitarianism in which ‘individuals are viewed basically as cells of an organic whole, and thus

find significance and meaning in their contributions to the common good', and liberal communitarianism that 'seeks to incorporate liberal values into its moral culture' (2021, 53–4). While other countries opted for muscular interventions, Sweden and Japan both argued that their constitutions and legal systems did not allow their governments to enforce measures such as lockdowns and curfews. They relied instead on appealing to individuals' sense of responsibility to adhere to public health instructions.³

Even so, the Japanese government shut down private and public schools on 2 March 2020 and moved educational activities to digital format until June 2020. Additionally, 90 per cent of universities postponed their opening from early April to mid-May (Tokumoto et al. 2021, 18). On 7 April 2020, a state of emergency was declared in seven prefectures, extended nationwide from 16 April to 25 May 2020. Borders were closed and foreign residents who were abroad were unable to return until restrictions eased from 26 November 2020 (Tokumoto et al. 2021, 16).

In Sweden, the government adhered to the advice of the Public Health Agency (an independent government agency, Folkhälso-myndigheten, henceforth FHM) and kept schools open, initially with the aim of rapidly achieving herd immunity (although also contending that children did not significantly spread the virus). Swedes were able to return from spring holidays in the Italian and Austrian Alps without screening, testing or quarantine requirements, and borders were kept open. Workers who could arrange their job tasks remotely were encouraged to do so.

In February 2020, Japan established two special advisory groups: the Novel Coronavirus Expert Committee, comprising 12 medical and public health experts, and the COVID-19 Cluster Response Taskforce, a collaboration between the National Institute of Infectious Diseases, the National Institute of Public Health and various universities (Tokumoto et al. 2021, 14–15). From 1945, during the post-war period, and beyond, Japanese people have exhibited a fluctuating trust in central government directives – a trust that plummeted following the tsunami and Fukushima nuclear disaster in 2011 – in favor of prefectural authorities, including local health authorities (Wild et al. 2023, 4; Wright 2021). During the pandemic, physicians and infected patients acted as personal information sources, and were trusted the most, leading to higher engagement in infection prevention (Okada et al. 2023, 3). Media reported that Japanese trusted 'experts' – a category including health professionals, scientists and infectious disease experts – and central and local governments retained epistemic authority when they aligned

with these sources (Wild et al. 2023) in a ‘reciprocal interaction of trust, science and politics’ (Bergmann 2023b, 155).

In Sweden, with several restructures from 1993, the Swedish Institute for Infectious Disease Control (Smittskyddsinstitutet) was replaced by the Public Health Agency (FHM), an independent agency addressing general health, staffed with competent civil servants rather than research scientists. An almost unchallengeable epistemic authority in handling the pandemic was primarily vested in the FHM and its top representatives, including the director, the state epidemiologist and the former director acting as a consultant. These figures performed also as media-facing spokespersons. At the end of March 2020, a pandemic advisory group with virologists and former infectious disease control officers was formed but they were never included in general strategizing (Vahlne 2023, 83). Where scientists from universities or from the COVID-19 expert group of The Royal Swedish Academy of Sciences (Kungliga Vetenskapsakademien, henceforth KVA) expressed disagreement regarding pandemic management, they were discredited as ‘non-experts’ and ‘hobby epidemiologists’. Real science was excluded from decision-making (Bergmann 2023b, 137, 151):

Sweden is distinguished from others in a unique asymmetry of a) a high level of trust in politics, b) no trust from politics in science, and c) an ambiguous high-and-low level of trust from politics (Government and Authorities) in the people (trust in individual responsibility and distrust of citizens’ acceptance of tough measures). (Bergmann 2023b, 129)

At play here is what Peter Baldwin calls epistocracy, ‘a mode of governing that shifts politically unpalatable decisions in leaders who – pretending to act apolitically – make decisions that the public can accept as motivated by neutral expertise’ (2021, 19).

A marked difference between the two countries was their approach to recommending the use of Personal Protective Equipment (PPE). International studies in 2020 demonstrated the benefits of wearing masks, particularly N95 respirators, to limit transmission to others and one’s own contagion, and to reduce the severity of symptoms if infected (Peeples 2020, 187). One of the first countries to investigate airborne or aerosolized transmission of the virus was Japan, where researchers at the University of Tokyo conducted tests using nebulizers and collection chambers on mannequins to verify transmission by inhalation. The study revealed that various kinds of masks were effective in reducing

viral uptake, and that masks blocked over 50 per cent of viral emission (*Japan Times* 2020). In Japan, even if facemasks were primarily a means to protect others rather than oneself from COVID-19, thus matching altruistic intention with easing anxiety, the prominent motivation was ‘conformity to the mask norm’ (Nakayachi et al. 2020, 3).

In Sweden, local studies carried out at Uppsala University Hospital in April and May 2020 detected airborne virus mobility via swab samples of SARS-CoV-2 RNA in the ventilation system (Nissen et al. 2020), suggesting that a precautionary measure against airborne transmission would be reasonable. Sweden’s FHM, though, refused to acknowledge that the virus was airborne and continued to emphasize handwashing. Facemasks were both dismissed and opposed as potentially more dangerous for transmission, because they would create a false sense of security; they were presented as ‘uncharacteristic’ of Swedish culture (Orange 2022). People choosing to wear masks were ridiculed, stigmatized by staring and, at times, verbally or physically attacked (Etzioni 2021, 61). Two reports prepared by the KVA’s COVID-19 expert group acknowledged airborne as well as asymptomatic transmission, recommending good ventilation and the use of facemasks indoors and on public transport. They also dismissed the Public Health Agency’s assumption that mask wearing would increase contagion and risk behavior (KVA 2020, 2021b). There was an apparent misalignment between demanded trust in the government’s agencies and conspicuous lack of transparency in decision process (Hulth 2020), coupled with a postmodern view of science (Lindström 2021, 2). Scientifically based information was *de facto* stigmatized as anti-Swedish (Steineck 2023, 303).

Meanwhile, Japan relied on strong communitarian values and voluntary change to personal behavior – ‘self-restraint’ or *jishuku* (Wright 2021), with the exception of declaring a state of emergency after identifying highest-risk situations. This soft approach relied on public shaming, for example, when the name of the owners of *pachinko* parlors⁴ remaining open for business were published in local newspapers (Etzioni 2021). Public health measures were effective, and Japan had only 0.71 per million confirmed cases in June 2020, in a situation where tests were readily available (Etzioni 2021, 57). The shame and stigma attached to testing positive for the virus, implying that one had not exercised *jishuku*, extended to long COVID.

In Sweden, people did not face direct societal consequences for ignoring required limited measures. As asymptomatic and pre-symptomatic transmission were not addressed in public health communication, recommendations on self-isolation were not effective (Etzioni

2021, 59, 69). Testing was unsystematic, and in May 2020 the number of confirmed COVID-19 cases was 3,674.82 per million people (Etzioni 2021, 61). Sweden's public health measures focused on communitarian and libertarian values of freedom and solidarity, but the government took a libertarian not a communitarian approach (Etzioni 2021, 62, 65, 68). Solidarity in Sweden was expressed rhetorically: 'show consideration' and 'take care of each other'. Individual responsibility, based on measures at odds with most international scientific advice, was the main message (Bergmann 2023b, 140).

This appeal to the individual did not take the form of 'self-restraint' (as it did in Japan) but rather, of exercising sound judgement (assessing risk, necessity for social contacts, isolating, etc.) and taking 'personal responsibility' (*egenansvar*). This implied *folkvett* – 'a blend of good manners, morality, and common sense that is supposed to be innate to all good Swedes – to follow the voluntary recommendations' (O'Shea 2020). Admitting the country's mismanagement or failure of the pandemic was to be avoided 'at any price' (see Bergmann 2023b, 138ff). Shame, it appeared, was the ultimate stigma for Swedes.

While critical medical anthropology has long focused on the deployment of 'caring by numbers' models (Hartzler and Snyder 2017; Mason 2018), I examine how 'caring by words' is enacted via neologisms or ideologically meaningful terms that unveil the interplay between governments, health systems and citizens. In this chapter, I consider discussions and representations on the emergence and persistence of chronic conditions following infection with SARS-CoV-2, and how these were addressed in news outlets and other publications from both Sweden and Japan, presenting them in the context of other neologisms. Timelines addressed the length of incubation, contagiousness, quarantine and distancing and an assessment of symptom duration. The temporal difference implicit in the terms reflects opposite approaches to considering the virus's permanence in relation to its human hosts.

COVID-19 neologisms and old terms in Sweden and Japan: caring by words

Charles Briggs (2020) reminds us that a focus on language and communication can hold new insights for medical anthropologists. Carlo Caduff has already written that this pandemic was 'fabulously textual' even if it lacked a strong source of symbolization (2020, 482). New words proliferated to describe both medical and social phenomena during the

pandemic. They reveal undercurrents of sarcasm, irony and critique in facing both the virus and the measures to counter it. The focus on neologisms allows us to capture society's response involving both ground-up and the top-down discourses in their immediacy as keywords.

In Sweden, the Language Council (Språkrådet) annually compiles a list of neologisms.⁵ In 2020 and 2021, the pandemic dominated, with newly coined expressions such as *coronaanpassa* (adaptation to corona) and *coronahälsning* (corona greeting). *Hobbyepidemiolog* (hobby epidemiologist) had already been introduced in 2017 in connection to a woman, a 'self-taught infectious disease doctor' (*autodidakt smittskyddsläkare*) and a blogger, who was given space on TV to expand her views on the benefits of using vitamin A to reinforce a child's immune system so to avoid vaccination for measles.⁶ The journalist lamented that a qualified infectious disease specialist sat quietly in the TV studio and was discouraged from rebutting, and that on the internet 'every hobby epidemiologist can get acknowledgment' (Fällmar Andersson 2017). During the COVID-19 pandemic, *hobbyepidemiolog* and *soffepidemiolog* (armchair epidemiologist) were used condescendingly to name and reprimand individuals (particularly scientists not employed as epidemiologists, such as virologists, bacteriologists, infection disease experts and social scientists, but even epidemiology professors) who presented counterarguments to the FHM's pronouncements (Svensson 2020). When infectious disease specialists (*smittskyddsläkare*) at provincial and municipality levels tried to introduce stricter measures, they were treated likewise. The dismissal of dissenting voices de facto instituted an opinion corridor (or *åsiktskorridoren*, a well-established term in the Swedish vocabulary to indicate a narrow range of 'acceptable opinions'). Opinions outside its boundaries were deemed unacceptable, and the values of conformism, conflict avoidance and a collective sense of safety (*trygghet*) dominated, turning into a form of public health nationalism and patriotism (Bergmann 2023b; Gustavsson 2021). Those who dismissed the government agency's recommendations were *covidiot* (a combination of *covid* and *idiot*). The 2021 list included 18 additional terms, such as: *coronabubbla* (corona bubble, for restrictions on socializing with outsiders), *genombrottsinfektion* (breakthrough infection, in people who had been vaccinated), *maskne* (a blend of 'mask' and 'acne', referring to the skin rash that could develop with the use of respiratory protection). The 2022 list featured fewer new words connected to the pandemic, with perhaps only *väntesorg* (mourning the impending loss of a loved one) being directly related.

New nouns likewise started proliferating in Japan as 'COVID-19's linguistic side-effects' (Backhaus 2022). They could be written using

existing *kanji*-based terminology to create compound words or adopt *katakana* (the syllabic script regularly employed to transcribe foreign words into Japanese) to form new terms that sounded like their English counterparts. Minister of Defense Taro Kono took to Twitter in March 2020 to reprimand the proliferation of *katakana* neologisms, encouraging the population to use available Japanese words written in *kanji* (Backhaus 2022), so to preserve Japanese linguistic identity. Even where well-established Japanese terms existed however, English-sounding words with *katakana* were introduced. For example, ワクチン (*wakuchin*) was used along with or instead of the existing 接種 (*sesshu*) for vaccine. Deputy Prime Minister Taro Asō attributed the successful management of the pandemic to Japan’s ‘quality of people’ (*mindō*, 民度, cultural standard of a people) (O’Shea 2020). The *kanji* of the year for 2020 was declared to be 密 (*mitsu*) ‘dense’ or ‘close’. The word gained prominence as the core element of Tokyo governor Yuriko Koike’s popular 3密 (*sanmitsu*) campaign, also known as 3Cs, whereby people were urged to avoid closed spaces, crowded places and close-contact settings (Norrbon 2020). In March 2020 several new terms meaning ‘self-restraint police’ were introduced, the most common form being 自粛 (*jishuku*) meaning ‘self-restraint’ and 警察 (*keisatsu*) meaning ‘police’ – or 自粛経団連 (*jishuku keidan*), ‘Japan business federation’; 自粛自警団 (*jishuku jikeidan*), ‘vigilante’; and 自粛ポリス (*jishuku porisu*), ‘police’. These terms were coined ‘to refer to grassroots individual or group vigilantes working to identify, doxx, shame and harass people perceived to be ignoring government requests for *jishuku*’ (Wright 2021, 466). A survey conducted by the Government of Japan’s Agency of Cultural Affairs identified the words with widest acceptance: おうち時間 (*o-uchi jikan*), meaning ‘at-home time’; 黙食 (*mokushoku*), meaning ‘silent eating’ (see Figure 18.1); 人流 (*jinryū*), meaning ‘flow of people’ and ワクチンパスポート (*wakuchin pasupōto*), literally ‘vaccine passport’.⁷

Prefixes between urgency, severity and chronicity

If neologisms enriched the communication around COVID-19, so did the use of simple adjectival words to specify definitions of symptoms and the condition itself, in Sweden and Japan, and internationally. One group deals with graduated severity (mild, moderate, severe, critical) and its dismissal, the other group with (im)permanence or time-related aspects of the infection (long-, post-, after-). A brief review of these terms in the



Figure 18.1 Poster asking people to eat silently [黙食 *mokushoku*] to prevent new coronavirus infection (COVID-19), on the restaurant floor of Sogo Chiba department store, in Chuo-ku, Chiba City, Chiba Prefecture. Source: CC BY 4.0, RuinDig/Yuki Uchida via Wikimedia Commons, <https://commons.wikimedia.org/wiki/File:Sogo-Chiba-Mokushoku.jpg>.

global discourse helps contextualize the emergence of forms of caring and un-caring about affected individuals.

Chinese authorities used ‘mild’ Covid in February 2020 to downplay the emerging crisis, with the term ‘mild to moderate’ including cases in isolation or hospitalized, with or without pneumonia (Callard 2020b). This was later adopted by the World Health Organization (WHO) and health authorities worldwide to give the impression of a condition that, even if prolonged, could be managed by individuals. This led to the marginalization of patients’ experience, with the infection characterized as mild in biological terms (Chan 2021; Esposito 2021), and to an explosion of the use of ‘mild’ Covid in medical talks (Callard 2020a, 2020b; Callard and Perego 2021). Scientific advisors to the UK government made statements to the press suggesting that most people would barely notice

if they were infected, experiencing only ‘very, very mild symptoms’ similar to the ‘common cold’ (Callard 2020b). Individual experiences and perceptions of COVID-19 symptoms varied, with mild symptoms worsening only after several days: ‘The mild is always potentially or not-yet severe’, with little indication of the severity of illness (Callard 2020b). People with no pre-existing or underlying health conditions (a problematic notion that erases political responsibility, see Herrick 2020) found themselves unable to function or fully recover weeks or months after first falling ill. The coexistence of divergent models of the ‘mild’ might conceal actual suffering, and was likely to become the focus of government bodies, health professionals and patients. ‘Cases of mild Covid-19 might well be used in efforts to firm up a stoic nation, recalibrate citizens’ understanding of suffering, and moralize further over the healthy and unhealthy body’ (Callard 2020b, 6).

The birth of Long COVID: discontinuing time

Terminological choices carry an implicit temporal dimension in considering the permanence of the SARS-CoV-2 virus in relation to its human hosts, as either a transient (post-Covid) or a lasting (long Covid) condition. Long Covid, as an elementary term, imposed itself over the post- and chronic, and ‘challenged how the time of suffering [was] commonly mapped by epidemiology and medicine’ (Callard 2020a, 729). It challenged medical classifications that were ‘used to adjudicate suffering, disability, and chronicity’ (Callard 2020a, 742), where detailed diagnostic criteria with clearly defined ‘specific diseases’ was the norm (Löwy 2021). As the term caught international attention, we encounter it in several forms such as ‘long Covid’ (especially at its inception), ‘long-Covid’, ‘long-term Covid’, ‘Long Covid’ and ‘long COVID’ (for example, the United States Center for Disease Control and Prevention uses this form, together with post-COVID), in both medical and popular publications. These ‘variants’ in capitalization and hyphenation testify to the uncertainty and fluidity of the linguistic creativity that hints at specific nuances, with a slight preference for Long Covid and Long COVID to become a firmer illness category, while the others are adopted contextually. In the remaining text, I opt for Long COVID when addressing the condition of persisting symptoms or sequelae as an illness category, and will keep other forms when quoting other authors verbatim.

COVID-19 is opportunistic in relation to co-existing vulnerabilities, leading to ‘chronic living’ (Manderson and Wahlberg 2020), whether one

considers it revealing a ‘syndemic’ system – a synergy among epidemics of infectious, chronic and social conditions (Herrick 2020; Mendenhall and Gravlee 2021) or not (Manderson and Wahlberg 2020). Conditions can become chronic through the availability of and access to techno-medical intervention (or lack thereof) that can control, sustain and manage them, including multiple medications (‘polypharmacy’, see Ecks 2020) and their iatrogenic effects, while the management of multi-morbidity during the pandemic and lockdown became uncertain in resource-poor settings (Ecks 2020; Manderson and Wahlberg 2020; Wahlberg et al. 2021). Chronic living and the associated ‘chronic homework’ translate into choices to deprioritize one’s own health in favor of others’ in the household (Manderson and Wahlberg 2020) and to a ‘radical restructuring of time’ (Kleinman and Hall-Clifford 2010, 248). Mildness was associated with faster recovery time (see Callard and Perego 2021).

Medical terms for the condition of living with lingering symptoms after COVID-19 infection are PASC (Post-Acute Sequelae of SARS-CoV-2 infection) and ‘chronic Covid syndrome (CCS)’ (associated with Chronic Fatigue Syndrome). In February 2020, a WHO-China statement established the persistence of symptoms ranging from two weeks to three, suggesting the definition of a chronic condition as extending beyond six weeks. As early as March and April 2020, several people, including medical doctors, shared their stories in the international press about persisting and new symptoms several weeks after being ill (Callard 2020b; Callard and Perego 2021). In Sweden a group of doctors with Long COVID published regularly about their experience (Norén, Oskarsson and Rose 2020; Sveriges Radio 2021c).

One of the first terms to appear in April 2020 to describe protracted symptoms was ‘Long-haul’ Covid, and by extension ‘long-haulers’ and ‘Long haul Covid fighters’ (both terms proposed by US-based Amy Watson, convenor of the Long Haul Covid Fighters group). In May 2020 Paul Garner, professor of infectious diseases at the Liverpool School of Tropical Medicine and Director of the Centre for Evidence Synthesis in Global Health, shared his own experience of what he called COVID-19’s ‘long tail’ in the *British Medical Journal*. He underscored that ‘this illness can last for weeks, and the long tail is not some “post-viral fatigue syndrome” – it is the disease’ (Garner 2020). The same month, ‘an all-patient team’ published an account of over 50 symptoms including ‘cognitive impairment/fatigue, chills/sweats, appetite loss’ (Callard and Perego 2021, 2). In June it was established that ‘COVID-19 can last for several months’ and that the condition was ‘cyclical, progressive, and multiphasic’ (Yong 2020, in Callard and Perego 2021; Perego 2020),

therefore questioning the validity of a ‘post’ category. Elisa Perego was the first to use the hashtag #LongCovid in social media; this quickly started trending. WHO documents in late August 2020 mention Long Covid (WHO 2020), and a study conducted with patients in the UK indicated that ‘[a]ll these narratives were characterized by disrupted chronology: the trajectory of recovery in which they had been led to believe (an uncomplicated restitution narrative) was unexpectedly upset, and – given the uncertain prognosis – there was no indication of when it would be restored’ (Rushforth et al. 2021, 5). Time is discontinuous, the body landing in an uncertain and constant present.

Medical anthropologists have engaged with the complexities of COVID-19, providing critical analyses of experiences, fast-paced changes, diverse government responses and effects on entire medical systems. The introduction of catastrophe medicine and war triage were focal points. ‘On the pulse’ responses, keeping up with the most recent changes, flourished in blog series, reflections and field reports flourished.⁸ Many of these early explorations expanded into full-length articles and special issues, as exemplified by Adams and Nading’s work in 2020, Manderson and Levine’s in 2020 and edited volumes like the one edited by Manderson, Burke and Wahlberg in 2021. Central to this discussion was the critical role of statistics as absolute truth, and the exposure of the surprising fragility of health infrastructures in the Global North (Caduff 2020; Ecks 2020).

As Wahlberg and colleagues commented,

The pandemic may well become chronic as COVID-19 endemically settles alongside (and in syndemic interaction with) an already long list of communicable and non-communicable diseases that are lived and contended with by patients, families, healthcare workers and governments alike on a daily basis. (Wahlberg et al. 2021, 1)

Manderson and Wahlberg (2020) noted that this likelihood would create a double burden especially in lower-income countries.

As Callard and Perego (2021, 1–2) noted, ‘long Covid’ is the first patient-made illness that carried the potential to change how the pandemic unfolded. It mobilized subjective evidence, turning individual experiences into collective experience, contesting other classifications used to define the condition, challenging the normative role of clinical evidence and filling the knowledge gaps during the health crisis, albeit blurring ‘the boundaries between the clinical and sociological understanding of long COVID’ (Roth and Gadebusch-Bondio 2022, 2).

Using the previous AIDS pandemics as an example, Jain (2020) explored the potential role that historical and social scientists should have in shaping and contesting epidemiological and biomedical responses and claims by pursuing ‘the deeper story-behind-the-story’. Both paths challenged ‘epistemic injustice’ (Fricker 2011) and are exemplified by how Covid patients could claim epistemic authority, which usually tends to coalesce around some authors (given the amount and speed of publications on COVID-19) (Callard and Perego 2021). Personal experiences left the anecdotic realm and turned into subjective evidence that was politically employed (Roth and Gadebusch-Bondio 2022; see above for Japan’s shift to trust personal testimonies).

‘Long Covid’ was subsequently incorporated into the ‘scientific literature, the media, and in clinical, policy, and governmental spaces’ (Perego et al. 2020). The term was also seen as disability-inclusive, with a patient-centered approach that ‘helps the fight for fair recognition on a global scale’ (Perego et al. 2020). As COVID-19 is a multi-systems disease, the term Long COVID presents the advantage of: a) going beyond the gradients of severity (mild, severe and critical) and the nature of its duration in stages (acute-, post-Covid syndrome, post-acute, chronic); b) doing away with the acute-chronic dichotomy that marks the temporality of biomedicine by pointing out, to use Smith-Morris’ (2010) term, the ‘continuity in disruptions’; and c) signaling the traumatic experience of many patients inhabiting a new body.

The term ‘long Covid’ usually refers to ‘an entirely new set of symptoms that may start weeks after the patient is “cured,” are multiform, and change over time’ (Löwy 2021, 2). This is reminiscent in some respects of other post-viral syndromes which can sometimes arise years or decades after an initial infection has occurred, ‘shingles following chicken pox; post-polio syndrome decades after poliomyelitis; immune-compromised conditions after dengue infections; cervical cancer following human papillomavirus’ (Wahlberg, Burke and Manderson 2021, 20).

Long COVID draws attention to the prolonged and continuous nature of the condition resulting from SARS-CoV-2 infection, instead of implying, as happens with the term post-Covid, that the symptomatology constellation was a new entity that emerged after the virus was defeated or had left the body. Proponents of the term ‘Long Covid’ dislike the term Post-Covid Syndrome because ‘it carries not only risks of misdiagnoses and mismanagement, but also of leaving those with persistent illness behind, especially in a post-vaccine world’ (Perego et al. 2020, 5).

The significance of gender to Long COVID is noteworthy; some research indicates that it appears to be more prevalent among women who had a mild case of infection. A systematic review of therapeutic interventions on Postural Orthostatic Tachycardia Syndrome (POTS) or long-Covid (encompassing reports from eight countries) showed a ratio, overall, of 3:1 female to male patients. The study authors also noted that a ‘female preference in the incidence of POTS has been previously documented’ (Abbate et al. 2023, 27). Other research indicates that, as with chronic fatigue syndrome, the assumption that ‘long-Covid’ was mostly psychosomatic came to the fore (Löwy 2021). The vagueness in attributing neurological symptoms with long-lasting and debilitating effects, and assumptions that this had psychosomatic origin, was compounded by the use of the generic term ‘brain fog’ which diminished people’s experience (Mendenhall and Kaplan 2023). These kinds of approach perpetuate an historical tendency to downplay conditions that are challenging to identify and are often attributed to psychosomatic or biopsychosocial causes.

Some patient associations produced support material, conducted surveys and published reports, and academics affected by Long COVID (Callard 2020a, 2020b; Callard and Perego 2021; Perego 2020; Mendenhall and Kaplan 2023) played a crucial role in bridging the gap between patient-driven pressure to get the condition acknowledged and academic debates. The global network Body Politic (a queer feminist wellness collective established in March 2018) established a COVID-19 Support Group which now (as of January 2024) counts more than 14,000 members.⁹ The Patient-Led Research Collaborative conducted a survey organized by decentralized teams of COVID-19 patients and distributed to members of the COVID-19 Body Politic Slack Group (Patient-Led Research Collaborative 2020). In the United States, C19 Recovery Awareness,¹⁰ whose members call themselves Long Haul Covid Fighters, advocates for continuous research and support for survivors.

For those who could afford it, the pandemic ushered in the possibility to move to remote work and education via digital platforms, and several measures of physical distancing contributed to displace in-person social contacts in favor of the virtual world. Health care and patient activism on Long COVID increasingly used digital platforms, taking the form of ‘virtual biosocialities’ (Esposito 2021) and compounding the ‘entwining of biologically based identities and digital-based practices’ that characterizes bio-digital citizenship (Petersen, Schermuly and Anderson 2019, 481). In a pandemic that made corporeal presence invisible and almost

de-realized, patients took to social media to establish communities of experience around vague and debilitating symptoms that rendered bodies both estranged and conspicuous.

In Sweden

Prolonged symptoms and long-term effects did not receive adequate consideration in the Swedish strategy. In 2021, *Postcovid* and *långtidscovid* (long-term covid) were introduced, although the latter term was avoided by the National Board of Health and Welfare that wanted, as they put it, ‘to distinguish between an ongoing infection (Covid-19) and a subsequent health condition without infection (post-Covid)’.¹¹ The term ‘post-Covid’ – a shortened form for ‘postinfektiöst tillstånd efter covid-19’ (‘post-infectious condition after COVID-19’) – encompasses two possible meanings: the first refers to a condition that arises after the infection has cleared; the second to symptoms that arise with infection and linger. While this second meaning appears to apply to the use of the term ‘postakut Covid-19-syndrom’ used by the Royal Swedish Academy of Sciences, the first meaning prevails in public debate and in conflict with those who have advocated for the term ‘long Covid’ to call attention to the continuity and chronicity of the condition. Clinicians and researchers with direct experience of the condition and its long-term consequences established a grassroots network, publishing in several outlets (Norén 2022) and maintaining a website with updated information on policies and scientific publications.

Sweden’s state epidemiologist considered ‘post Covid’ to be a health care issue rather than a public health issue, and referred this back to the National Board of Health and Welfare (*Socialstyrelsen*) (Bergholtz 2023, 109; Kristoferson Hedlund and Norén 2021). KVA’s expert group on COVID-19 defined it ‘a significant public health problem’ (KVA 2021a, 2). Post Covid first appeared ‘on the website of FHM as late as in April 2021’ (Bergholtz 2023, 109). Strategic plans did not adequately consider the possible effects of Long COVID; potential future outcomes of infection with long-term complications were not discussed in the public debate, and fell off the radar for Swedish public health authorities (Bergmann 2023a, 66; KVA 2021a, 1, 5). This was largely attributed to the slow establishment of specialist health care centers, which further limited the availability of data and research efforts (KVA 2021a, 1). During the summer of 2022, several regions started closing down specialist clinics (of the 12 that had been operating), sending patients with ‘post-Covid’ back to primary care (Trysell 2022).

In March 2021, the National Health Insurance (*Försäkringskassan*) in Sweden reported that 4,600 people had been on sick leave for more than 90 days due to post-acute COVID-19 syndrome. Of these, about 170 patients had received specialist care from Karolinska University Hospital's interdisciplinary team for symptoms leading to different degrees of disability (KVA 2021a, 1–3). The same year, the National Board of Health and Welfare (*Socialstyrelsen*) acknowledged the lack of reliable statistics on this phenomenon (Karlsmark and *Sweden Radio* 2021). In November 2022, lower conservative estimates were of about 50,000 people living with post-Covid; an immunology professor describes the process as 'very clearly caused by various physiological systems that are derailed and not working as they should' and not an imaginary illness (SVT *Nyheter* & Hüll 2022, my translation). Patients complained at having received incorrect mental diagnoses when seeking care on their condition (Karlsmark and *Sweden Radio* 2021).

A study based on statistical data from sick leave registers describes the problem with long Covid in Sweden as in line with other studies and found that '13 per cent of people with sickness benefits due to COVID-19 were on sick leave for long Covid'. Studies drawing on self-reports suggest that this is an underestimate (Westerlind et al. 2021, 4). According to other sources, in December 2021 approximately 200,000 people were sick with Long Covid in Sweden (Bergmann 2023b, 140).

Given the assumption that children would not be effective vehicles of transmission, Sweden's strategy focused on keeping schools open; the same logic would later explain the limited number of studies on paediatric long-COVID or PASC among Swedish children (see Höög 2023, 218, 224). Similarities were observed between Kawasaki disease (a pediatric condition with inflammation of blood vessels that can lead to heart complications) and MIS-C (Multisystem Inflammatory Syndrome in Children) whose symptoms include 'abdominal pain and brain inflammation, which is very rarely seen in Kawasaki disease. Children also become more severely ill with multi-organ failure' (KVA 2021a, 4, my translation). In 2021, 135 children in Sweden were affected by MIS-C, of whom 50 required intensive care (KVA 2021a, 4).

In 2021 the Swedish government allocated 50 million kronor (approximately 4.5 million Euros) to support research into long-term Covid (Sveriges Radio 2021a, 2021b). In April 2023, the Karolinska Institute initiated a randomized controlled trial (RCT) 'to investigate the efficacy of orally administered nirmatrelvir/ritonavir [Paxlovid] compared with placebo/ritonavir to improve quality of life in non-hospitalized adult participants suffering from post-acute COVID-19

syndrome'.¹² The study is reported in the *Läkartidningen* (journal of the Swedish Medical Association) as targeting those with 'severe' post-Covid (replicating the 'mild'/'severe' dichotomy of COVID-19) and the presentation of objective symptoms (Trysell 2023).

In Japan

The term indicating COVID-19 long-term symptoms in Japan is 後遺症 (*kōishō*), which literally means 'prognostic symptoms', 'sequelae' or 'after-effects'. When it appears in Japanese articles published with an English version, the term is usually glossed as 'COVID aftereffects' (Fukano 2022; Hayashi 2021; Hayashi and Nakagawa 2021) or 'long COVID' (Watanabe 2023b, 2024) or 'long-term effects' (Akita 2022a; Nippon 2021). *Kōishō* also appears on official websites of prefectures and the Ministry of Welfare, Labor and Health.¹³ An alternative form is コロナ後遺症 (*korona kōishō*). On X (formerly Twitter) and other social media, the term used to indicate 'long COVID' – often accompanied by a hashtag – is more often 長期微熱組 *chōki binetsu-gumi* where the specific *kanji* reads as long-term (長期 *chōki*), mild fever (微熱 *binetsu*), group (or set) (組 *kumi*). In Japan the number of days from symptom onset (60 days) at the time of observation was significantly lower than in other countries (Matsunaga et al. 2022), suggesting early referral to health care.

Japanese authorities were quick in identifying the issue of protracted or newly surfacing symptoms after the initial COVID-19 infection had been treated. Although the mechanism behind the development of these symptoms remained unclear, Japanese experts suspected that myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a neuroimmune disease, was responsible for the diagnosis of 27.9 per cent of COVID-19 respondents meeting the criteria (Hayashi 2021; Hayashi and Nakagawa 2021). A collaborative survey involving Japan's National Center for Global Health and Medicine showed that over 26 per cent of COVID-19 patients had 'long COVID' (Nakanishi 2021); the health ministry reported that of 1,066 hospitalized patients, 30 per cent 'had one or more of 24 representative symptoms such as fatigue, shortness of breath, weakened muscles, insomnia, decline in concentration and hair loss, and saw their symptoms persist 12 months after diagnosis' (Otake 2022).

Newspapers reported that young people suffered prolonged and serious after-effects even when they had only experienced 'mild symptoms' when testing positive for COVID-19, or had even tested negative, with fatigue more common among women than men. Doctors

lamented that many patients' symptoms were initially dismissed as due to 'mental conditions' (Hayashi and Nakagawa 2021; Nakanishi 2021; Noguchi 2020). News reports of scientific studies on COVID symptoms conducted by universities in Japan and the United States suggested central nervous system damage (Steenhuysen 2022; Watanabe 2023a, 2023b), and personal testimonies from studies in specific prefectures' governments echoed these findings (see for example Fukano 2022).

A reporter from *Kyodo News* detailed her quest for a possible explanation for her protracted symptoms, and posted a picture of her brain perfusion scan that indicated a reduction in blood flow in areas of the brain marked in bright blue with consequent 'deterioration of brain functions and immune disorder possible effects of long COVID-19' (Akita 2022b). She encouraged patients to come forward, and described her broken relationship with her own body as one of continuous betrayal: 'I fell into a state of self-loathing at the prospect of not being able to work for even a short period. My body, I felt, was continuing to betray me' (Akita 2022a).

The COVID-19 pandemic produced a double stigmatization, where both 'felt stigma ... judgmental responses from others are imagined and anticipated' and 'enacted stigma, whereby relationships are deliberately altered in response to illness' (Dowrick et al. 2023, 2; Scambler and Hopkins 1986) played a role. In Japan, the anticipated stigma (that is, the expectation and fear of stigmatization) attached to the condition (Fuiji and Hashimoto 2023, 3–4) was directed especially against health care workers and their families, including their children (Jecker and Takahashi 2021). This follows a well-established historical pattern of shunning and marginalizing people carrying certain disabilities or conditions: for example, people with Hansen disease were ostracized to live in leprosaria; there are detailed accounts of how victims of the Minamata industrial disaster, who suffered devastating neurological damage, were shunned (Thornber 2020). *Seken-tei*, a term that can be translated as 'public appearance' or how people are seen by others, drove the stigma also in the case of COVID-19 (Jecker and Takahashi 2021). The stigma persisted when disclosing past infection, even after several months, as it was taken to indicate that the person had not strictly complied with government guidelines (Dowrick et al. 2023; Fujii and Hashimoto, 2023, 6). The government introduced the 'Go To Travel' campaign on 22 July 2020, to encourage domestic tourism to aid the local economy (Suppasri et al. 2020, 2). Volunteer 'self-restraint police' chased down infected individuals not following the directive of isolating or who were traveling, and vandalized cars with registration plates from

other prefectures (Etzioni 2021). A form of ‘coerced solidarity’ led by stigmatization and punishment of those acting in a deviant manner was in place (Wright, 2021, p. 468). Japan has effective ‘peer pressure’, as Tomoya Saito – director of the Department of Health Crisis Management at Japan’s National Institute of Public Health – remarked (Saito 2020).

In 2022 Japan’s health ministry devoted 200 million yen (c. 1.3 million Euros) into a Long COVID study, and on April 28 it released official guidelines to help medical workers diagnose symptoms ‘and support patients in their efforts to resume normal lives. The aim is to create an environment where sufferers can get treatment as soon as possible’ (Nakanishi 2022). From initially being dismissed as having mental conditions by their family doctors, patients could now rely on the introduction of Long COVID as a category of illness to access treatment.

Discussion and conclusions

Sweden and Japan had markedly different approaches to the extent of physical distancing and the use of respiratory protection to limit the spread of the virus, and subsequently for people who likely had Long COVID. In both countries shame and stigma occupied relevant positions in dealing with citizens, albeit in very different ways. In Japan those acquiring the virus faced stigma for exposing themselves to risk of infection (implicating lack of self-restraint) and as vectors of further contagion. In Sweden, those ‘exceeding’ the guidelines by, for example, following international scientific consensus and using respiratory protection (implicitly applying more self-restraint) were stigmatized (at least initially) for patently distrusting FHM’s denial of aerosolized transmission. Citizens in both countries thus faced stigma via peer-pressure forms of shaming (‘corridor of opinions’ in Sweden, ‘self-restraint police’ in Japan) in relation to discursive or practical deviations from the health agencies or government policies, but for opposite reasons. Neologisms (*covidiot* in Sweden, *jishuku keisatsu* in Japan) and terms indicating national character (*folkvett* in Sweden, *mindō* in Japan) framed much of the public health discourse towards consensus and conformity by way of civil society pressure.

The patient-made ‘Long Covid’ illness category, with its unassuming simplicity, superseded others used in biomedical and public health discourses to define severity and chronicity related to the Covid pandemic, reframing the temporal dimension of the relation between the virus and the body. This ‘discontinuity of time’, in which a condition could return in

another guise at a later period, after the initial viral infection had resolved, is mirrored in models from other conditions, such as the relationship between chicken pox and a subsequent shingles infection. People with COVID-19 in Japan were subjected to a stigmatizing attitude that echoed exclusionary models of earlier epidemics. In Sweden, patients were not stigmatized, but those worried about getting sick were. However, Sweden's policy meant that people with Long COVID symptoms tended not to be taken seriously, or received mental diagnoses or were suspected of imaginary diseases. Patients with symptoms of Long COVID were made invisible, since the existence of the condition countered Swedish ideas of herd immunity. In Japan, guidelines were issued to all GPs (doctors) to identify the condition and return patients to the community; in Sweden patients who seemed unable to fully recover undermined the epistocracy of FHM on the 'mildness' of the condition. In Japan, the government retained epistemic authority if its position matched scientists' opinion; in Sweden FHM retained a certain level of trust (at least in 2020), even when at odds with international scientific consensus.

The words that most subverted the vocabulary of nationalistic ideals and the temporality of biomedical diagnoses came from Long COVID patients who organized themselves into 'virtual biosocialities'. Direct individual communication and personal stories claimed epistemic authority and turned into evidence, struggling to gain visibility and recognition in Sweden, but in Japan displacing both central and local governments in gaining people's trust, into a better form of caring by words.

Notes

- 1 I was the co-investigator responsible for qualitative research for the multi-country HIVE consortium, funded by Research for Health in Humanitarian Crises and the Wellcome Trust. Website for the project <https://hiveconsortium.webspace.durham.ac.uk>
- 2 A search was carried out via the EPPI Centre (Evidence for Policy & Practice) resource on Long COVID evidence. (<https://eppi.ioe.ac.uk/cms/Projects/DepartmentofHealthandSocialCare/Publishedreviews/COVID-19Livingssystematicmapoftheevidence/tabid/3765/Default.aspx>. Accessed 2 March 2023.) for publications on Long COVID where Sweden (25 items) or Japan (40 items) appeared in the title or abstract, as well as via Google Scholar. Other sources include official government websites and selected Japanese news platforms in Japanese and English. For the Swedish context, I consulted news and government websites in Swedish. No human participants were directly involved in this study, which was based solely on publicly accessible information.
- 3 Both countries, however, have a history of implementing strict, clamp-down measures in the face of transmissible diseases (see Baldwin 2021, 71ff; Gordon 2020).
- 4 Pachinko (パチンコ) is a pinball game machine resembling a slot machine. Game arcades with pachinko are very popular in Japan, especially among pensioners.
- 5 Part of the government authority Isf – Institutet för språk och folkminnet ('The Institute for Language and Folklore'). Annual lists of neologisms are available online at www.isf.se.

- 6 Following swine flu vaccination campaign with Pandemrix in 2009–10, Sweden experienced severe side effects in the form of narcolepsy in approximately 400 children and young adults (Läkemedelsverket 2020). They received monetary compensation for the damage incurred. The number of antivaxxers in the country increased after this incident (see Lundgren and Holmberg 2015).
- 7 See https://www.bunka.go.jp/tokei_hakusho_shuppan/tokeichosa/kokugo_yoronchosa/pdf/93774501_01.pdf (in Japanese).
- 8 For examples, see The COVID-19 Forum edited by Christos Lynteris at *Somatosphere*. Accessed 31 October 2024. <https://somatosphere.com/2020/covid-19-forum-introduction.html>; the ‘Curare corona diaries’, 2020–21 at *Curare. Journal of Medical Anthropology* hosted by Boasblog, 2020–21. Accessed 31 October 2024. <https://boasblogs.org/curarecoronadiaries>.
- 9 Body Politic. Accessed 30 October 2024. <https://www.wearebodypolitic.com/>.
- 10 The group C19 Recovery Awareness can be found on X (formerly Twitter) at <https://x.com/c19recovery?lang=en>.
- 11 From the list of neologisms for 2021, published by Språkrådet (my translation). Accessed 24 June 2023. <https://www.isof.se/download/18.6c60ddae17dc25fe728d37b/1640525737545/Nyordslistan%202021.pdf>
- 12 Karolinska Institutet. 2023. imPROving Quality of LiFe In the Long COVID Patient (PROLIFIC) Clinical trial. <https://clinicaltrials.gov/ct2/show/NCT05823896>.
- 13 Post-illness symptoms (so-called sequelae) of new coronavirus infection. Accessed 30 April 2023. https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/0000121431_00402.html (in Japanese).

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COVID-19 continues to cause severe morbidity and ongoing mortality. *Covid's Chronicities* documents the shifts that have occurred in the face of the pandemic, the state and community responses to it, its continuing toll on health services, economies and communities, and its compounding effects on people's health, lives and livelihoods.

This volume draws on research from across Europe, North and Latin America, Asia and Africa, providing surprising contrasts and consistencies of experience. As the pandemic has shifted from urgency to chronic unpredictability, everywhere people have struggled to make sense of state actions in infection control, testing strategies and the rollout of vaccines, and to remake social life. The contributing authors illustrate with poignancy how chronic social problems and pandemic effects have worked bidirectionally, compounding multiple inequalities and exacerbating, for some, despair and disassociation. They also demonstrate the ingenuity of communities – of Indigenous ways of knowing and providing care in some settings, and elsewhere, the power of robust local community networks and informal innovations. While this book exposes the pandemic's exploitation of deep structures of state and societal neglect, and describes the resultant morass, it also illustrates the determination and imaginations of caring communities to withstand Covid's harms.

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