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Eclipse Phase:

Examining Global and Local Pandemic Vulnerabilities Among Home and Community Based Services Recipients and Providers in Pennsylvania;

a Case-Based Report During the Year 2020

Michael Benjamin Singer

A Thesis in the Field of International Relations

for the Degree of Master of Liberal Arts in Extension Studies

Harvard University

May 2022

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Abstract

As the US population ages, more and more senior citizens are receiving care and services in their homes rather than in nursing facilities, a trend that is only set to accelerate over the coming decades. This project examines the US home-based health care system, including the service providers and service recipients, to illuminate unexplored systemic vulnerabilities to a pandemic or other health crisis. Interviews of relevant current and former employees of the Commonwealth of Pennsylvania, a perspective absent from the existing literature, use the *co*rona*vi*rus *d*isease 20*19* (COVID-19) pandemic of 2020 as a natural experiment, demonstrating heretofore theoretical vulnerabilities. Several themes recurred repeatedly during these interviews. First, that planning was inadequate; that the structural weaknesses of the workforce raised in the previous chapter are not only real but understated; and that the service delivery systems and their administrators were able to innovate and adapt to challenging new conditions more rapidly than anyone expected. (111) The experiences of the first full year of the pandemic, January 2020 to January 2021 offer visceral lessons to be learned to better prepare providers for inevitable future pandemics and health crises.

Frontispiece



Figure 1. Children wear plastic bottles as makeshift masks while waiting to check in to a flight at the Beijing Capital Airport in January 2020.

Source: Frayer, K. (2021, March 12). The defining photos of the pandemic—And the stories behind them. CNN. https://www.cnn.com/interactive/2021/03/world/coronavirus-pandemic-cnnphotos/

Dedication

The author would like to dedicate this work to the professionals, volunteers, and family members who provide care for Pennsylvania's – and America's – disabled or elderly citizens. The work you do is boring, backbreaking, underpaid, and underappreciated, but it is both necessary and noble.

This work is also dedicated to the late, great, and much-lamented Marshall Singer.

Acknowledgments

This work, and innumerable other good works, would not be possible without the help and contributions of current and former employees of the Commonwealth of Pennsylvania, particularly the Office of Long-Term Living. Their service to the most vulnerable citizens of the State has not and does not go unappreciated. Thank you for all that you do.

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Chapter I.

Introduction

It is a truism, even a cliche, that hindsight is 20/20. The year 2020 has lived up to this reputation in at least one respect - it has proved undeniably true the generations of warnings about the risks and dangers of a major pandemic. Coming on the heels of the hundred-year anniversary of the 1918 influenza pandemic, COVID-19 has exposed the fault lines and hidden weaknesses of health systems around the globe. The United States has suffered worse than any of its peers in the developed world and even woefully less resourced countries – during the first year of the pandemic it has had more infections and more deaths than any other nation, despite not being the original locus for the outbreak nor the greatest population (Johns Hopkins, 2020). The US is one of the most prepared and resourced for disasters according to an Epidemic Preparedness Index created in 2018 based on public health infrastructure, physical infrastructure, institutional capacity, economic resources, and public health communications that rated the United States as category 1, ranking with the most prepared of nations (Oppenheim et al., 2019). And yet America suffered more than twenty million confirmed cases – and almost half a million deaths – in a single year (Ritchie et al., 2021). Clearly, something, or many somethings, went terribly wrong, and that needs to be examined, because pandemics are neither a new nor an ended phenomenon. They have come before and will come again, and it is incumbent on concerned citizens and policymakers to learn from them to minimize the impact of the ones to come. In virology, the “eclipse phase” is the period after a virus has infected a cell, but before it has manifested disease (Venes, 2013). A person experiencing

this phase is in acute danger, but cannot know it. Given the long asymptomatic but infectious period associated with COVID-19 (discussed in detail in Chapter II) this seems an apt metaphor for the disease more generally in a public health context. Disease and the death it brings spring seemingly from nowhere…unless policymakers and a concerned public devote the time and attention to address it before it erupts into visibility.

As a new virus is encountered and health systems are mobilized against it, one would expect that as treatments are devised, lessons learned, and public health measures applied, both infections and deaths would decline. But even cursory analysis of one full year of coronavirus shows this not to be the case in the US. Why has this experience been so counterintuitive? What makes the same virus in the US so much deadlier than in other developed countries like South Korea or New Zealand or even in less developed ones like Thailand and Senegal? Difficulties of measurement are always an issue with epidemic disease, but the evidence presented further in this project clearly establishes that life for life and dollar for dollar, the United States was anomalously bad at responding to a global threat.

Many easy explanations leap to mind, from a lack of leadership at the federal level to the peculiarities of the American health insurance market. Much research is yet to be done on this subject, certainly, and many questions have to be addressed, far outside the scope of this work. However, there is one aspect of the American system that remains undiscussed, a quirk of how care is provided to some of the nation's most vulnerable citizens. This vulnerability – the frail and elderly receiving care in their homes – cuts across multiple distinctly American features: It is both privately-run and (partly) government-funded, it varies across state lines and is subject to America's

decentralization/federalization, and it is demonstrably prone to issues of trust in medical science and expertise. It is a microcosm of profound trends running through the American body politic and permits a narrow, specific examination of them without broadening the scope of this work unmanageably.

For decades public health experts have warned of the danger of worldwide pandemics, disease outbreaks spreading across the whole globe, indifferent to national borders or regional boundaries. Such outbreaks are not unprecedented, and barely a hundred years ago the 1918 influenza pandemic, the "Spanish flu," blazed like wildfire around the globe in three distinct waves, killing an estimated 50 million people (Medina, 2018). That was out of a world population estimated at 1.8 billion; even by the most conservative estimates, the Spanish flu killed perhaps one percent of the world's population (Roser, 2020). Disease treatment and prevention have come far since then, which include antibiotics and vaccinations that have increased the life expectancy worldwide, but so has the global movement of people and goods, the concentration of people in urban environments, and the number of interactions between humans and the environment. There have been flu pandemics since 1918, and outbreaks of other diseases – Sudden Acute Respiratory Syndrome (SARS), Middle Eastern Respiratory Syndrome (MERS), as well as Ebola, Zika, and more, meaning that the threat is not resolved, the 'boogeyman' not laid to rest, and the increasing complexity of medical care has developed new vectors of attack that are if not completely unprecedented, then understudied.

The year 2020 has been a spectacular demonstration of emergent viral threats, as Sudden Acute Respiratory Syndrome – Coronavirus – 2 (SARS-CoV-2) has defined the

social and political agendas of multiple countries around the world. Despite its unprecedented scope of effect, SARS-CoV-2 is only the latest of a series of coronavirus outbreaks. SARS and MERS are both close genetic relatives that likewise swept the globe in 2003 and 2012 respectively (Nature Microbiology, 2020). By way of comparison, SARS is associated with 8,096 cases and 774 deaths in 2002, and MERS with 2,229 cases and 791 in 2012, against the millions of fatalities from SARS-CoV-2 (Krishnamoorthy et al., 2020). Though the number of countries and individuals affected were comparatively low for both SARS and MERS, the potential for global outbreaks concerned many countries and sparked preparedness efforts worldwide.

Older diseases recur as well – the shadow of the terrible 1918 influenza pandemic lingers still today, because the last flu pandemic recognized by the World Health Organization (WHO) was only 11 years before 2020 (*CDC H1N1 Flu | WHO Pandemic Declaration*, n.d.). The WHO's highest state of alert, the Public Health Emergency of International Concern (PHEIC), has been declared six times since it was created by the International Health Regulations in 2005, for influenza (2009), Ebola virus (2013-2015 and 2018-2020), polio (2014), Zika virus (2016), and COVID-19 (2020) outbreaks (Wilder-Smith & Osman, 2020). It's not merely fallacious but fatuous to suggest that the world couldn't or didn't see this pandemic coming.

America is an outlier among developed nations in that it does not have public health insurance for all citizens and the vast majority of health insurance is provided by private insurers. People over 65 (and a small subset of people with disabilities) are insured through Medicare, a New Deal-era program dating from the 1930s run by the Centers for Medicare and Medicaid Services, a Federal agency that's part of the

Department of Health and Human Services (*Medicare Program*). Care for low-income citizens is through Medicaid, a sister program that crucially is Federally-funded but administered by each state differently (*Medicaid*). State-run Medicaid programs attempt to allow people to live in their homes as long as possible, a philosophy of service provision called Home and Community Based Services (*Home & Community Based Services*). As of 2014, more than half of all long-term care spending was on services in people's homes or communities, rather than in more isolated settings like nursing facilities, a total amount in excess of $80 billion (*Home & Community Based Services*).

Pandemics are neither unforeseeable nor unforeseen, and alarms were raised in advance by both national actors like the US intelligence community (Just Security, 2020), and by non-state actors like The Bill and Melinda Gates Foundation (Gates, 2015). Governments plan for disasters, including pandemics. The dangers of a "Novel respiratory disease" were forecast in a 2017 Pentagon planning paper. If this danger was predicted, and planning was taken to prepare for it, why did it infect 23 million people, almost 7% of the population, and kill more than 385,000 Americans in the 365 days since January 20, 2020 (Sepkowitz, 2021)? Why did more than 3 million Americans perish in one year, the deadliest year in American history (Stobbe, 2020)? What went wrong so badly, that America, its public and private health institutions, and the academic community needs to understand in order to mitigate the *next* pandemic?

There are many possible answers to these questions, including declaring poor or absent leadership from the national level, but this thesis will first test the hypothesis that the decentralization imposed by America's federal system, particularly structural vulnerabilities inherent in America's partly private, partly public, hybrid state and federal

healthcare system, exacerbated the effects of the COVID-19 pandemic in 2020. This had tragic effects that are still ongoing. Even if these factors taken together have formed a "perfect storm" unlikely to be repeated, it nonetheless means there are valuable lessons to be taken from this experience to apply to potential future pandemics. American citizens died who need not have, and it is incumbent on all of us to learn from mistakes made.

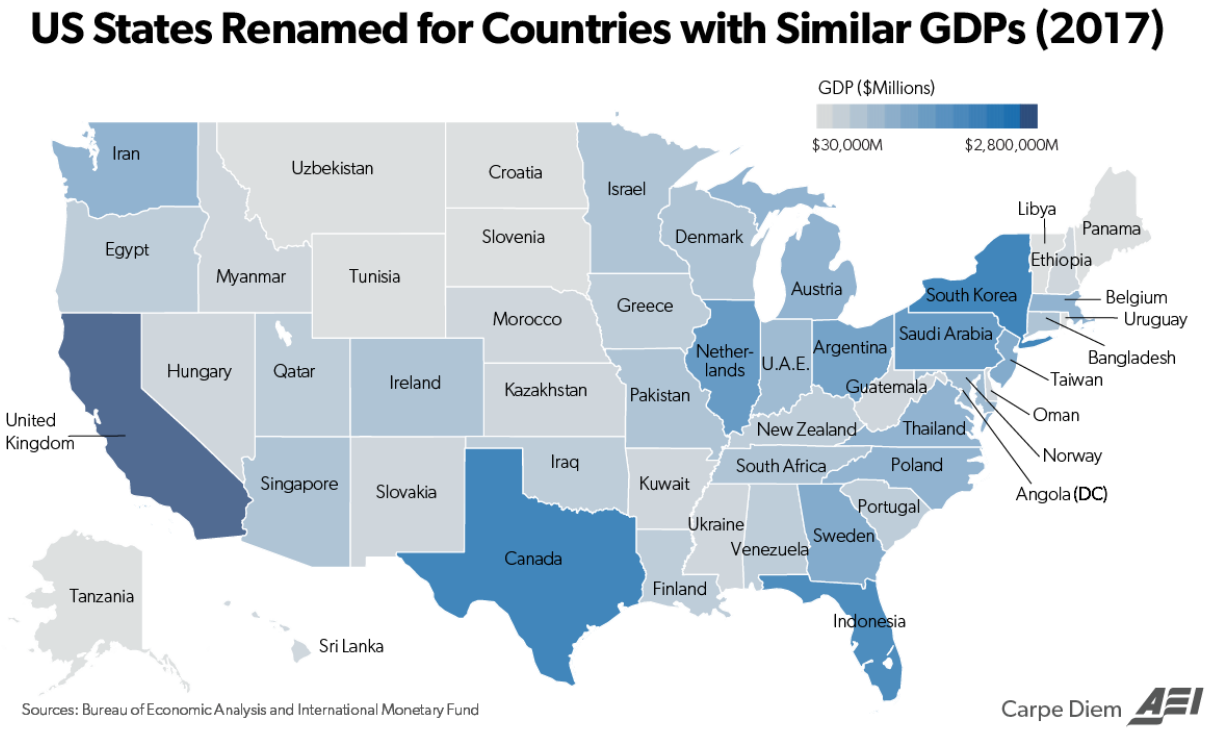


Figure 2. US States Renamed for Countries with Similar GDPs (2017).

Source: Putting America's enormous $19.4T economy into perspective by comparing US state GDPs to entire countries. (2018, May 8). American Enterprise Institute - AEI. https://www.aei.org/carpe-diem/putting-americas-enormous-19-4t-economy-into-perspective-by-comparing-us-state-gdps-to-entire-countries/

The United States has the largest economy on Earth, depending on method of calculation, and is a nation-state with few peers in sheer scale of population, territorial area, and economic heft. Figure 2, above, demonstrates this nicely by replacing the names of US States with those of countries with similar Gross Domestic Product (GDP). GDP is a measurement of the total value of goods and services produced in a given country over one year, and is by no means a truly comprehensive way to compare one country to another. However, it offers a general way to explain how the US ranks with other nation states. Along with the considerable internal differentiation imposed by its federalist structure, this makes direct country-to-country comparisons to the United States difficult. Accordingly, though there are examples of past successes in responding to previous pandemics in countries like Mexico, France, or Israel that can highlight the utility of specific interventions, the primary comparisons will be between publicly available US planning documents and planning guidance documents from the World Health Organization (A checklist, 2018) or the European Union, which is collectively roughly equivalent in population and economy to the US. Documents like the creation of the new European Health Union (EUR-Lex, 2020) and the Decision 1082/2013/EU (Decision, 2013), which it is partly replacing, highlight the distinctions with the American experience including better coordination between subunits (states and member nations, respectively). The bidding war over desperately needed ventilators between individual US states is a particularly shameful example of poor internal coordination (Mervosh & Rogers, 2020) because scarce resources were hoarded rather than distributed to the places of greatest need and as a result people died who might otherwise have lived.

The other logical point of comparison, the People's Republic of China, has very few planning documents available for comparison and we have to rely on what that government allows to be published. There remains considerable debate over the accuracy of the official figures given by the Chinese government, given that it certainly appears that deliberate delays or miscommunications about the severity of the pandemic in its first days and the exact nature of the threat – including holding back the genetic sequence of the virus until other labs were about to publish it (Sparrow, 2021). Doubts as to the efficacy of Chinese-produced vaccines and the refusal to provide comprehensive clinical trial data even as foreign tests return lackluster results does nothing to ease these concerns (Gan, 2021).

Second, the thesis will examine the potential weaknesses of the current home and community-based services delivery systems under Medicaid, using Pennsylvania as a sample. I will interview state administrators of federally-funded home and community-based services programs. Because the Medicaid program is federally funded but state-administered, there is substantial variation from state to state in administrative process. This will be original qualitative research, focused on a specific group of subject-matter experts whose contributions are not historically featured in existing literature. The national movement towards Home and Community-Based Services is primarily focused on that program, they are the relevant subject matter experts (especially so, given the disparities in administration, eligibility, and delivery mechanism between States) and should be able to best describe how the state institutions most directly involved in day-to-day operations with these two populations would respond and have responded to a catastrophic disruption like the outbreak of a pandemic.

Third, the thesis will feature review of existing literature on the subject of home care workers as a workforce. Special focus will be placed on the unique qualities – and vulnerabilities – of this community to the direct health effects and indirect disruption of a pandemic. Comparisons and contrasts will be made with existing literature on the nursing facility workforce, especially their experience during the COVID-19 pandemic.

Background of the Problem

Pandemics as a subject exist at a junction between multiple disciplines with distinct priorities and points of view. As a fundamentally medical condition, they are studied in medicine in terms of effects and countermeasures; as social phenomena driven and mediated by a wide variety of social conditions, they are central to the public health field; and as inherently transnational events with no regard for international borders, they are automatically subject to study by international relations scholars. Accordingly, the literature consulted for this work spans gaps between and within multiple disciplines and attempts to draw a holistic view of what is known about preparing for pandemics, what is still in contention, and what gaps appear yet to be filled where this research can contribute. Principally that contribution lies in soliciting contributions from a group of subject-matter experts not as yet consulted in the literature and by approaching a domestic problem – crisis preparedness – from a global, security-based perspective focusing on identifying and responding to vulnerabilities identified via comparative analysis.

SARS-CoV-2 is distinct from other pathogens, a new threat with parameters not yet fully understood (Weston & Frieman, 2020). While it is part of a pattern of emergent zoonotic coronaviruses, related to SARS and MERS, it is itself a new thing about which

much has yet to be determined ("The Species Severe Acute Respiratory Syndrome-Related Coronavirus," 2020). However, it does not exist in a vacuum and the programs, people, and institutions that have responded and continue to respond to it predate it. While COVID is a new phenomenon in many ways, influenza is not, and comparisons between the two diseases are easily made (He et al., 2020). This is helpful because influenza pandemics are recurring phenomena, and this makes comparative research, especially over time, much easier. Patterns of demonstrated or inferred vulnerability to an influenza pandemic also exist as potential weaknesses for coronaviruses or other novel airborne pandemic diseases.

Valuable for establishing this empirically is research like that of Merler et al. (2013), demonstrating unevenness in infectivity and disease experience across population cohorts. Specifically, this study examines the elderly population and why they contracted influenza at a lower rate than expected during the 2009 influenza pandemic. Their research suggested that about 16% of the population of Italy was infected by the virus, a rate they specify is similar to that in other countries, and that pandemic influenza vaccination in Italy was about 1% of total population (Merler et al., 2013). This observation has been demonstrated to tragic effect in COVID-19, as a study in Indiana found that residents aged 60 or over were almost 200 times more likely to die of the disease than those under 40 (Menachemi, 2020).

More generally, research like that of Merler et al. indicates that populations that are especially vulnerable to pandemic influenza that should be promptly treated might not fit into prior preconceptions of vulnerability. It is intuitively obvious that the elderly, especially those with prior infections, are more vulnerable to influenza or opportunistic

infection; it is less obvious, but shown by the data, that several groups that appear young and healthy can also be at greater risk than the population as a whole.

Several of these works imply a greater lesson: While understanding a disease process, vulnerabilities, and treatment protocols is essential to planning a response to any disease outbreak, this alone is not sufficient. Treating a disease alone ignores the broader bio-social implications and extended consequences of the disease. A fully-featured plan to respond to such a contagion requires examining the second- and third-order effects of a pathogen, not just on the infected individual but on the social networks within which they live and health care systems that support and treat them.

Public health as a discipline is obviously central to the study of pandemics. As this thesis identifies America as being both unusually vulnerable to an outbreak of pandemic influenza and more vulnerable than planning supposes, it is vital to establish some points of comparison, even if a true baseline is elusive. Because pandemic influenza is a recurring phenomenon, it serves as a natural experiment, allowing researchers to compare and contrast different national responses. For example, Krumkamp et al. (2009) conducted a survey of national responses to the 2009 flu pandemic among European nations to identify critical weaknesses among and between responsible institutions in those countries, finding a need for clear communication strategies and policy harmonization across different levels of government.

In a similar vein, Kohn et al. (2012) make an interesting set of observations regarding how Israel organized its pandemic response planning, given that as of 2005, pandemic response was the explicit responsibility of the Ministry of Defense rather than the Ministry of Health. This is a fundamentally different model of organization and

public-private partnership as compared to examples in Europe or the United States, but one that is perhaps uniquely suited to Israel's national character. Given the Ministry of Defense's large pool of skilled labor to draw upon and expertise with rapid response and mobilization, the Defense-led, Health-advised, Defense-executed approach was validated in 2006 when 1.25 million poultry suspected of being exposed to – and thus possibly contagious with – H5N1 influenza were culled and destroyed within 17 days (Kohn et al., 2010). While this model is only dubiously applicable to other countries, and its efficiencies probably amplified by Israel's relative smallness in area and population, it demonstrates what a coordinated, cross-governmental approach can look like, and should thus serve as a point of comparison with other national examples.

Mexico also serves as a useful point of comparison with the United States, in terms of comparative national responses to the 2009 H1N1 pandemic. Ear (2012) produces just this analysis, comparing responses by the Mexican and American governments to the 1976 and 2009 pandemics, using the biological similarity of the pathogen as the point of similarity. Mexico is lauded for a rapid and transparent response that featured substantive, active cooperation with partner nations, especially the United States and Canada (Ear, 2012).

Making health care decisions can be complex and fraught, and one of the communities most identified by this paper as worthy of further investigation – home health care workers – are not necessarily highly-educated in disease response, pandemics, and how to evaluate their level of risk. Dionne et al. (2018) conducted a web-based survey of health care workers in Montreal, finding suggestive evidence that workers' perceptions about a pandemic strongly affect their willingness to report for work. The

desires to protect themselves from infection (50% of respondents) and/or protect their families (36%) were cited in the hypothetical scenarios as reasons not to report for work, and the authors concluded that perception of health care workers' evaluation of risk and timely education of the risks and risk mitigation methods should be strongly encouraged by employers (Dionne et al., 2018).

Valuable as this research is, this area does not seem to be widely studied; further, web-based surveys are not the ideal research instrument and while the total number of respondents (3,574) is quite high, it is broken out across a wide variety of health professional fields, from doctors, nurses, and pharmacists to administrative staff (Dionne et al., 2018). Of that total, 1,063 were classified as "social worker in health care," the closest analogue in the study to the home health care worker population that is the focus of this thesis, which raises doubts as to the broader applicability of this research (Dionne et al., 2018).

Worth observing in the survey of the research above across various target areas and populations is that America does not have a centralized national health care program, a notable difference from the research in Montreal by Dionne et al. More, the specific system discussed in this thesis, Medicaid, is administered separately by each state, with wide local variance in policy. This poses a substantial challenge in finding sufficiently parallel examples, but the American fragmentation should also amplify the lessons drawn from other nations – if increased coordination and communication is being highlighted as valuable under conditions where those are already more prevalent than in America, it is at least worth considering that the benefits of implementing those policies might have commensurately greater impact in the United States as well. Together, these facts indicate

that trans-national comparisons have research value but must be combined with local data sources and other research to moderate the risk of false parallels and other potentially misleading data.

International relations, especially as a subset of political science more broadly, are particularly relevant to this research topic both because pandemics are national-security issues that are at least partly the concern of national security institutions. This field also studies interactions between and among different governmental institutions at different levels of government. Inevitably overlapping with the previous field, the most useful and relevant research here addresses either or both differences in pandemic preparation and response in different countries with different institutional setups, and the interactions between different governments in preparing for and responding to pandemics as multilateral issues.

As a field concerned with issues of national security, especially those that are transnational, works produced by the United States government go a long way to establishing both the severity of pandemic influenza as a national security threat, and the seriousness with which the national security infrastructure tries to prepare for it. Discussing the level of preparedness in the United States especially would be impossible without a close examination of the formal plans prepared by the Departments of Homeland Security and Defense. The Department of Homeland Security's publicly released plan clearly lays out the clear importance of addressing pandemic response planning as a mission as well as the intensely multilateral nature of the task, requiring input and consultation from a wide variety of state and non-state actors (*Pandemic Influenza Preparedness, Response and Recovery Guide for Critical Infrastructure and*

Key Resources, n.d.). Additionally, it inferentially helps to establish the space that this thesis aspires to fill: It makes no mention of home care workers nor the population they serve receiving services at home.

This topic has been an area of active concern by national security bodies more recently than 2006. A report from the Government Accountability Office (GAO) in 2017 details ongoing concern about the methods of coordination between US Federal Departments in planning for and response to a pandemic (Office, 2017). This lack of coordination supports the hypothesis that pandemic influenza is a serious concern that merits extensive planning and preparation and that friction between agencies of government can pose serious challenges to clear, coherent policy formation and implementation. Notably, however, the GAO is an agency of federal government charged with investigating similar bodies and making recommendations to them. Challenges in coordination among federal agencies is indicative of the type of issue this thesis predicts, but different in kind because this report does not specifically discuss interactions between federal agencies and their state equivalents nor intra-state collaboration and/or competition (Office, 2017).

National security scholars outside the direct auspices of the US government have additional contributions to make, particularly about the process of disease surveillance. This is the first stage of interaction with an emergent epidemic or pandemic, the ongoing process of monitoring the health of the population and looking for trends like a new pathogen. Better surveillance means earlier detection, and ideally leads to a shorter timeframe to response. Sell (2010) provides an excellent background on the techniques and processes involved in this activity, including its intensely multilateral character. This

research also provides insight into the weaknesses and challenges posed by the fragmentary nature of the activity, most notably the challenge of integrating more than 300 disease surveillance programs in the United States alone and the difficulty in maintaining funding for a process that is most necessary when there is no visible threat from a pathogen, noting that in 2008 and 2009 staffing reductions cut more than 15% of local health department's workforce (Sell, 2010). It follows logically that coordinating other types of disparate pandemic preparedness programs among a wide variety of domestic, international, and non-governmental actors will pose similarly challenging.

Research done by Wilson echoes the same theme but adds an interesting angle: a private "disease intelligence" company, the Veratect Corporation, that was active in 2009 and played a key role in detecting reports of "atypical pneumonia" in Mexico that was in fact an outbreak of pandemic influenza. The report goes on to add that this demonstrates both the utility of non-state actors in disease surveillance and early-stage pandemic response but also the value contributed by having different institutional cultures among investigating and reporting agencies (Wilson, 2017). Veratect was a United States corporation, operating from two American cities, continuously monitoring open-source data from Mexico. Despite this vigilance and the early warning they published to major international bodies (including the American Centers for Disease Control, the World Health Organization, and the International Committee of the Red Cross) the disease had spread across borders by the time it was identified, let alone an institutional response mobilized (Wilson, 2017). Not unreasonably, the Centers for Disease Control refused to declare an infection to be influenza without laboratory confirmation, but this meant an inevitable time delay while cultures were grown and tests conducted (Wilson, 2017). This

example, only a decade old, demonstrates the high transmission speed of airborne pathogens in a world with modern transportation infrastructure and the stresses this puts on institutions to respond. Where to strike the balance between maximum speed and maximum precision is an unanswered question, but this research suggests there may be merit in having a diversity of opinions from a diverse cast of actors with different incentives.

Collectively, the academic literature consulted on foreign countries and the international dimensions of pandemics as a topic contributes by illustrating the distinct features of the US healthcare system in distinct contrast. Principally, this refers to the fact that the public health insurance system for the indigent, Medicaid, is funded by both State and Federal governments, but administered by States, with substantial differences in operations. For example, Hawaii and Alaska both have different standards for the Federal Poverty Level (FPL) that is used to judge eligibility, and each state gets to determine the upper bounds of income that are eligible for services, as a percent of the FPL, which can vary substantially: Georgia allows pregnant women making up to 220% of the FPL to qualify, while nearby Louisiana only extends it to those making less than 133% of the FPL (Understanding Eligibility, 2021). Generosity in eligibility is not the only thing that varies – the Centers for Medicaid and Medicare Services, the Federal body that administers those programs, allows individual States to apply for waivers from the requirements in order to experiment with different models of service. The Home and Community Based Services 1915(c) waiver programs allow States to refocus Federally-provided Medicaid funds into different service settings. More than 300 waiver programs

are currently active across almost every State (Home & Community Based Services, n.d.).

Further, there is a nebulously large and difficult-to-measure community of people receiving services in their homes through private pay, which would be even more difficult to monitor in a crisis situation like a pandemic. If the hidden vulnerability identified in this thesis exists as the hypothesis argues because of the complex interactions of the unique contours of the American health care systems, one of the best ways to demonstrate this is by examining pandemic responses by other countries with very different systems and why successes elsewhere might not be replicable in the United States. In brief, examining foreign counterparts helps illuminate the distinctive features of the American health care system. It provides clear demonstration that the unique features of American health care and public insurance drive different behaviors in preparing for and responding to pandemics.

Research Methods

This project will first examine and interrogate existing research in the international relations and public health fields, focusing on analyses of successful and unsuccessful responses to pandemic disease outbreaks. Because of a limited sample size, this body of research will include both previous coronavirus outbreaks as well as past influenza pandemics.

Additionally, publicly available disaster response plans from the U.S. Departments of Defense, Homeland Security, and Health and Human Services will be compared to comparable documents from the World Health Organization (A checklist,

2018) and European Union (EUR-Lex, 2020; Decision, 2013). This comparison will establish the critical gap in pandemic response planning identified in the thesis: Individuals receiving services at home are not accounted for sufficiently in planning, and America's State-based model and lack of integrated national health care insurance means that this vulnerability does not occur in other countries and so is invisible to conventional planning.

Additional original research will be centered on interviews of senior staff at the Pennsylvania Department of Human Services who administer the State Medicaid program. These programs distribute billions of taxpayer dollars every year to companies providing services – home care aides, but also nursing, physical and occupation therapy, and more – to allow tens of thousands of citizens to remain living in their homes rather than nursing facilities. Their first-hand knowledge of this population, the services they receive, and the public and private institutions that provide that care is unrivalled. Because they work with these programs every day, they can provide a perspective not found in the literature about how they might function in the midst of a crisis. Indeed, if a crisis – pandemic or otherwise – were to affect the population of people receiving services in their homes, the Department of Human Services and its subsidiary Offices (particularly the Offices of Medical Assistance Programs and Long-Term Living) would be instrumental to the State's response.

Because I worked in the Office of Long-Term Living and know several current and former Bureau Chiefs and Deputy Secretaries, I have a unique level of access to a group of subject-matter experts that are an unexploited resource in the available literature, and thus represent a novel data source and new contribution to the field. All of

Harvard University's Institutional Review Board applicable protocols and policies regarding the use of human subjects will be complied with in this research.

Merler et al. indicate in their research of the effects of the 2009 influenza pandemic that even a comparatively mild strain with low lethality can be extremely widespread: They concluded 16% of Italians contracted the pathogen (Merler et al., 2013). This presents the possibility and even likelihood that any future pandemic – let alone a highly-lethal future pandemic like the one in 1918 – would cause enormous societal disruption completely apart from actual casualties. The experience of 2020 with COVID-19 visibly demonstrates just how widely a society can be shaken, even with comparatively minimal casualties. COVID-19 is already indirectly affecting 80% of the world's children and precipitating a possible global crisis in food insecurity, with attendant long-term costs (Lancker & Parolin, 2020). Economic impacts across primary, secondary, and tertiary sectors already amount to billions of dollars lost, with more than $2 trillion in relief approved in the European Union alone (Nicola et al., 2020). Data from the Bureau of Labor Statistics for 2020 indicates that unemployment spiked from around three and a half percent at the start of the year to over fourteen percent in April (*Bureau of Labor Statistics Data*, n.d.). This is a profound shock to the labor market by any measure.

Taking one-sixth or more of the population out of the workforce in a brief span of time is going to have consequences for society more generally; the interview questions will attempt to get specifics – without infringing on the statutory guidelines and requirements of the Health Insurance Portability and Accountability Act (HIPAA) – of how broad and how severe those consequences might be for the home caregiver

community and thus for the populations they serve. After all, the pandemic influenza guidance on the Centers for Disease Control's website advise that it "May cause major impact on the general public…Potential for severe impact on domestic and world economies" (*CDC H1N1 Flu | WHO Pandemic Declaration*, n.d.). A worst-case scenario like the 1918 flu pandemic has the potential to temporarily remove as much as half of a local workforce (Taubenberger & Morens, 2010). All of this provides the background for a series of questions for my interviewees concerning the ability of the systems they manage and oversee to handle temporary incapacitation of a sixth, a third, or half of the home health worker population, especially if hospital capacity is simultaneously mostly or fully utilized.

Additionally, the interview questions will address the ongoing, nation-wide transition from the Fee-For-Service model of care delivery to a model mediated by Managed Care Organizations (MCOs). The former, traditional model features services provided by private companies (for-profit and not-for-profit) that then bill the State for reimbursement. Managed Care institutes a large company in-between that relationship, paid a flat fee per person by the State and responsible for providing all necessary care, and incentivized to increase efficiency because their profit is the difference between that flat rate and their expenses. This is a fundamentally different way of arranging care to the populations receiving Home and Community-Based Services, and is in practice, in various formulations, across the United States. Pennsylvania makes a useful test case because it is currently completing the process of rolling out a Managed Care-style system and still maintains an institutional memory of the Fee-For-Service model. This means that insights from senior staff should be at least partially applicable across the United

States, as many states use either or both models in various combinations. Because many of the MCOs are nationwide or at least multistate, impressions from staff at Pennsylvania's Department of Human Services – and interviews with senior staff of one of the MCOs – will go some way to describing how these third parties might be instrumental in response to a pandemic or other major public health crisis.

Research Limitations

The home caregiver occupation is one of the fastest-growing in the United States – expected to grow by 40% between 2016 and 2026 but it is one that is poorly understood (*Bureau of Labor Statistics Data*, n.d.). Home health aide, home caregiver, personal aide and home care worker are just some of the names listed by the Bureau of Labor Statistics (*Bureau of Labor Statistics Data*, n.d.). There is no national union or representative organization that advocates for these workers – which means there is no unified, national dataset on these workers. Even if such a dataset existed, it would necessarily be incomplete because it could not capture the uncounted and probably uncountable number of Americans who provide some level of services to family and friends, the area of services called "informal supports". While there are organizations like PHI that aspire to that role and publish analyses of the workforce, they primarily collect their data from the US Census and the Bureau of Labor Statistics (*Bureau of Labor Statistics Data*, n.d.).

All of this makes accurate apprehension of the home care worker population difficult on a national scale and introduces at least the possibility of doubt about the nature and vulnerabilities of this population. This project will address this by using the best data and analysis available, acknowledging the weakness of the dataset, and making

the argument that given the information available, particularly PHI's analysis of the gender, age, and ethnicity of this workforce it is likely that even if we had perfect knowledge of this community, it's likely they would skew more towards that pattern and away from the broader American workforce (*Key Facts & FAQ - PHI,* n.d.). Ultimately, the dataset is incomplete but strongly suggestive.

This thesis primarily concerns itself with persons receiving government-funded services in their homes (as opposed to nursing facilities) under the philosophy of Home and Community-Based Services. These programs are primarily operated through the Medicaid program, which is Federally-funded but State-run (*Medicaid | Medicaid,* n.d.). This means that there are wide variances between States in eligibility, application processes, and what services are called. Interview with – or a survey of – senior staff in Medicaid administration across the country is an interesting research prospect and appealing, but well outside the scope of the available time and resources of this project. For logistical reasons, the primary staff to be interviewed will be from Pennsylvania. Given the available resources in time and space, a focus on one State is necessary. This does pose a sample size problem, but Pennsylvania has some features that should make it an acceptable if imperfect proxy for the country as a whole. It has both Fee For Service and Managed Care programs operational, it features both high-density urban counties and extremely rural ones, and it features a large retiree population. This project will cope with this limitation by both making the case that Pennsylvania can be seen as a microcosm, and trying to narrow my scope to this case merely being an example that invites further research, rather than definitively establishing a nation-wide trend.

The administrators I intend to interview can only speak to the population served by their programs, which means the population receiving these services but paying for them individually is unaddressed and uncounted. The National Center for Health Statistics conducts a study of long-term care providers. Their analysis of 2015-2016 data suggested that 12,200 agencies employing approximately 145,000 staff served more than 4.5 million people in their homes (National Center for Health Statistics, 2019). These numbers are far from comprehensive – they address only providers of skilled services that are enrolled in Medicare and Medicaid. In 2018, the American Association of Retired Persons (AARP) estimated that 14 million Americans required Long-Term Services and Supports, and that more than twelve and a half million of these – including 6.7 million seniors over the age of 65 – resided in their homes rather than in nursing facilities (Hado & Komisar, 2019). As America ages, this population is growing, and the vast majority of the services required are provided by unpaid labor from friends and family. The AARP estimated that in 2013 this consumed 37 billion hours of care provided by nearly 40 million caregivers (Hado & Komisar, 2019).

Like the statistics on home care workers generally, this is data that simply isn't well collected or tabulated. I intend to address this concern by interviewing senior staff at the Managed Care Organizations, by seeking out any inter-corporate groups representing the home care industry, and by making it clear in the thesis that the full scope of this vulnerability cannot be assessed given the private-employment component of this market. Hopefully the Managed Care Organizations and organizations like the National Association for Home Care and Hospice (*About NAHC – National Association for Home Care & Hospice*, n.d.) and the Alliance for Home Health Quality and Innovation

(*AHHQI_2019_Home_Health_Chartbook_Final_Updated_10.3.2019.pdf*, 2019) will be able to better illuminate this gap in the research methods selected.

COVID-19 is an ongoing issue with a great deal of uncertainty and rapid movement in the news; for the sake of simplicity this work will be limited to looking at the first year of the coronavirus and will examine the timeline from the emergence of the virus in November 2019 to the one-year anniversary of the first coronavirus death in the United States on January 21, 2021. A comprehensive timeline of events, especially decisions made by various governments, will be a prominent piece of the work and will ground the observations and original research in the historical evolution of the understanding of the virus and the responses to it.

Finally, 2020 has been an unusual year by any measure, and the ongoing response to COVID-19 has prominently featured in political news all year, despite the ongoing presidential election. An analysis of pandemic response is inherently going to be have an essential political dimension at any time, but especially this year with the serving US President. Because much of the response has been delegated to and conducted by individual States, the original research for this project should be insulated from these extraneous factors. Nonetheless, a section of the work will be dedicated to the timeline of events around the emergence of COVID-19 and how and when various responses were implemented. This will address the public messaging by the White House, critical Federal agencies like the Department of Health and Human Services and the Centers for Disease Control, and the differences between the two. Existing literature on public communications during emergency situations will be relevant here, especially that on the lessons learned from public relations during Ebola outbreaks in West Africa.

Additionally, a section will be dedicated to addressing the unique nature of United States of America, including the increasingly powerful distrust for expertise, medical advice, vaccines, and the Federal government as a whole. This paper does not assume a political slant or bias in this project, the information presented will be as clinical an examination as possible of the differences in popular culture between the United States and peer countries, as relevant to pandemic response in 2020. This will include addressing the substantial but variable racial disparities in health service delivery and efficacy.

This project will establish its central thesis by first addressing the essential nature of the COVID-19 pandemic by analyzing both the virus that causes it, SARS-CoV-2, and the sequence of events rippling out from the first infections. It will then proceed to address questions of America's capacity and incapacity to respond to the pandemic, the slack in the emergency care and nursing care systems, and the costs and consequences of America's response to the pandemic in an international context. Following that will be an in-depth examination of what is known and unknown about the twin communities of individuals receiving services in their homes and those that provide these services. Complementing the preceding analysis of existing secondary sources on the home health care community will be original research, quantitative and qualitative analyses of interviews of Medicaid program administrators whose voices do not appear in existing literature on this subject. Finally, the project will summarize its central arguments and conclude with some speculative notes as to the implications of this pandemic, this subject, and this research on the future. Further pandemics are not likely, they are certain, and it behooves policymakers to strike while the iron is hot and act quickly to mitigate whichever virus comes next.

Chapter II.

Life in a Time of Coronavirus

COVID-19, the disease that killed almost half a million Americans in a single year and more than any other country in 2020 (*Coronavirus (COVID-19) Deaths - Statistics and Research*), is caused by the SARS-CoV-2, a coronavirus of the genus betacoronaviridae (Mayo Clinic). This is a true statement, but it conveys no information about the experience of the virus, for either patients or caregivers. What does the virus look like, experientially? How does it progress, and how quickly? How does the treatment progress? From the point of view of the humans involved and the social consequences and implications of the disease these are essential questions.

It's important to make a distinction first off between SARS-CoV-2 the virus and COVID-19 the disease, which is caused by the virus. Infection occurs when bacteria, viruses, or other microbes enter the body and begin to replicate and multiply within the host (Venes, 2013). For an airborne virus like SARS-CoV-2 (or SARS, MERS, or influenza), this exposure comes from inhaling droplets or virus particles shed from an infected person (CDC, 2021). We know now that transmission can rarely occur from touching a surface previously touched by an infected person and then touching one's own mouth or eyes; in the early stages of the pandemic this was a considerable fear (CDC, 2021). This process of infection is invisible and undetectable – after all, the average person takes between 17,280 and 23,040 breaths a day, and if exposed with a virus any one of them could be the vector for infection (Brown, 2014). For SARS, a previous coronavirus the estimated infective dose is just a few hundred particles; for MERS, the infective dose required is much higher, on the order of thousands of particles (Mandavilli,

2020). Current research tentatively suggests that the infective dose of SARS-CoV-2 is smaller than past coronaviruses, perhaps around a hundred particles (Karimzadeh et al., 2021).

Between two to fourteen days after infection, a person notices they're sick – they become symptomatic (CDC, 2021). The median infection period is about five days, but can stretch longer (CDC, 2021). Exactly how long this takes varies from person to person, and was the subject of considerable debate and research in the early stages of the pandemic. The long infection period poses a substantial public health hazard, because it increases the time when a person can feel fine and display no symptoms but nevertheless infect those they come into contact with.

COVID-19 presents with chills or fever, muscle aches or headache, fatigue, sore throat, congestion or runny nose, nausea or vomiting, and/or new loss of taste or smell (CDC, 2021). If most of this list sounds familiar, it should: These are also listed as "flu-like symptoms" or "influenza-like illness" (*Influenza (Seasonal)*, 2018). As the name implies, they are also caused by influenza, but also by rhinovirus, the cause of the common cold, and other types of respiratory infections (*Influenza (Seasonal)*, 2018). This means that as a patient experiencing COVID-19, the first symptoms may be familiar and are quite common between all of these pathogens. If for whatever reason one is not particularly concerned about the virus – perhaps it's early in the progression of the virus, or they are young and healthy, or think that the health risks of COVID-19 are exaggerated – one is likely to ignore the symptoms. After all, almost everyone has had them before, and it was just a cold then, or at worst the flu. If one is aware of the dangers, perhaps

because they're in a high-risk group, then these relatively minor symptoms provoke fear and anxiety greatly disproportionate to their severity.

About 80% of the people who develop symptoms of COVID-19 have a minor case and recover without hospital treatment (*Coronavirus Disease (COVID-19)*, 2021). Of the remainder, three-quarters (15%) require oxygen and the last 5% need intensive care (*Coronavirus Disease (COVID-19)*, 2021). Complications from COVID-19 that lead to death include respiratory failure, acute respiratory distress syndrome, sepsis, and/or multiorgan failure (*Coronavirus Disease (COVID-19)*, 2021). It should be noted that this breakdown is the culmination of the lessons learned over 2020, and that these percentages were not known at the start of the year.

Treatment for COVID-19

As the pandemic spread through communities across the globe, greater experience has led to improvements. As detailed in the timeline later in this chapter, the genome of SARS-CoV-2 was rapidly sequenced, and the medical community quickly knew they were dealing with a coronavirus. This meant that in early 2020, treatment for COVID-19 was based on older treatment modalities for previous coronaviruses, SARS and MERS (Hu, Huang, & Lin, 2020). Over the course of the year, treatment and survival improved as experiments were conducted and more effective drugs were tested and approved.

The first step is to prevent it from spreading further, driving down the R_0 or "R naught", the basic reproduction rate of the virus (Achaiah et al., 2020). Those infected can do this by washing their hands, staying 6 feet away and wearing masks, a collection of measures called "social distancing" (Pearce, 2020). Because one does not know that one is infected until symptoms develop, without test results indicating viral load, these

measures need to be employed by everyone in the community. Ideally, if someone has the virus, and perhaps are manifesting the disease or has a positive test result, they are isolated from others and can manage their symptoms at their own residence with usual treatment for symptoms including over-the-counter drugs (*Advice for the Public on COVID-19 – World Health Organization*, 2021). More serious cases presenting with hypoxemia, respiratory distress or shock need instant oxygen therapy to keep blood oxygen levels over 90% for adults (Moazzam et al., 2020). This definition of serious is used by clinicians, and cases that don't meet these criteria might easily be extremely unpleasant and perceived as serious by patients or laypeople. "Non-serious" cases can still be debilitating, frightening, and extremely unpleasant (Wilson, 2020).

Critical patients are those that experience an autoimmune response that causes hyper-inflammation, a 'cytokine storm' (Hu, Huang, & Lin, 2020). This phenomenon is a complex network of effects along multiple axes, the biochemistry of which is quite complicated and not yet fully understood (Mahmudpour et al., 2020). The practical effect on a vulnerable patient is simple, however: an inflammatory response that stresses and sometimes over-stresses the body, leading to acute respiratory distress syndrome or multi-organ failure (Moazzam et al., 2020). Attempts to head off this chain of events focus on a variety of immunomodulator drugs like corticosteroids intravenous immunoglobulin or drugs that interrupt particular cytokines, called cytokine antagonists (Moazzam et al., 2020). Remdesivir, a broad-spectrum anti-viral that is the therapy of choice for several viral families including Ebola, SARS-CoV, and MERS-CoV, is also used across mild, moderate, and severe cases (Moazzam et al., 2020).

Most people will recover fully within one to two weeks; severe cases may last longer – the average hospital stay for Wenzhou patients was 27 days (Bendix, 2020). In the most severe cases, long-lasting and possibly permanent damage to heart, kidneys, lungs and brain might result (Post-COVID Conditions, CDC, 2020). Because this is a newly emergent pathogen, there simply isn't very much known about the long-term effects of severe cases. "Long COVID", the term for this cluster of effects, is a subject of ongoing study, but there's much yet to learn ("Researchers Are Closing in on Long Covid," 2021). Evidence has emerged about substantial neurological damage, though whether that's caused specifically by COVID-19 or by the ventilators used in treatment is unclear ("Researchers Are Closing in on Long Covid," 2021). There exists every possibility that a decades-long public health crisis has been created as a legacy of the coronavirus, of which the full scale and implications are still obscured.

Coronavirus and Lethality

How deadly is the coronavirus? That's a surprisingly hard question to answer with any kind of certainty for several reasons. First, not everyone who is infected with SARS-CoV-2 (the virus) develops COVID-19 (the disease). These asymptomatic individuals are at no risk themselves, though they may infect others. Second, knowing how many people are infected requires testing. Not all testing regimes were or even are now at time of writing are remotely comprehensive, which this project will address in Chapter Three. As indicated above, many cases are relatively mild and might be mistaken for the common cold or treated independently of the health care system. Someone might develop symptoms, self-isolate, use over-the-counter medications, and thus never appear in

hospital admissions records, especially if they're under- or uninsured and/or live in a rural area with less healthcare availability.

The classical measurement of the mortality of any disease is called the case fatality rate, or CFR, and it is a simple time series of confirmed cases divided by confirmed deaths (*Principles of Epidemiology | Lesson 3 - Section 3*, 2019). Unfortunately, it leaves much to be desired in cases like 2020, with a newly emergent disease, incomplete testing, and wide variances in the effects of the disease in different populations. The CFR for COVID-19 has been calculated and recalculated across 2020 and 2021, with wide variances and considerable imprecision. Given the weaknesses of this measurement under these circumstances, it is not being used as a measurement in this project.

The alternative approach is to estimate the number of people who would probably have died from all other causes by extrapolating from past years and then comparing against the known total death toll, producing a measurement called excess deaths. This is inherently a "fuzzy" measurement, because it relies extensively on estimates and extrapolations. Not all nations or sub-national units report total deaths the same way or on the same timescale, which makes compiling these totals difficult and imprecise. Additionally, in some jurisdictions – particularly rural areas in the developing world – deaths may not be properly recorded at all. In May of 2021, horrifying drone footage emerged from India of hundreds of decomposing bodies floating in the Ganges or washed up along its banks; because of overcrowding and expense at crematoriums, families have been consigning their dead to the river, uncounted to official statistics (Pandey, 2021). Even when deaths are accounted for, they might not be reported accurately by

governments eager to minimize the impact. Reporting from around the same time suggests that in Gujarat province alone, COVID-19 deaths were underreported by a factor of ten (Biswas, 2021). These examples are both from one country in 2021, but there's no reason to suspect that they're unique, and if total death tolls are inaccurate, then measurements like excess deaths derived from them will also be so.

Even sophisticated extrapolation from past data is still at best an estimate, but it probably provides the most complete answer for how many people died of COVID-19. An analysis by the Economist Intelligence Unit in May 2021 seeking to find the global excess deaths attributable to COVID-19 estimated from 7.1 million to 12.7 million ("There Have Been 7m-13m Excess Deaths Worldwide during the Pandemic," 2021). It is important to note that even as this project is being written and billions of vaccinations have been delivered across every country on Earth, that number is still growing. We will never know exactly how many died in the 2020 pandemic, but it is certainly vast and not over yet.

Viruses, like all other living things, mutate and change over time. Because the lifecycle of an individual virus particle is so short, SARS-CoV-2 has had a great many generations to change and adapt in a year, which is a short time by the lifespan of humans. Sometimes variants are harmless, and these often pass without notice, but some variants are more infectious, more lethal, more resistant to treatment or vaccines, or some combination of all three. By September 2020, a new variant of the virus was detected in England; by December, it was the most common variant in the United Kingdom and had been detected in the United States (*New Variants of Coronavirus*, 2021). As of the time of this writing, four variants of concern have been identified globally, all present in the

United States, assigned Greek letters as identifiers by the World Health Organization: Alpha, Beta, Gamma, and Delta (*Tracking SARS-CoV-2 Variants,* 2021). As long as the virus persists in the human population, new variants will emerge, meaning that humanity is locked in a race between vaccination and mutation.

(Not) Just Like the Flu

COVID-19 presents with flu-like symptoms, as established earlier (CDC, 2021). Many cases are mild and can be treated at home with over-the-counter medication (*Coronavirus Disease (COVID-19)*, 2021). This is especially true with those who are young and healthy; patients 65-74 were assessed by the CDC as being 1,300 times more likely to die of infection than those age 5-17, and patients over 85 were estimated at 8,700 times more likely to die (CDC, 2020). Together, these facts make it easy for younger and healthier individuals to be skeptical of the seriousness of the disease. Given the similar symptoms, flu is the natural comparison. Unfortunately, flu is only superficially comparable to COVID-19. There are some intuitive and even valuable parallels, which this section will examine in detail.

Structurally, coronaviruses like SARS-CoV-2 and influenza viruses are quite similar – they are both RNA viruses that use a spike protein to infect cells in the respiratory tract (Manzanares-Meza & Contreras, 2020). SARS-CoV-2 is about twice as complicated as influenza in terms of information encoded into its genome, and incorporates an error-checking mechanism that drastically reduces the mutation rate compared to influenza (Manzanares-Meza & Contreras, 2020). The incubation period for influenza tends to be 1-2 days, though it can be as long as 4; the novel coronavirus varies more widely, with most patients experiencing symptoms about 5 days after infection, but

symptoms can appear from 2 to 14 days after infection (CDC, 2021). Both diseases, COVID-19 and influenza, are spread the same way, from droplets exhaled during respiration, and pass person-to-person at distances of under 2 meters (*COVID-19 (Coronavirus) vs. Flu*, 2021).

When most people refer to the flu, they're referring to seasonal influenza epidemics, outbreaks of which occur every year and infect an estimated 1 billion people annually (*WHO Launches New Global Influenza Strategy*, 2019). Global influenza pandemics are irregular – the last one was in 2009 – but not uncommon, and were the subject of most pandemic response planning before 2020 (Fukuda & World Health Organization, 2009). Like SARS-CoV-2 and other coronaviruses, influenza is an airborne virus, spread by respiration. It obviously presents with flu-like symptoms, is relatively minor in most cases, and is most dangerous to the very young, very old, and/or those with comorbidities like asthma, heart disease, liver or kidney disease, diabetes, or obesity (CDC, 2021). Naturally, several of these are routinely contemporaneous with each other, magnifying risk.

Seasonal influenza outbreaks are not generally very dangerous…to healthy adults. There are some specific populations that are more vulnerable. Namely, these include the elderly (over 65), the very young (under 2), and those who have comorbidities, including asthma, heart disease, or diabetes (CDC, 2021). Given the structural similarities detailed above, it isn't surprising that COVID-19 shares almost all of the same comorbidities, with much higher risk of worse clinical outcomes in patients who share one or more of those other issues (Beckman et al., 2021). People with these conditions, especially those with more than one of them, are exceptionally vulnerable to death or serious impact from

viral infections like SARS-CoV-2. It follows that communities made up wholly or primarily of those with at least one of these conditions are vulnerable by definition.

Being viral in nature rather than bacterial, neither influenza nor COVID-19 is treatable by antibiotics. Most anti-viral drugs are usable on influenza, but only remdesivir is demonstrated effective against COVID-19 (*Coronavirus Disease 2019 (COVID-19) - Symptoms and Causes*, 2021). Because both viruses are spread the same way, the same measures can be used for prevention: mask wearing and social distancing to reduce risk of transmission (CDC, 2021).

For all that influenza virus is similar to coronaviruses biologically, there are some noteworthy differences. Most significantly, COVID-19 is vastly more deadly than the seasonal flu. As of May 2021, the Mayo Clinic estimated that approximately 32 million Americans had been infected with SARS-CoV-2 and developed COVID-19, of whom more than 580,000 had died; by comparison, the 2019-2020 seasonal flu had infected 38 million Americans and killed around 22,000 (*COVID-19 (Coronavirus) vs. Flu*, 2021). Less visibly, a higher but as yet not fully-understood percentage of those infected with SARS-CoV-2 are asymptomatic but can still infect others, presenting an invisible disease reservoir to public health responses. Investigation is still being conducted into the phenomenon of "long COVID" where some of those who survived infection, even a mild case, present ongoing symptoms indicating possibly permanent damage ("Researchers Are Closing in on Long Covid," 2021).

Not all of the differences are purely negative, however. The reduced mutation rate in SARS-CoV-2 implies that natural vaccination – or the immunity generated in those who survived after being infected rather than receiving a vaccination – is likely to be

more effective for longer than it is against flu viruses (Manzanares-Meza & Contreras, 2020).

Because the influenza virus and coronaviruses are spread the same way, via inhalation or exposure to the mucous membranes of viral particles, it follows that all the counter-infection measures taken for one will be effective against the other. It seems probable that the social distancing and mask use that was widely if incompletely in place due to concerns over COVID-19 saved lives that would have otherwise perished to the seasonal flu, being especially effective given the lower transmissibility of flu viruses. The data bears this out: The confirmed cases of seasonal flu in the 2020 to 2021 season are historically low (Resnick, 2021). Positive tests for the flu dropped 98% year on year in the United States, even as tests performed dropped only 61% (Jones, 2020). These measures are not new inventions or the result of radical new science. Their use, and imposition by government mandate, is just the result of justifiable fear over the impacts of the coronavirus. It is proof that lives could have been saved from the flu every year if these measures had been in place. What level of risk and attendant cost in lives is appropriate for the country to implement restrictive public health measures is a philosophical as much as policy question, and outside the scope of this research.

Historically, every year there is a seasonal flu vaccine, recommended for those who are especially vulnerable or are in close contact with those who are. This vaccine is targeted at the strains of influenza that scientists estimate will be most prevalent and dangerous. Unfortunately, the nature of vaccine production required them to make this prediction about 18 months in advance of the coming flu season, which meant that there was substantial room for error (*Influenza Vaccine Production and Design | NIH*, 2019).

The advancements in vaccine testing, production, and deployment that were tested successfully with the various vaccines seem likely to shorten this time in coming years, improving the accuracy and effectiveness of seasonal flu vaccines. It's also possible that greater focus and attention to the risks posed by respiratory disease and the effectiveness of vaccines might increase the uptake and use of seasonal flu vaccines, improving the individual and collective defenses against it. SARS-CoV-2 or its descendants may be with us for many years to come, but some of the tools developed to overcome it will also likely remain and save lives that would otherwise be lost to it or to other scourges.

A Year Under the Crown

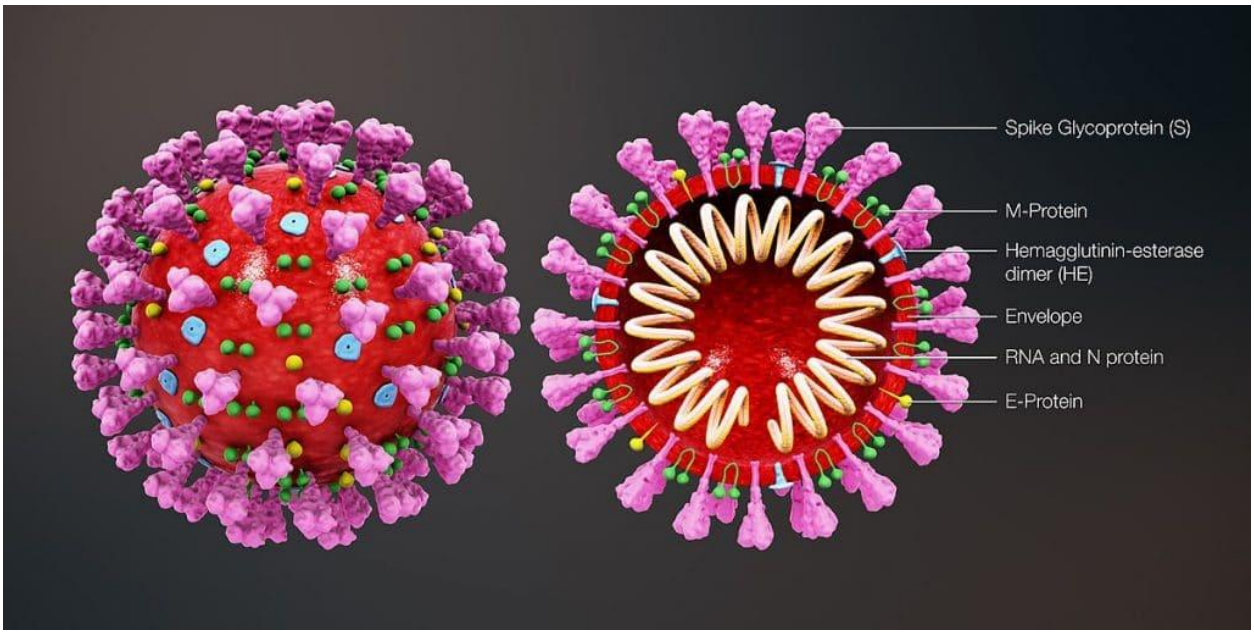


Figure 3. Image of SARS-CoV-2, Bulletin of the Atomic Scientists.

Source: Coronavirus Collection. (n.d.). Bulletin of the Atomic Scientists. Retrieved May 27, 2021, from https://thebulletin.org/tag/coronavirus/

Coronaviruses, those viruses of the genus coronaviridae, are visually distinct because of the spike proteins that project outward in order to bind to the ACE2 protein in the human lung (Bulletin of the Atomic Scientists). This spiky, jutting array looks like rays from a sun or the tines of a crown, and so the family received the name of corona, from the Latin for crown.

As Figure 3 makes clear, the coronavirus is innocuous-looking, even beautiful, and it's about a thousandth the thickness of a human hair (*What Size Particle Is Important to Transmission of COVID-19? | Aerosol Laboratory*, n.d.). But it has had profound, even dominating effect on the political and social life of the entire planet for more than a year, and as of late 2021 looks likely to continue to have a global impact for at least months if not years and decades to come. A full description of the effects of the pandemic is far outside the scope of this work and a comprehensive oral history of 2020 could fill libraries. Nonetheless, some understanding of the timeline of events in the American context is necessary for appreciating the speed and scale of events. As the pandemic is still ongoing and developing as this project is being written, this timeline and description will instead be limited to the first year of the pandemic in the United States, starting with the first cases in January 2020 and ending one year later in January 2021. Some events prior to this will be presented for context, but the focus will be the first year of the American experience with COVID-19.

It's Been a Long, Long Year

December 31, 2019	Government of Wuhan confirms reports of dozens of cases of pneumonia originating from an unknown cause (Taylor, 2020).
January 3, 2020	The Trump administration receives its first formal notification of the outbreak of coronavirus via a call to Robert Redfield, Director of the CDC, from George Gao, head of the Chinese CDC (Abutaleb et al., 2020). Redfield emails and then calls Gao, questioning whether the new virus is capable of human-to-human transmission and offering to deploy the Epidemic Intelligence Service, the "elite virus-hunters" from the CDC – they are refused permission to deploy (Woodward, 2020).
January through March	Redfield, Health and Human Services Secretary Alex Azar, and National Institute of Allergy and Infectious Diseases (NIAID) Director Anthony Fauci form a task force to deal with the virus. As the virus continues to spread, reports from the US Intelligence Community track it. In January, the State Department informs the Director of National Intelligence that the virus was likely to spread globally and become a pandemic.

January 6, 2020	The CDC posts a Level 1 travel notice for the Wuhan area, warning travelers to the region to "practice usual precautions"; the Situational Report of the same day notes that the market at the center of the known cases is located right next to a train station and that domestic train routes will soon be crowded as the Chinese New Year begins on January 24 (Woodward, 2020). This is the lowest of the CDC's three travel notices – Watch, Level 1; Alert, Level 2; and Warning, Level 3 (*Travel Health Notices | Travelers' Health | CDC*, n.d.).
January 7, 2020	The CDC establishes an Incident Management Structure, usually reserved for serious health concerns "to prepare for potential domestic cases and to support the investigation in China or other countries if requested" (Woodward, 2020).
January 9, 2020	Government of China publicly identifies new pneumonia-like virus as a novel coronavirus (*A Timeline of COVID-19 Developments in 2020*, 2021).
January 10, 2020	Government of China reports the first confirmed death caused by the new virus.
January 11, 2020	China releases the genetic sequences of COVID-19. Forty-one patients have been diagnosed with the novel pathogen, seven seriously and one

	fatally. There is no evidence yet of person-to-person spread, or community transmission (Taylor, 2021).
January 14, 2020	Robert Kadlec, Assistant Secretary for Preparedness and Response at the Department of Health and Human Services, draws up contingency plans to activate the Defense Production Act, which allows the government to compel private companies to produce equipment for national security; meanwhile, the Chinese government insists that there is “no clear evidence of human-to-human transmission” (Abutaleb et al., 2020).
Late January	US Diplomats in Wuhan urgently return home, warning the State Department that there is a significant public health risk (Harris et al., 2020).
January 17, 2020	CDC begins entry screening of passengers on direct and connecting flights from Wuhan China to the three main ports of entry in the United States, which shortly after expands to include Atlanta and Chicago. CDC issues an updated interim Health Alert Notice Advisory to state and local governments, and a CDC team in Washington State is deployed to trace contacts from the first reported case in the United States.

January 18, 2020	Health and Human Services Secretary Alex Azar has his first briefing with President Donald Trump about the virus via a phone call (Harris et al., 2020).
January 20, 2020	The United States and South Korea both announce their first cases of COVID-19 (Holshue et al., 2020). Responses by the two governments are a study in contrasts, and will be examined in depth elsewhere in this paper; South Korea's response is immediate and deploys vast resources to test for the virus and trace its progress (Lee et al., 2020). Chinese officials confirm for the first time that the virus is capable of human-to-human transmission (*A Timeline of COVID-19 Developments in 2020*, 2021).
January 22, 2020	While in Davos, President Donald Trump is asked about the coronavirus by a reporter for the first time; asked whether he was worried, he replied, "No. Not at all. And we have it totally under control. It's one person coming in from China…it's going to be just fine." (Abutaleb et al., 2020)
January 23, 2020	The World Health Organization releases Novel Coronavirus (2019-nCoV) Situation Report 3: "The initial source of 2019-nCoV still remains unknown. However, it is clear the growing outbreak is no longer due to ongoing exposures at the Huanan seafood market in

	Wuhan; as in the last one week, less than 15% of new cases reported having visited Huanan market. There is now more evidence that 2019-nCoV spreads from human- to- human and also across generations of cases…WHO assesses the risk of this event to be very high in China, high at the regional level and high at the global level." (*Coronavirus Disease (COVID-19) Situation Reports*, n.d.) The government of China takes the radical step of shutting down the city of Wuhan, home to 11 million people (Abutaleb et al., 2020).
January 24, 2020	The Lancet publishes "Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China", an early scientific study of the emergent pathogen over December 2019. The earliest case in the study is identified on December 1, 2019. Of 41 lab-confirmed cases by January 2, 2020, there is one confirmed cluster; 13 (32%) patients were admitted to ICU, and 6 (15%) died. (Huang et al., 2020). The novel virus is identified as "2019-nCoV", i.e. a novel or new virus of the coronaviridae family discovered in 2019; the authors confirm that by the time of publishing, there were more than 800 confirmed cases, more than twenty times the population they observed in their study less than three weeks earlier (Huang et al., 2020).
January 28, 2020	According to reporting by Bob Woodward, at a top-secret briefing President Trump is informed by National Security Advisor Robert

	O'Brien that coronavirus will be "the biggest national security threat" of his presidency (Woodward, 2020).
January 30, 2020	Director-General of the World Health Organization Tedros Ghebreyesus declares "a public health emergency of international concern over the global outbreak of a novel coronavirus" (Taylor, 2021). Hours after the Director-General's declaration, President Donald Trump declares that the virus is "under control" and that it would have "a very good ending for us." (Oprysko, 2020)
February 2, 2020	The Trump Administrations suspends entry into the United States for travelers from China (*A Timeline of COVID-19 Developments in 2020*, 2021).
March 11, 2020	World Health Organization declares the novel coronavirus a pandemic, with more than 100,000 confirmed cases and 4,000 deaths globally (*WHO Director-General's Opening Remarks at the Media Briefing on COVID-19*, 2020). In response, pro sports leagues close their seasons, schools shut down, people start working from home, and American life starts to grind to a halt (Thebault et al., 2021).

March 12, 2020	Dr. Anthony Fauci, Director of the National Institutes for Allergy and Infectious Disease informs the US Congress that the testing system is failing (Thebault et al., 2021).
March 13, 2020	President Donald Trump declares a national emergency (Hawkins et al., 2020).
March 16, 2020	The Centers for Disease Control recommends cancelling or postponing any events with 50 or more people for at least 8 weeks; the states of California, Ohio, and Illinois begin issuing shutdown orders for bars and restaurants (Miroff et al., 2020).
April 2, 2020	Most Americans are living under stay-at-home orders (Thebault et al., 2021). By this point, more than one million people have been sickened by the disease, and millions more have become unemployed, including more than ten million Americans (Taylor, 2021).
April 3, 2020	The Federal government reverses policy and recommends all citizens wear masks in public (Thebault et al., 2021).
April 11, 2020	The United States passes Italy, attaining the blood-stained honor of the highest coronavirus death toll in the world (Thebault et al., 2021).

April 24, 2020 Governor Brian Kemp of Georgia allows businesses to reopen, the first state to do so (Thebault et al., 2021).

April 30, 2020 Federal social distancing guidelines expire and more States begin reopening (Thebault et al., 2021).

May 15, 2020 “Operation Warp Speed”, the Federal vaccine development program, is announced (Thebault et al., 2021).

May 19, 2020 Forty-three states have either reopened or never locked down (Thebault et al., 2021).

May 25, 2020 While on the wane in New Jersey and New York, COVID-19 expands enormously in multiple states wear lockdowns and mask mandates are nonexistent or unenforced with mass unmasked parties and gatherings (Heseltine, 2020).

May 28, 2020 The US death toll surpasses 100,000 (*A Timeline of COVID-19 Developments in 2020*, 2021).

June 8, 2020 More than a dozen states set new infection records (Thebault et al., 2021).

June 11, 2020 There are at least 200,000 cases across Africa; according to estimates by the WHO, it took 98 days for the virus to infect 100,000 people, but only 18 days for that number to double (Taylor, 2021).

June 17, 2020 "It's dying out," Trump states in press conference (Thebault et al., 2021).

June 25, 2020 America records highest-ever daily case count (Thebault et al., 2021).

June 22, 2020 A study suggests that up to 80% of Americans seeking care for flu-like symptoms in March were actually infected with SARS-CoV-2; if one-third of them had sought testing, it could have it could have produced 8.7 million infections (*A Timeline of COVID-19 Developments in 2020*, 2021).

June 26, 2020 As infections and hospitalizations soar, Texas and Florida shut down bars and restaurants (Thebault et al., 2021).

July 7, 2020 On the same day that the United States passes three million confirmed infections, the Trump Administration announces it's withdrawing from the World Health Organization, citing pandemic response failures (*A Timeline of COVID-19 Developments in 2020*, 2021).

July 11, 2020 President Trump wears a mask in public for the first time (Thebault et al., 2021).

July 13, 2020 A report finds that more than 5 million Americans lost their health insurance between February and May, 2020, the largest drop in history (Taylor, 2021).

July 27, 2020 Moderna vaccine begins full-scale, 30,000-member clinical trials, the last phase of testing (*A Timeline of COVID-19 Developments in 2020*, 2021).

July 31, 2020 More than 150,000 Americans have died to coronavirus (Thebault et al., 2021).

August 1, 2020 The United States recorded more than 1.9 million new cases in July, more than double any previous month since the pandemic began (Taylor, 2021).

August 3, 2020 Across the country, teachers protest school reopenings, warning of deaths among students, faculty, and families (Thebault et al., 2021).

August 9, 2020	Students return to schools across the country; some are virtual, some in person, some a mix, and many school districts change or modify their plans, to much confusion (Thebault et al., 2021).
September 10, 2020	President Trump grandly announces that America has "rounded the final turn." He is publicly contradicted by Dr. Anthony Fauci the next day (Thebault et al., 2021).
September 18, 2020	Evidence emerges about the attempted silencing of a CDC doctor by White House officials (Thebault et al., 2021).
September 22, 2020	US death toll to coronavirus exceeds 200,000 and still rising (Taylor, 2021).
September 23, 2020	A new strain of the virus is discovered, more contagious than the baseline (*A Timeline of COVID-19 Developments in 2020*, 2021).
September 26, 2020	The White House throws a party in the Rose Garden to celebrate the nomination of Amy Coney Barrett to the Supreme Court; few attendees wear masks (Thebault et al., 2021).

October 2, 2020	President Trump announces that he and First Lady Melania Trump have tested positive for the virus; within 24 hours they are airlifted to Walter Reed Medical Center for treatment (Taylor, 2021).
October 5, 2020	After a course of cutting-edge, experimental treatment unavailable anywhere else, President Trump returns to the White House; “Don’t be afraid of covid,” he tells reporters (Thebault et al., 2021).
November 1, 2020	The US records more than 100,000 new cases in 24 hours for the first time (*A Timeline of COVID-19 Developments in 2020*, 2021).
November 3, 2020	Election Day. Early voting, voting by mail and absentee ballots shatter records nationwide (Thebault et al., 2021).
November 9, 2020	Pfizer-BioNTech announces that its vaccine is more than 90% effective in testing (Thebault et al., 2021).
November 16, 2020	Moderna announces that its competing vaccine is nearly 95% effective in testing (*A Timeline of COVID-19 Developments in 2020*, 2021).
November 18, 2020	The US death toll reaches 250,000 (Taylor, 2021).

November 20, 2020	The CDC pleads with Americans to stay home for Thanksgiving, traditionally the busiest travel holiday of the year (*A Timeline of COVID-19 Developments in 2020*, 2021).
November 23, 2020	Air travel reaches a pandemic-year high and epidemiologists fear a surge in cases (Thebault et al., 2021).
December 8, 2020	President-Elect Joe Biden announces his plan to tackle coronavirus in his first 100 days in office (Thebault et al., 2021). The United Kingdom begins administering vaccines, the first in the world (Taylor, 2021).
December 11, 2020	The Food and Drug Administration grants emergency use authorization to the Pfizer-BioNTech vaccine (*A Timeline of COVID-19 Developments in 2020*, 2021).
December 14, 2020	US death toll exceeds 300,000, and infection and death rates are still rising (Taylor, 2021).
December 18, 2020	Moderna's vaccine also receives emergency use authorization (*A Timeline of COVID-19 Developments in 2020*, 2021).
December 21, 2020	Air travel sets a new record, even greater than Thanksgiving (Thebault et al., 2021).

December 26, 2020	A new, more contagious variant of the SARS-CoV-2 first discovered in the United Kingdom spreads globally; little genetic sequencing is done in the United States, and no one is sure whether it's present or not (Thebault et al., 2021).
December 30, 2020	Amid chaos and confusion, the vaccination drive is off to a slow start; the US will fall well short of its goal to administer 20 million doses by the end of the year (*A Timeline of COVID-19 Developments in 2020*, 2021).
January 6, 2021	Rioters storm the US Capitol, protesting the certification of the election results; several announce that they are partially motivated by opposition to restrictions and lockdowns (Thebault et al., 2021).
January 8, 2021	More than 313,000 cases in America in a single day shatter all previous records – the result of holiday travel and superspreader events (Thebault et al., 2021).
January 14, 2021	Multiple companies race to produce vaccines as quickly as possible; they estimate that enough doses will be available to vaccinate 70% of Americans by July (Thebault et al., 2021).

January 15, 2021	The UK variant is now estimated to be 50% more contagious than its predecessor; it is predicted to be the dominant strain in the US in less than two months (Thebault et al., 2021).
January 19, 2021	US death toll tops 400,000 on President Trump's last day in office; Joe Biden begins his term with a requiem at the Lincoln Memorial (Thebault et al., 2021).
January 20, 2021	President Biden signs the first executive order instituting a mask mandate on Federal property; 4,440 Americans die to coronavirus, a new daily record (Thebault et al., 2021).
January 29, 2021	Johnson & Johnson's single-shot coronavirus vaccine is demonstrated effective in clinical trials, raising hopes that a third vaccine will soon be available (Thebault et al., 2021).
January 31, 2021	States prioritize those aged 65 and up over essential workers, allocating scarce vaccines to those most likely to suffer worse effects over those most likely to be infected (Thebault et al., 2021). More than four hundred and forty-nine thousand deaths have been confirmed caused by the coronavirus pandemic as of today (*COVID-19 United States Cases by County*, 2021). The disease was the third-largest killer, after heart disease and cancer, contributing to a 15% spike in total deaths year-on-

year and making 2020 the deadliest year in American history (Cancryn, 2021).

Controversies and Conspiracies

A pandemic seems tailor-made for the generation of conspiracy theories and controversies. A mysterious new ailment spreading across the world naturally inspires fear and in the charged and contentious political and media landscape of 2020. Fear and doubt were exacerbated also by poor communication and leadership from senior figures in a number of governments. It is not the purpose of this project to systematically enumerate the conspiracy theories that surrounded COVID-19 when it emerged into the public consciousness, nor to engage with and resolve them. A selection of these controversies are presented here to provide some social context for how the disease was experienced and felt even by those who never had a single symptom. Most Americans know or are related to someone who suffered COVID-19, and almost all Americans at least had someone in their social circle experience it first-hand, live or die. But every American without exception can be said to have heard about it, read about it, talked about it, and thought about it. They too experienced the pandemic, if not the virus.

On the Origin of a Virus

There is ongoing scientific debate as to the origin of the novel coronavirus SARS-CoV-2 (Wade, 2021). Novel viruses can emerge naturally, a process called zoonosis (*Zoonoses*, 2020). This involves the mutation or recombination or both of a virus from a form that infects some other mammal to one that attacks humans; this is where SARS and

MERS, previous emergent coronaviruses, came from (Peiris & Poon, 2021). It is, therefore, the default explanation for the origin of SARS-CoV-2, and been widely endorsed by the scientific community, particularly virologists (Ward, 2021).

Pursuant to World Health Assembly directive WHA 73.1 of May 2020, the World Health Organization conducted a major study of the origins of the novel coronavirus SARS-CoV-2 (*WHO-Convened Global Study of Origins of SARS-CoV-2: China Part*, 2021). Begun in July 2020 and finalized in Wuhan over a period of January 14, 2021 to February 10, 2021, the joint team of 34 international Chinese experts examined four scenarios for virus introduction – direct zoonotic transmission to humans, introduction via an intermediate host, via the food chain, and via a laboratory accident. They concluded that "…a laboratory origin of the pandemic was considered to be extremely unlikely" (*WHO-Convened Global Study of Origins of SARS-CoV-2*, 2021).

It is not the only competing explanation, however. Wuhan, the city where the virus first erupted, is home to the Wuhan Institute of Virology, which specializes in researching coronaviruses (*About WIV----Wuhan Institute of Virology*). The wet market that has been presumed to be the source of the initial infections is practically across the street from the Institute (Wade, 2021). While the Chinese government has been close-lipped about the operations of the Institute, several ongoing programs there were partly funded by grants from the US National Institutes of Health (Wade, 2021). Such grants are matters of public record, and what information is available seems to indicate that the Wuhan Institute of Virology was conducting "gain-of-function" tests with coronaviruses, in the hopes of predicting and preparing for future emergent pathogens (Wade, 2021). These experiments involve deliberately modifying a virus to increase its infectivity in

human analogues in the form of humanized lab mice (Wade, 2021). It's a matter of record that these activities are assigned a lower level of biosecurity precaution than working with known pathogens themselves; the possibility presents itself that in the lower security regime, a lab worker was accidentally infected (a virus would hardly have to mutate to jump from a human analogue to a human) and then spread it to consumers at the market. A tragic accident of tragic proportions, with dramatic implications for the way virology research should be conducted.

It is important to note that there is no conclusive evidence for either of the two competing scenarios established above. It is possible, even likely, that there will never be fully convincing evidence for either. Much of the evidence that exists is ambiguous, and lies deep in the molecular biology of viruses and is thus difficult for laymen to parse. There are two particular implications of the debate, which this paper in no way seeks to answer. The first is that the risk of future pandemics is even higher than currently anticipated – planning exists for zoonotic emergence, and for malicious acts by state or non-state actors – but there is barely even acknowledgement that virological research poses risk on this scale. The second is that even the plausibility of accidental release and accompanying coverup by Chinese authorities is a dramatic vindication for the conspiracy theories that blazed like wildfire in the first days of the pandemic and the first news cycles.

Everybody's Kung-Flu Fighting!

Much ink has been spilled and hair pulled on the subject of conspiracy theories and conspiratorial thinking in American politics, and the history of that topic is outside

the scope of this work. But it is not irrelevant, because conspiratorial thinking has been rife on the subject of the coronavirus, and it has not all been harmless talk.

In the emotionally-charged atmosphere of a global pandemic overlapping with an especially-tense election year, accusations of blame were incendiary. Establishing a direct link between political rhetoric and physical violence is difficult, but there is evidence to support it: Stop AAPI Hate revealed that of more than 2,500 incidents of violence or bigotry aimed at Asian-Americans and Pacific Islanders reported to the center, 789 or nearly 30% used rhetoric or comments associated with China and the pandemic, including ‘China virus’ and ‘kung flu’ (Fung, 2021).

Polling supports that the perceptions of many Americans have changed over the course of the pandemic. The Pew Research Center reported in July 2020 that nearly four-in-ten Americans agree that hearing racist views about Asian people has become more common since the pandemic began (Ruiz et al., 2020). More than 30% of Asian-Americans surveyed reported that they had been subject to ethnicity-based slurs or jokes since the coronavirus outbreak began, and about a quarter that they had feared physical violence in such incidents (Ruiz et al., 2020). An earlier Center for Public Integrity/Ipsos poll found that 44% of Americans surveyed believed a specific organization or group was responsible for the pandemic, mostly blaming either China or Chinese people; one third of respondents reported that they had witnessed someone blaming Asian people for the coronavirus (Jackson et al., 2020).

Like the other myths and controversies explored here, this one has had real life consequences, including substantial and in some cases permanent harm. Conclusively proving that statements by political leaders directly led to violent hate crimes like the

shooting spree of Robert Aaron Long in May 2021 is probably impossible and certainly outside the scope of this work, but the increase in violence and change in broad perceptions is certainly clear.

Hydroxychloroquine, Bleach, and Sunlight

For every affliction there seems to be a snake-oil salesman out to sell the perfect miracle cure. The more mysterious, threatening, or untreatable the ailment, the more desperate the audience is and the more appealing they become to scammers. The pandemic in 2020 was no exception to this. By the end of September 2020, the Federal Trade Commission had collected over 200,000 complaints of fraud, estimating that Americans had lost over $145 million to scammers (Morales & Hauser, 2020). Many of these concerned government stimulus checks, but some were for fraudulent coronavirus tests or miracle cures (Morales & Hauser, 2020). The same effect was seen in the brutal second wave of coronavirus half a world away in India: Thousands have been arrested for lethal fraud, including selling fire extinguishers as desperately-needed oxygen tanks (Aijaz, 2021).

Poorly chosen communications from trusted public figures can ease these tensions and doubts…or accelerate them. One of the worst examples of this is the strange saga of hydroxychloroquine. The chloroquine family of drugs is a category of toxic pharmaceutical well-established in use as an anti-malarial after decades of use (Rogers, 2020). They also have some prospective use in very severe cases of COVID-19 or other infection because it can interfere with one of the chemical pathways that leads to the cytokine storm discussed earlier in this chapter (Boulware et al., 2020). Early in 2020 the

drug was tested for use against SARS-CoV-2 as post-exposure prophylaxis, with mostly minimal results; combined with the sometimes-severe side effects, including cardiac damage, the Food and Drug Administration revoked the emergency use authorization they had issued for it on June 15, 2020, concluding that "…in light of ongoing serious cardiac adverse events and other potential serious side effects, the known and potential benefits of chloroquine and hydroxychloroquine no longer outweigh the known and potential risks for the authorized use." (COVID-19 Update: FDA Revokes Emergency Use Authorization, 2020).

When a novel disease emerges the medical community rushes to provide the best treatment available and test and develop new ones. Hydroxychloroquine would have been simply another drug tested and discarded after unsuccessful testing of no notice outside the medical community, if it had not been for a tweet by the sitting President of the United States. Indeed, it would not have even been offered the emergency use authorization at all without his personal involvement (Rogers, 2020).

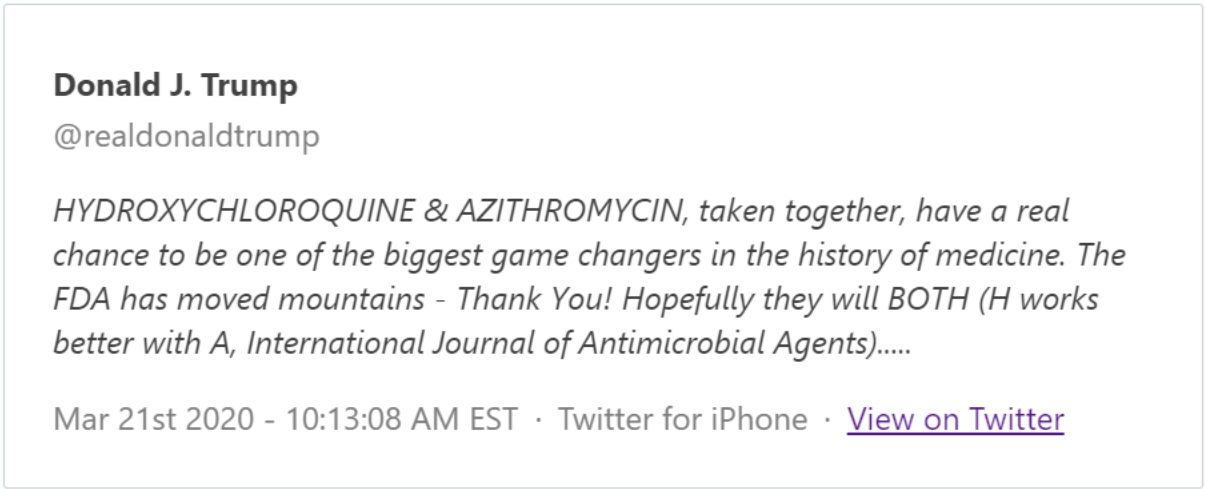


Figure 4. Donald J. Trump, The Trump Archive

Source: Trump, D. J. (2020, May 21). HYDROXYCHLOROQUINE & AZITHROMYCIN, taken together, have a real chance to be one of the biggest game changers in the history [Tweet]. The Trump Archive. www.thetrumparchive.com.

This tweet, which was liked more than three hundred thousand times was only the first of more than two dozen tweets and retweets on the subject, all viewed and retweeted tens or hundreds of thousands of times (Brown, n.d.). Tweets weren't the only communications to the public from the White House on this subject, which included press conferences and interviews (Azad et al., 2020). Theodore Roosevelt described the office of the White House as "a bully pulpit", and President Trump had massive reach to the public, not least to his nearly 80 million Twitter followers (Trackalytics, 2020). A sitting President calling hydroxychloroquine "one of the biggest game changers in the history of medicine", mentioning it in press briefings, and retweeting videos by highly-controversial doctors espousing its use naturally drove the national conversation on the topic (Rogers, 2020). Institutions tried to educate the public about advice that was at best misleading and at worst actively harmful, publishing guides to misinformation (*The COVID-19 Vaccine Communication Handbook*, n.d.). Internet platforms like Twitter took down some posts or added tags indicating it was misleading or contested (Rodrigo, 2020). But enforcement of such policies was inconsistent, arbitrary, or unclear, since other posts by similar authors escaped this treatment (Robertson, 2020).

This surge in demand put a limit on the drug's availability, forcing pharmacists to ration dosages they dispensed, with obvious harm to those already prescribed it for other conditions (Folorunsho-Francis, 2020). President Trump's other comments regarding the use of household disinfectants taken internally as treatment or prophylaxis for the

coronavirus evidently had an effect as well: On June 5, the CDC reported significantly greater number of calls to poison control for exposure to household cleaning products (Nelson et al., 2020). In May 2020, the CDC conducted an opt-in internet panel of 502 US households about household cleaning and disinfection during the COVID-19 pandemic; 39% of those surveyed reported that they were "engaging in nonrecommended high-risk practices with the intent of preventing SARS-CoV-2 transmission, such as washing food products with bleach, applying household cleaning or disinfectant products to bare skin, and intentionally inhaling or ingesting these products" (Gharpure et al., 2020). In this case, misinformation from a trusted source didn't harm business, or government, or democracy itself – it directly harmed lives, in ways and to degrees that are impossible to measure.

Bill Gates' Microchips

Vaccine hesitancy is not a new phenomenon in America, and there was good reason to be concerned about persuading citizens to vaccinate. After all, the first inoculation drive in America, against smallpox, provoked such opposition that pro-vaccination Boston minister Cotton Mather had a bomb thrown through his window (Ault, 2021). The intense antagonism to vaccines for SARS-CoV-2 in 2020 thus has historical precedent, but some unique features.

One of those features is the assumption of a deep connection to one man in particular: Bill Gates. The link of a tech pioneer and philanthropist to vaccination concerns is a strange one. In part, Gates is a victim of his own success. The Bill and Melinda Gates Foundation has done laudable work in vaccinating some of the poorest

people in the world, by some measures having saved millions of lives in only a few years (*Our Story | Bill & Melinda Gates Foundation*, n.d.). In 2015, Gates stated outright that nuclear war was less of a concern than emergent pandemics (Wakabayashi et al., 2020). In this he was probably correct and certainly prescient – apparently too prescient. Combined with his attendance at conferences where global overpopulation was a topic, his foresight has been ascribed to an early reveal of a plot aimed at curbing the global population, either through the disease itself or a lethal vaccine (Wakabayashi et al., 2020).

This theory is the most conspiratorial and convoluted of the objections to widespread deployment of vaccines, and it goes without saying that it is baseless. But its falsity does not diminish its impact, and more than a quarter of Americans surveyed by the Kaiser Family Foundation in December 2020 reported that they would probably or definitely not get vaccinated once the vaccine was deemed safe by scientists and available for free (Hamel et al., 2020). These numbers decreased from September to December across all age and racial groups, but significant disparities remained – Black Americans, who suffer disproportionately from the pandemic, had considerably higher distrust of vaccination (Hamel et al., 2020). This reflects a dark legacy of morally atrocious conduct by the medical profession towards Black Americans, from the Tuskegee experiment to the decades-long exploitation of Henrietta Lacks.

One of the lessons of 2020 was the demonstration of just how far mRNA technology has advanced and how enormously the long investment into the science has paid off. The development and deployment of not one but more than a dozen vaccines – on the scale of more than three billion doses – in little more than a year and a half is

revolutionary speed, the fastest development and deployment cycle in history (Felter, 2021). The extraordinary effort involved in this program will be examined in more detail later. This new capability is not going away, and responses to future pandemics will surely include and count on rapid development and deployment of tailored vaccines. Given that vaccination as a public health strategy is dependent on high utilization rate for maximum effectiveness, pandemic response strategies for the future must also plan for vaccine hesitancy and work to mitigate it both before future pandemics and during them, in the times of greatest urgency. No matter how effective the vaccine is in testing, it will fail in the real world if it cannot be gotten into people, and so demonstrated obstacles to vaccine uptake need to be noticed now and addressed and accounted for, because without concerted and continual effort, the vaccine hesitancy isn't going away either.

Chapter III.

Capacity and Incapacity

Much remains unanswered or unclear regarding this coronavirus pandemic. This is natural – it continues even as this project is written, and by all estimations will for some time yet to come, and accurately describing a complex global phenomenon while it progresses is both impossible and beyond the scope of this work. Nonetheless, there are some broad facts that are surprising and undeniable. Despite its size, scale, expertise and experience, the United States fared worse in terms of morbidity and mortality than many other advanced nations, and even worse than some much smaller and poorer states. Merriam-Webster defines "capacity" as "…the ability to do something: a mental, emotional, or physical ability" (*Definition of CAPACITY*, n.d.). The story of 2020 is thus one of both capacity to respond – large budgets, sophisticated health systems, world-class research institutions – and incapacity to apply those resources effectively, as demonstrated by proportionately worse outcomes than other nations. Many papers and even books will be written in the near future to comprehensively describe what went wrong here, a task far exceeding the scale of this project. Instead, the following section will investigate the capacity of some features of the American health care system in our homes and the community outside the hospital system, to examine their vulnerability to sudden surges in demand, provide a brief examination of how the American pandemic response was on the whole insufficient and exploring several of the competing, correct, and individually unsatisfactory explanations, and finally, apply some international context by comparing the response in America to that of several other nations.

Hospital Capacity – Beds to Spare?

One of the phrases that entered the public lexicon during this pandemic – alongside concepts like “hydroxychloroquine” and “social distancing” – was “flattening the curve.” By this, public health experts meant slowing the spread of disease and reducing the number of patients hospitalized at any one time with COVID-19, thus lowering and thereby “flattening” the vertical axis of a hospital usage graph (Gavin, 2020).

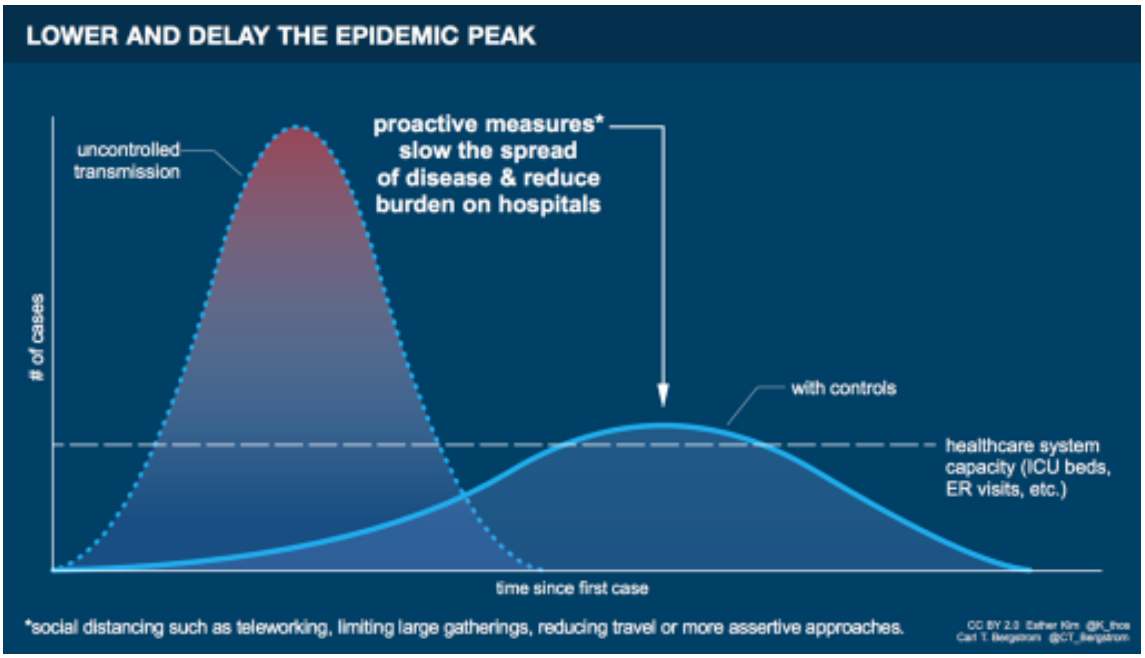


Figure 5. Flattening the Curve, Salisbury MA Health Department.

Source: Flattening the Curve | Salisbury MA. (n.d.). Retrieved November 16, 2021, from https://www.salisburyma.gov/health-department/webforms/flattening-the-curve

Even if the recommended measures like social distancing, self-quarantining, mask usage, and lockdowns didn't reduce the absolute number of individuals who contracted the disease, reducing the number of them at any given time was vital because it lessened the stress on the healthcare system. A pandemic, after all, doesn't automatically eliminate all the other health issues that people might have that require a visit or a stay at a hospital. Mothers were still expecting, appendices still grew inflamed and required surgical removal, and heart attacks, strokes, and other traumas still required care. In short, serious medical care was and remains a limited resource that cannot be much increased over the short term and in any case cannot be fully allocated to the victims of a pandemic.

When curves are not flattened as they mostly were during 2020, the consequences are as tragic as they are predictable. Two thousand and twenty-one has delivered several stinging demonstrations of this fact, like children hospitalized for relatively routine treatments who cannot get a bed because of the load imposed by (mostly unvaccinated) COVID-19 sufferers, and nearly die from the resulting lack of care (Deam, 2021). These demonstrations are savagely ironic because many of them come after effective vaccinations were widely available – the very availability of a successful countermeasure justified discontinuing the restrictions used in 2020. Though not directly relevant to the events of 2020, the serious and all too often fatal impacts of healthcare system overload show precisely what could have happened in 2020 if unvaccinated populations combined with a reduced or absent social distancing, mask usage, and other preventive measures. Research published in Health Affairs confirmed that government-imposed social distancing dramatically slowed the daily growth rate of confirmed cases of COVID-19

and that without those interventions there would have been between ten- and thirty-five-times greater spread (Courtemanche et al., 2020).

Hospitals are highly regulated in the United States, and that has some advantages in terms of research, namely, highly accurate administrative data. The American Hospital Association compiles an annual report about the nature and state of American hospitals, drawing from their own survey data of hospital administrators and from the Centers for Medicare and Medicaid Services' Healthcare Cost Report Information System. Their report states that as of 2019, there were 5,141 community hospitals in the United States with 787,995 staffed beds (*Fast Facts on U.S. Hospitals, 2021 | AHA*, 2021). Counting intensive-care unit (ICU) beds is trickier because those units often specialize – cardiac, neonatal, pediatric, burn, etc. – but medical/surgical ICU beds amounted to 55,663 across the whole country (*Fast Facts on U.S. Hospitals, 2021 | AHA*, 2021). That sounds like a lot, until one tries to divide those numbers by more than three hundred and thirty million, which is the population of the United States. In fact, according to data from the Organization for Economic Cooperation and Development (OECD), a club of mostly rich countries, the United States is well below average in its number of hospital beds per 1,000 people – approximately 2.8, compared to an average of 4.7 and far below countries like Japan (13.1), South Korea (12.3), or Germany (8.0) (Health at a Glance, 2019).

In March 2020 as the pandemic was picking up steam in the United States, a team of researchers from ProPublica and the Harvard Global Health Institute estimated what the impacts would be across America's 306 hospital referral regions under nine different scenarios: the novel coronavirus infecting 20%, 40%, or 60% of the population, over a time period of 6 months, 12 months, and 18 months (*Hospital Capacity*, 2020). They

based these numbers off of the estimates of Marc Lipsitch, head of Harvard T.H. Chan School of Public Health's Center for Communicable Disease Dynamics (Powell, 2020). Their lower bound, 20% of the population infected in total, is only about twice the number who get the seasonal flu every year, and even under the most optimistic scenario (20% infected over 18 months) American hospital beds would be 95% full (Waldman et al., 2020). The moderate scenario, with a 40% infection rate, would require the country to more than double the available hospital beds and increase ICU beds by 74% (Waldman et al., 2020).

This research, conducted in March before the pandemic had flowered into full deadliness, was not alone in its conclusions. A Fact Sheet from the Johns Hopkins Bloomberg School of Public Health Center for Health Security estimated that US hospitals in total owned about 62,000 mechanical ventilators, and could press into service around 98,000 ventilators that lacked all features, but could serve in an emergency capacity (Kobokovich, 2020). As of March, the CDC Strategic National Stockpile of ventilators numbered between 12,000 and 13,000, even as emerging data from Wuhan, China suggested that more than 3% of COVID-19 cases required mechanical ventilation, nearly 50% of those admitted to the intensive care unit (Kobokovich, 2020). A healthcare analytics company, GlobalData, estimated around the same time that 880,000 ventilators were needed worldwide to address the pandemic, 75,000 of them in the United States alone, and that "All ventilator manufacturers have full order books and hold little in stock – receiving orders not only from regular customers such as hospitals, but also directly from governments." (Parker, 2020)

Hospital beds, especially those in intensive care units, and the medical devices required to support them were under considerable strain in the US during the rapid growth of cases in March and April; leanly-stocked health institutions struggled to supply sufficient beds, tests, ventilators, protective equipment and other supplies (Alexander, 2021). Inadequate staffing – hospitals in more than two dozen states reported serious shortages of clinical staff, along with more than a fifth of nursing homes – led to burnout, exhaustion, and post-traumatic stress disorder, leading to high turnover rates, office closures, and strikes by nurses in South Carolina, Illinois, and Pennsylvania (Alexander, 2021).

Nursing Facilities – All Full Up

Nursing facilities are a highly regulated industry, subject to stringent State and Federal standards, at least if they intend to participate in Medicare and Medicaid. Nursing home services are extremely expensive, with a median cost of a private room more than $100,000 per year according to the Genworth Cost of Care Report (*Cost of Long Term Care by State | Cost of Care Report | Genworth*, 2021). The combination of heavy regulation and high cost means that beds in facilities are actually quite scarce, and are in sharply-limited supply. In Pennsylvania, there were a total of 87,707 beds across 691 facilities in 2019 (*Nursing Home Reports*, 2020). The total occupancy rate over that year across all facilities was 84.9%, determined by dividing available bed days (one bed, available for one day) by the total days of care provided to patients (*Nursing Home Reports*, 2020). Given the rapid aging of the 'baby boomer' cohort, this is only a fraction of the elderly population of the State, with nearly 40% of the State's population being over 50 ("Pennsylvania Senior Care Resources," 2021). According to 2019 Census data,

nearly 19% of Pennsylvania's total population of more than 12.8 million were over age 65 (*U.S. Census Bureau QuickFacts*, n.d.).

One of the most stringent sets of regulations governing nursing facilities concern minimum staffing levels, and the provision of safe care is limited by the lower of either the number of available beds or staff to monitor them. Recruiting nurses and aides to work in facilities is a long-running challenge, particularly for facilities located in more rural areas, exacerbated by the effects of COVID-19 (Trahan, 2021). One of the slower consequences of the pandemic of 2020 is an exodus of health care employees to other sectors of the economy. Some jobs reports in 2021 suggest a loss of over half a million such jobs since February 2020, with the vast majority coming from nursing and long-term care facilities across the country (Reed, 2021).

The movement of care workers to other fields or settings does not account for the casualties caused by COVID-19 in 2020. No one truly knows how many healthcare workers in total were killed by the pandemic, but it's certainly significant. By August 2020, a report by the Centers for Medicaid and Medicare Services stated that 767 nursing home staff had died, a factoid that led the Washington Post to opine that it was, "the most dangerous job in America" (Martin, 2020). By September 2020, National Nurses United, a trade union, were reporting the loss of more than 200 registered nurses, out of more than 1,700 healthcare workers (Akhtar, 2020). A report from the New York Department of Health suggests that the true toll is likely far higher: Between May and June 2020, after twice-weekly testing of nursing home staff was implemented, more than 9,000 staff tested positive, meaning "that out of approximately 158,000 nursing home employees in the state, approximately 37,500 nursing home staff were presumed or confirmed positive

for COVID-19 – one out of every four workers were infected." (*Factors Associated with Nursing Home Infections and Fatalities in New York State During the COVID-19 Global Health Crisis*, 2021) Under this kind of threat environment, it's hard to blame workers who want to change settings or professions, but their loss makes it harder to replace these casualties of the virus, much less increase staffing against future needs.

These facts have two implications for the scenario of 2020, and any future pandemics like it. First, it helps explain the ongoing and continual drive towards home and community-based care. People with nursing-level care needs must receive them in their homes if there aren't available nursing facility beds, even if they were willing to move. Second, it illustrates a persistent demand for trained care staff across a variety of settings, imposing an upper limit on "front-line workers" across facility and home and community settings.

The experience of 2020 – and the ongoing trends in pricing and staffing that predate it – shows clearly that there simply isn't much if any 'slack' or spare capacity in the array of nursing facilities in Pennsylvania. There is little reason to assume that the situation is on the whole better across the country. Certainly, Pennsylvania is an outlier when it comes to the elderly as a share of the population – being a prime retirement destination will do that – but that is a persistent and long-running phenomenon, and no reason to suppose that the staffing and facility levels are any better proportionate to demand compared to any other State. Further, while Pennsylvania is aging faster than other States and the country as a whole, the ongoing demographic transition is not limited to Pennsylvania or any State, which means that stresses present here are likely to emerge elsewhere even if they are not already present.

EMS – Stretched Too Far

Less immediately visible than hospital staff but directly relevant to a pandemic response is the emergency health system, the network of dispatchers, emergency medical technicians (EMTs), paramedics and support staff who provide life-saving or -sustaining care and deliver the critically injured or ill to hospitals for treatment. The Pennsylvania Department of Health Bureau of Emergency Medicine produces an annual report about clinical, operational, and workforce data. The 2020 edition, containing data from 2019, reveals some illuminating facts about the nature of statewide emergency medical care, the providers of that care, and how that workforce is changing.

Because EMTs and paramedics in Pennsylvania are entered onto a State registry when they complete the testing for the position, firm numbers are readily available at the State level. In 2019, 1,339 provider agencies responded to 2,171,285 emergency response calls (EMS Data Report, 2020). Separating out the total number of individual staff can be difficult, as individuals can maintain registration in multiple overlapping categories, and simply maintaining a registration does not necessarily imply actually responding to calls as either a professional or a volunteer. Still, the total number of registrations offers some insight into the size of the workforce, and stood at 29,243 EMTs and 6,676 paramedics as of 2019 (EMS Data Report, 2020). To give those numbers some context, for 2019 the US Census Bureau estimated the population of Pennsylvania at 12.8 million (*U.S. Census Bureau QuickFacts*, n.d.). This translates to approximately one emergency call each year for every six people, served by approximately one responder for every 350 citizens, a ratio of less than a third of a percent.

Equally important to the size and skill level of the workforce is how that force is changing over time, and the information there is less than positive. As of January 2020, the number of registered EMTs and paramedics in Pennsylvania both dropped compared to 2018, by 262 and 272, respectively (EMS Data Report, 2020). The worst decline was among the younger generation: In 2019, 41.5% of non-renewed EMT certifications were for those under 30 and both paramedics and EMTs had decreased since the previous year (EMS Data Report, 2020).

Many cases of coronavirus are mild and do not require hospitalization; this was examined in detail in the previous chapter. Serious cases that do necessitate hospital care often require transport, and it's both possible and likely that the determination of whether a given case requires oxygen supplementation or an external ventilator is beyond the skillset of the average adult. If you or someone in your household starts having trouble breathing, you're going to call 911, and they're going to dispatch an ambulance, paramedic, or other EMS resource. And of course, there remain all sorts of medical emergencies that might prompt a call, pandemic or no pandemic. These frontline health care workers are thus utterly necessary to the provision of health care, almost certain to be repeatedly exposed to the virus, and struggling with sufficient staffing levels without a global health crisis. How much does a pandemic have to affect them, or their own families and loved ones, to diminish their effectiveness?

While a full answer is still pending, some evidence from 2020 indicates that the answer is probably, "not much." Like much of the rest of the United States, Pennsylvania has some very rural counties where many public resources are stretched over large areas, including emergency responders. Policies requiring self-quarantine after confirmed

exposure required that 22 first responders in Montgomery County remove themselves from duty rosters during April, 2020 (*Officials Say Pandemic Will Accelerate EMS Crisis in Pa.'s Small Towns, Rural Areas*, 2021). Who knows how many similar incidents didn't make news headlines, and officials across the country have issued warnings about the stress that the pandemic is placing on rural emergency health care delivery, adding minutes to hours to safely delivering patients to hospitals (*Covid-19 Is Causing Ambulance Delays and Longer ER Waits — Even for Those without Coronavirus*, 2021). Combined with the preexisting concerns over workforce maintenance visible in the 2019 EMS Report, this should give us as concerned citizens and scholars pause. Ultimately, the various systems that American health care depends on are made up of people, and as we try to understand the pandemic we are emerging from (and plan for the next one) it behooves us to recognize how great the load is, and how slender the shoulders we expect to carry it.

South Korea – Starting in the Same Place

Pandemics offer an opportunity for a grim natural experiment: Given the same pathogen at the same time, studying how outcomes in mortality vary across national or regional boundaries becomes if not necessarily easy then at least straightforward. One such example that seems particularly apt in 2020 is the case of the Republic of Korea. This is a sophisticated, wealthy country with advanced health and technology sectors, deeply integrated into the world economy at least somewhat analogous to the United States…and both countries discovered their first confirmed case of SARS-CoV-2 on the

same day (Bump, 2020). What followed in the first few months of response illustrates the power and value of a swift, well-coordinated public health response.

In a meeting on January 27, 2020, representatives from twenty South Korean companies met with government officials and were informed of the dire necessity for a testing kit to detect the novel coronavirus (Terhune et al., 2020). A week later they had the kit, and by the end of February had deployed it nationwide in famed drive-through testing lanes; by the middle of March, almost 300,000 tests had been performed while the United States, by contrast, had tested barely a fifth as many people in the same seven weeks (Terhune et al., 2020). Proportionate to population, this works out to almost 5,200 tests per million inhabitants in South Korea, as compared to 74 tests per million in the United States (Normile, 2020). Forty-three testing centers performing up to 15,000 tests per day collected huge amounts of epidemiological data, which allowed for the rapid detection of clusters of cases, like the one originating from the Shincheonji megachurch in Daegu (Thompson, 2020).



Figure 6. A medical officer prepares to take samples from a visitor at a drive-through testing center at Yeungnam University Medical Center.

Source: Normile, D. (2020, March 17). Coronavirus cases have dropped sharply in South Korea. What's the secret to its success? Science. *https://www.science.org/content/article/coronavirus-cases-have-dropped-sharply-south-korea-whats-secret-its-success*

Better information about the dimensions of the threat posed by the novel coronavirus allowed for more targeted interventions and shorter lockdowns that imposed less on the population. A strict three-legged policy of "test, trace, and isolate" was dependent on public trust, which was nourished by daily briefings by Ministry of Health officials without any political involvement (Thompson, 2020). Easy allegations are made that the receptiveness of the South Korean citizenry to these measures is the result of a Confucian collectivist ideal or the engrained habits of a nation that was a military

dictatorship within living memory, but South Korea is a fully functioning democracy and must be responsive to the electorate. Paul Choi, a consultant in Seoul, remarked that, “It’s about civic memory, not Confucius,” he said. “We remember MERS. We remember other epidemics. We know this is a marathon. But we’re in a better place because the entire society has been in this game, fighting together,” (Thompson, 2020). MERS, as referenced in preceding chapters, is Middle Eastern Respiratory Syndrome, a disease caused by a coronavirus closely related to SARS and SARS-CoV-2, responsible for substantial disruption in South Korea in 2015, including a government-imposed quarantine of almost 17,000 people (Oh et al., 2018).

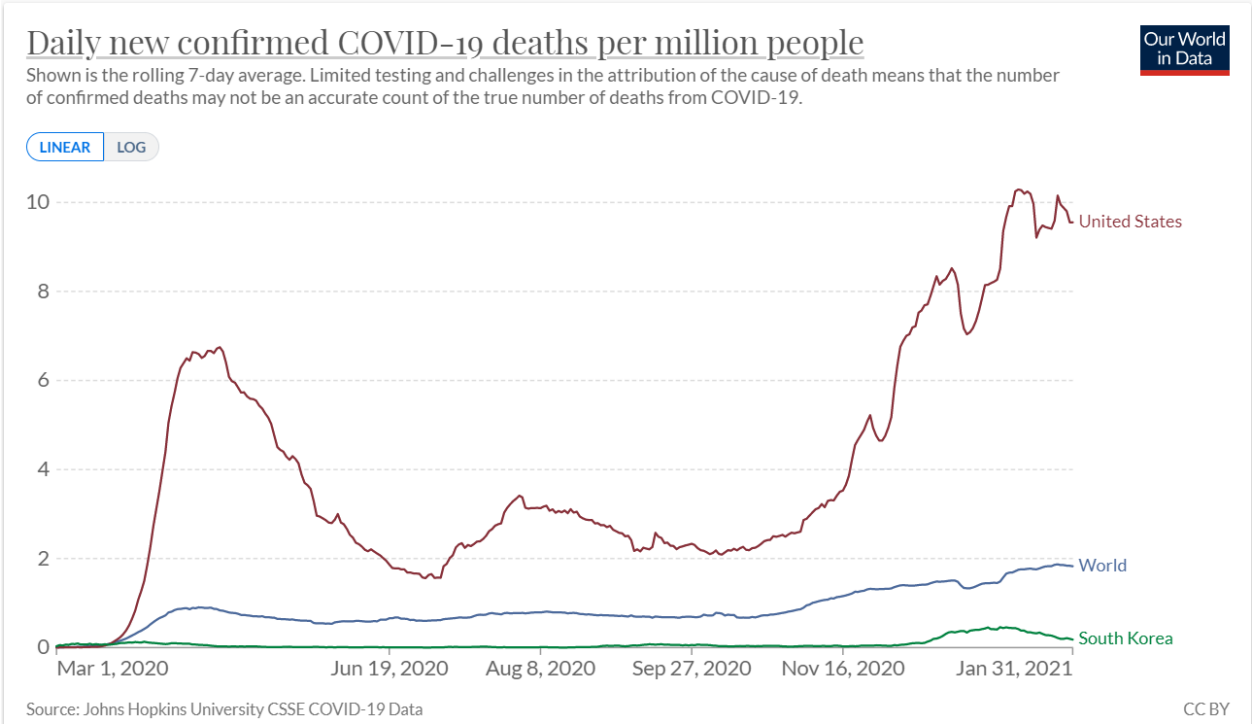


Figure 7. Daily new confirmed COVID-19 cases per million people, South Korea.

Source: Ritchie, H., Ortiz-Ospina E., Ritchie, D., Mathier, E., Beltekian, D., Hasell, J., Macdonald, B., Giattino, C., Appel, C., Rodes-Guirao, L., & Roser, M. (n.d.). Mortality Risk of COVID-19—Statistics and Research. Our World in Data. Retrieved June 23, 2021, from https://ourworldindata.org/mortality-risk-covid

The bitterly ironic lesson of the South Korean experience is that the playbook of "test, trace, and isolate" they used so effectively is not a new or unique formula. Because the virus can be spread by one person to multiple (possibly dozens or hundreds, in the worst cases) it is capable of exponential growth, describing a curve that starts slowly – almost invisibly slowly – and then hits an inflection point where it becomes seemingly omnipresent. The "secret sauce" was simply applying the existing playbook and tools energetically early enough to avert the worst of the geometric curve, and maintaining the public trust so that the effort was both top-down and bottom-up.

New Zealand – Sometimes Smaller is Better

Being a small, island nation and closely adjacent to the primary source of the contagion, New Zealand was both immediately threatened by COVID-19 and blessed by a natural defensive cordon, if they took action quickly enough. To their credit, they did. On March 26, 2020, less than a month after the WHO declaration about the pandemic and with less than one hundred confirmed cases and no deaths, Prime Minister Jacinda Ardern ordered an intense nationwide lockdown, requiring all citizens except essential workers to self-quarantine in their homes as part of a coronavirus elimination strategy (Baker et al., 2020). This included closing the borders to all foreign travelers, a task made both easier and more effective by the fact that New Zealand is an island nation (Matthews, 2020). The goal of this plan was not merely to slow or minimize the spread of

the virus, but to completely eliminate it from New Zealand, not to manage cases but to reduce them to zero. This they accomplished by late July, having gone more than 80 days without a single case of community-based transmission (Baker et al., 2020).

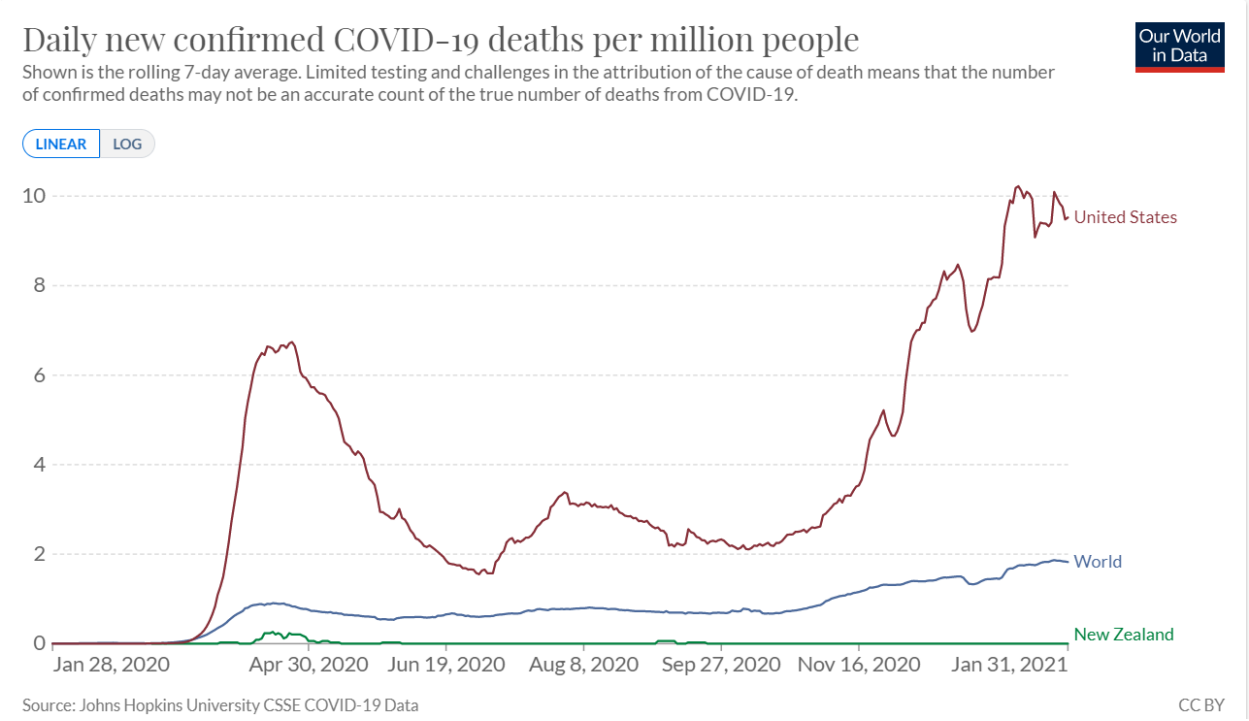


Figure 8. Daily new confirmed COVID-19 cases per million people, New Zealand

Source: Ritchie, H., Ortiz-Ospina E., Ritchie, D., Mathier, E., Beltekian, D., Hasell, J., Macdonald, B., Giattino, C., Appel, C., Rodes-Guirao, L., & Roser, M. (n.d.). Mortality Risk of COVID-19—Statistics and Research. Our World in Data. Retrieved June 23, 2021, from [*https://ourworldindata.org/mortality-risk-covid*](https://ourworldindata.org/mortality-risk-covid)

Communication with citizens was continual and concise, accomplished by a combination of formal press briefings and informal texts, delivered to the entire population (Smith, 2020). The small size of the country and the high penetration of

technology allowed for these means to reach a majority of the population, and the brevity of their contents meant that the message delivered to citizens was positive in tone and easily understandable (Hunt, 2021). The lockdown was unusually intense, one of the most restrictive in the world, and implemented when the actual effects of the virus on New Zealand were still minimal, all a recipe for widespread violation and civil disruption, but the clear messaging helped encourage adherence, which allowed for the lockdown to be extremely brief by international standards, which began gradually relaxing as early as April 28th (Baker et al., 2020).

Unfortunately, the success story in New Zealand, of which its citizens should feel justifiably proud, has limited applicability to other countries. In 2021, the population of New Zealand was estimated at just under five million ("New Zealand", 2021). There are 23 States (and two major metropolitan areas) in the United States of greater size (*US States - Ranked by Population 2021*, 2021). As detailed in Chapter Two, the United States is a continent, and contains multiple hub international airports, long land borders open to trade and travelers, and large, densely-populated cities. What works for a population of 5 million simply cannot be universally scaled to a much more diverse population of more than three hundred and thirty-million. America is also a multicultural nation, several of which have good reason to be extremely leery of national medical initiatives, as described in Chapter Two. Combined with a widespread distrust of institutions this communications strategy was inconceivable in the United States.

Still, the prompt and overwhelming response at the first signs of trouble clearly saved lives and allowed for much less total restriction of the populace, and the disease elimination strategy implemented here meant life could go back to normal for most

citizens, even as the crisis grew more and more severe elsewhere. This example poses a serious question about the wisdom of overreacting to early signs of trouble, and whether the financial and social costs of such a swift and severe response might outweigh the benefits, if a future pandemic might turn out to be much less serious than early reports suppose. New Zealand certainly benefited from structural advantages that made disease elimination a choice that other countries would find more difficult or impossible, but they set a benchmark for rapid response and clear communication that America – and the world – can, should, and must aim at.

Senegal – Money Doesn't Solve Everything

One of the first predictions in early 2020 about the new pandemic was that it would have a terrible effect in Africa, a continent filled with tightly-packed cities and fragile health systems (Nyenswah, 2020). Death tolls as high as three million were predicted by some public health analysts (Willis, 2020). This mostly turned out not to be the case – as described in Chapter Two, COVID-19 is vastly more dangerous among the elderly, and Africa as a whole has the smallest population of elderly citizens of any region (Africa Aging, 2020). Nonetheless, the continent rode out 2020 in astonishingly good shape, reporting only 46,000 confirmed deaths by the end of November (Fauzia, 2020). Testing in Africa in 2020 was on the whole substantially lacking, which makes confirmed case and death numbers even more unreliable than elsewhere, but such enormous disparities – Europe had reported a cumulative total of more than 395,000 on the same date, in a smaller population – reflect a profound difference in experience (Ritchie et al., 2020). Some nations stand out as having handled the pandemic particularly well, and high among them must be counted Senegal.

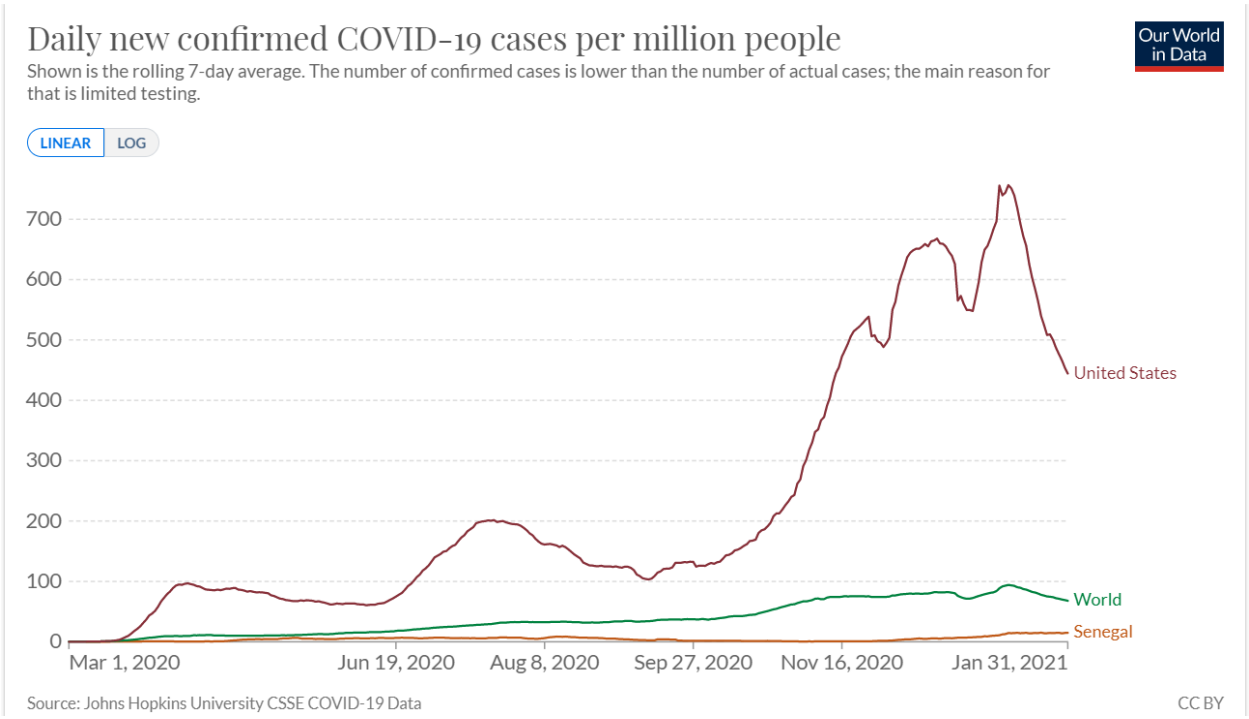


Figure 9. Daily new confirmed COVID-19 cases per million people, Senegal.

Source: Ritchie, H., Ortiz-Ospina E., Ritchie, D., Mathier, E., Beltekian, D., Hasell, J., Macdonald, B., Giattino, C., Appel, C., Rodes-Guirao, L., & Roser, M. (n.d.). Mortality Risk of COVID-19—Statistics and Research. Our World in Data. Retrieved June 23, 2021, from https://ourworldindata.org/mortality-risk-covid

Senegal, located on the western tip of the African continent sandwiched between Mauritania, Guinea-Bissau, and Mali, is a poor country – it reported a GDP of $55.26 billion in 2017, just $3,300 per capita ("Senegal," 2021). Despite this poverty – and averaging 7 doctors for every 100,000 population – Senegal has managed one of 2020's best coronavirus responses, enough to take second place in Foreign Policy's COVID-19 Global Response Index (Chakamba, 2020). Senegal did not have the MERS experience so pivotal in South Korea, nor its wealth and biotech expertise. It did not have the secure natural borders and highly-connected population of New Zealand. It had one advantage,

and used it ruthlessly: Ebola. Ebola is a hemorrhagic fever, a vicious disease endemic to the area that swept Senegal and its neighbors as recently as 2014, and the experience responding to that crisis stood Senegal in good stead. Having learned first-hand and the hard way that good coordination and communication is essential to responding to a health emergency, the Health Ministry staffed an emergency center on January 30 in response to the World Health Organization declaration of a pandemic (Shesgreen, 2020). This was more than two months before the first confirmed case, meaning that Senegal made good use of the "second-mover advantage" of seeing other countries experience the pandemic. This Health Emergency Operations Center was a product of 2014, meant to coordinate all responses at the operational level (Chakamba, 2020). According to data by KPMG, by the end of April, Senegal had established a contingency plan for the pandemic that included billions of francs for economic stimulus for the sectors most directly affected, reorganization of the national budget, and billions to support the health sector (*Senegal - KPMG Global*, 2020).

Senegal had the same issues with insufficient testing throughout 2020 that the United States did, and that imposes some level of doubt on numbers of confirmed cases seen in Figure 9. But between April 2020 and January 2021, America's daily new confirmed cases varied from between twenty times and *seventy times* Senegal's. Given that lack of testing was an issue for both countries, it is hard to argue that there was anything other than a profound difference in relative caseload. Population density can account for some of that disparity, but if the United States had maintained a rate of new confirmed infections within even an order of magnitude of Senegal's, tens if not hundreds

of thousands of its citizens would still be alive. Clearly, something different was going on here worth learning about and emulating, if possible.

Senegal had its first confirmed case of COVID-19 in the country on March 2, 2020 (Ba, 2020). The case was quickly tracked and the origin identified (an Air Senegal flight from France) and the individual quarantined, but the virus was present within the country and community transition swiftly began. By the middle of the month, schools had been ordered closed for two weeks, cruise ship dockings were banned, and public gatherings and pilgrimages were suspended (Magome, 2020). Restrictions on travel were accompanied by a quick increase in testing capacity, including mobile labs, and an impressive promise: Every person with a positive test would have a treatment bed, even the asymptomatic cases (Shesgreen, 2020). Statistics on the number of new diagnoses, cured patients, and deaths were publicized daily, an attempt to be totally transparent and keep the population informed about the seriousness and severity of the threat (Shesgreen, 2020). Senegal also proved that innovation is not in any way confined to the rich or developed world, deploying a low-cost packaged test kit that could be widely deployed, a robot for delivering medication or food automatically to patients in hospital rooms, the "Senegal Health Alert" app, and digital tools to allow constant communications between the citizens and the government (Eagles, 2020).

Senegal is in some ways a poor comparison to the United States. It is smaller, in area and population, more rural, and much poorer. Having a much younger population was a demographic advantage enjoyed by much of Africa that no American policy change could emulate. Being smaller and less highly-trafficked gave it several months to watch the pandemic unfold in other countries and prepare itself. But it managed to learn

from bitter experience with Ebola how to respond quickly and efficiently, and managed to mitigate a health crisis on the equivalent of a shoestring budget. It remains to be seen whether the experience of COVID-19 in 2020 will affect American citizens' public perceptions and attitudes in the same ways that Ebola did to the Senegalese, but the American experience of 2020 – worse in nearly every way than the rest of the world – drives home that there are lessons to be learned abroad from both the developed and developing worlds.

Was America's Response Worse?

Many of the questions addressed in this research are subtle and nuanced, requiring precise examination and diving into medical research or on-the-spot journalism to address. The question about whether the United States suffered worse that its contemporaries and worse than it might have been reasonably predicted to in December 2019 is not like those. It has a simple, unambiguous answer: yes.

On paper, in theory, even in exercises, America was massively resilient to a pandemic. The largest economy on Earth, spending the most on health care (absolute and per capita), with some of the world's most advanced infectious disease research facilities should be well-placed to handle a novel virus (Oppenheim et al., 2019). As recently as 2018 a review panel assessed the United States as among the most prepared nations on an Epidemic Preparedness Index (Oppenheim et al., 2019). And yet, the experience of 2020 was radically different. The SARS-CoV-2 virus first emerged in Wuhan, China in late 2019. By late January 2020, it was in the United States, a progression that is illustrated in the previous chapter. By August, the United States of America had the worst outbreak in

the world, according to its own top infectious-disease scientists (Higgins-Dunn, 2020). The world's wealthiest nation had 4% of the world's population but 25% of the world's cases of coronavirus (Andrew, 2020). What went wrong, so badly and so quickly? This section will briefly examine several explanations for what made the American experience in 2020 so different from other countries examined above.

The Buck Stops Somewhere Else

Two thousand and twenty was an election year, and to assume that this was not a consideration in Washington during the first days the pandemic is foolishly optimistic. National politicians, and particularly Presidents, are at the mercy of events, blamed or praised alike for things they have little to no control over. This was not lost on America's political class, and reporting as early as the first week of February was speculating as to the effect that the pandemic would have on the elections in November (Irwin, 2020). If the reporters were writing about it, certainly the politicians were thinking about it.

Leadership in a time of great uncertainty, against a mysterious disease about which little is known and of which much is feared, is a tall order in the best of times. The geometric growth of pandemic disease means that interventions early in the course of the pandemic are many times more effective than the same interventions later on. Leadership, in mustering the national energies against a disease is most important in the early days, when the least is known. As the cases of New Zealand and Senegal especially shown above prove, clear communication about the seriousness of the threat is essential

One of the other commonalities among the successful national responses examined earlier is a sustained national effort to plan for a pandemic or other health emergency. The truism that "a failure to plan is a plan to fail," plays out with dreadful

consequences. “Failure to anticipate” is not a failing that can be honestly attributed to the Federal government about a pandemic. Such a threat was anticipated, and planned for, and various scenarios wargamed, so leaders across the Federal government had an idea about what kinds of resources would be needed to mobilize a “whole-of-government” response and how such a large and complicated project could be deployed and managed.

Naturally, this kind of research and preparation is highly sensitive, and would be conducted under at least some level of secrecy. The best example of this work that has come to public light is the “Crimson Contagion” documents. Referring to a series of exercises that took place over 2019 between a host of Federal agencies and a dozen States, this was an effort to simulate an emergent flu pandemic as accurately as possible, to determine what would be the most likely issues to emerge, so that senior staff can be ready for them. Shortages of medical equipment, including ventilators, issues with school closures and identifying essential workers, and how rapidly – and what steps would need to be taken at the Federal level to ensure – America would be able to manufacture critical medical equipment were identified as issues during the exercise (Hicks, 2020). All of these would go on to be serious issues that Federal, State, and local governments would struggle with.

That the problems suffered by the United States were foreseen in an exercise proves *ipso facto* that they were foreseeable. But perhaps exercises that concluded in October 2019 did not leave the Federal government enough time to implement necessary changes. Unfortunately, that argument holds no water. A leaked document titled “Playbook for Early Response to High-Consequence Emerging Infectious Disease Threats and Biological Incidents” revealed that continuous, ongoing work was being

done to prepare the institutions and leaders of the United States at least since 2016 (Knight, 2020). Unfortunately, there's good reason to believe that the lessons of the exercise, eerily accurate in its predictions, were repeatedly ignored. Despite the leaked playbook calling for additional funding at the first declaration of emergency, the administration hesitated for past the timeline laid out in the playbook; diagnostic capacity was featured heavily in the playbook recommendations, but neglected for most of January and February, allowing for undetected spread and the growth of community transmission across the country (Diamond & Toosi, 2020).

As this document was leaked to the public rather than being formally declassified, it's difficult to say what the whole body of research and preparedness looks like – materials prepared for and by the National Security Council are unlikely to be made available to the public, after all. Clearly, there is a substantial corpus of preparedness documentation that remains classified and cannot be analyzed. However, the effectiveness of this body of work must at best remain in doubt, given America's comprehensive failure of preparedness in 2020.

In 2017, the Government Accountability Office (GAO) conducted a study as part of a report to the House Committee on Armed Services as part of the National Defense Authorization Act of 2016, which included funding to analyze the Department of Defense (DOD) planning to support civil authorities in the event of a pandemic. They concluded that the DOD predicted a major pandemic could cause as many as 1 million casualties – as many as the battlefield casualties of every war America has fought since 1776 (GAO, 2017). It indicates that the Department of Health and Human Services (HHS) was the lead agency for civil response to a pandemic or other major health crisis (GAO, 2017).

The Centers for Disease Control, part of HHS, published a national Pandemic Influenza Plan in 2005, and have updated repeatedly since. The most recent update, in 2017, spans seven domains, addresses rapid vaccine and antiviral development, disease surveillance, respiratory protection to limit transmission, and medical countermeasures (GAO, 2017). It includes precisely one mention of nursing homes – that "illness rates will likely vary by age group…and could create selective pressures on segments of the community, such as nursing homes" (GAO, 2017). Individuals receiving these sorts of services in their homes and communities get no mention whatsoever.

The National Biodefense Strategy of 2018, which defenders of the administration have cited as a primary guidance document for preparedness and response planning, likewise makes no mention of nursing facilities, home healthcare, or the workforce for either (National Biodefense Strategy, 2018).

The paradox of a predicted, prepared-for, preventable disaster going notably unprevented extends beyond the United States. The WHO's Independent Panel on Pandemic Preparedness and Response released a report calling the 2020 pandemic "a preventable disaster" (*WHO Report Calls Pandemic "Preventable Disaster," Calls Out Lack Of Global Leadership*, 2021). They concluded that "National pandemic preparedness has been vastly underfunded, despite the clear evidence that its cost is a fraction of the cost of responses and losses incurred when an epidemic occurs," and that "Too many national governments lacked solid preparedness plans, core public health capacities and organized multisectoral coordination with clear commitment from the highest national leadership" ("COVID-19: Make it the Last Pandemic," 2021). The Independent Panel continues that measures and indexes of preparedness had little

predictive value on the success or failure of nations through 2020, and that this indicates that existing metrics of preparedness themselves are insufficient, making particular note of the United States, which despite appearing at the top of Global Health Security Index received poor scores for public confidence in government and had an unexpectedly poor performance ("COVID-19: Make it the Last Pandemic," 2021). It mentions the importance of the ability to "surge the healthcare workforce," continuing that "The health systems that managed the COVID-19 response better quickly mobilized, trained and reallocated their health workforce with a combination of hiring new staff, using volunteers and medical trainees and mobilizing retirees. They took proactive steps to increase system capacity…" ("COVID-19: Make it the Last Pandemic," 2021). The report noted that "people in aged care were especially vulnerable to COVID-19" and that the death tolls in such facilities spoke of a major failure of prevention and planning. It certainly stands to reason that people with the same sort of healthcare needs receiving services in their homes are nearly as vulnerable, but this population is not addressed or mentioned in any way.

We Don't Need Tests Where We're Going

No matter the circumstances, it's difficult to impossible to fight an enemy one can't see. On a battlefield, one might use sensors – eyes, radar, sonar – to see the opponent; against a pandemic, one needs fast, reliable testing. Without them, there's no way to know how prevalent a pathogen is or how lethal it is, what communities it's in, or where to target preventative measures. Or rather, without testing there is only one way to know any of these things: counting autopsies. If anything, a thorough testing regime is even more necessary with a new pathogen from an unfamiliar family because there is less

accumulated knowledge and experience to make judgments with. In the previous chapter, I examined the comparisons made between SARS-CoV-2 and influenza precisely because this was the primary comparison that people were using in 2020. As explained there in detail, SARS-CoV-2 was a brand-new pathogen about which little was known. SARS and MERS, earlier cousins of SARS-CoV-2 had spread around the world but never caused anywhere near this level of impact. Getting a handle on the scope of the danger was an immediate, urgent need.

Unfortunately, this urgency was not felt at all levels. The United States is a large country with a devolved, federal system of government that allows for considerable local variation in the absence of clear mandates from Washington. This was exactly the trouble with testing in the first months of 2020. The genome for the novel virus was released by January, and an international effort to develop a cheap, reliable test kit was launched immediately (Wallach & Myers, 2020). Disdaining this WHO-led effort, the CDC focused on domestically produced kits instead, producing one by early February that was proven within a week to be faulty and unusable by most labs around the country (Wallack & Myers, 2020). By the end of February and the first death in America attributed to the virus, only 472 people had been tested (Madrigal & Meyer, 2020). It was bitterly ironic that demand for testing was diminished by the perceived low threat of the virus, as measured by the low count of confirmed cases…an artifact of the limited testing conducted, due to the low availability of tests (Madrigal & Meyer, 2020).

By March 12, a CNN chyron displayed that around 11,000 Americans had been tested for SARS-CoV-2, but that South Korea was conducting around 10,000 tests *per*

day (Shorrock, 2020). For want of a test, the month was lost, and for want of a month, the race was lost.

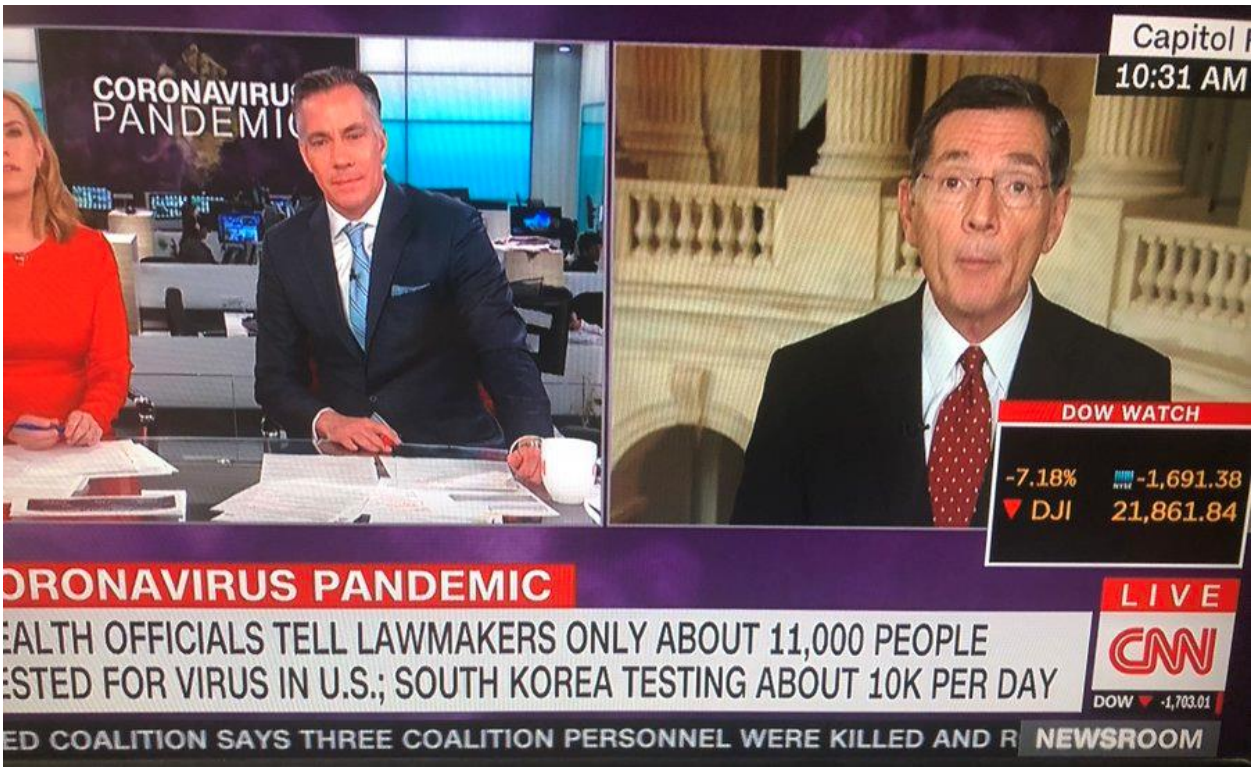


Figure 10. Tim Shorrock, 2020.

Source: Shorrock, T. (2020, March 12). The moment CNN realizes the US is a developing country that's only tested 11K people in total while the country [Tweet]. Twitter. https://twitter.com/TimothyS/status/1238112809944301569

Rapid deployment of mass testing allows for more comprehensive contact tracing – backtracking where infected individuals went during the infectious period, in the hope of identifying where they were infected and who they might have infected themselves – which in turn allows for more precise interventions to prevent the spread of the disease.

All three of the success stories examined in the previous section demonstrated this and implemented it. Senegal had difficulty getting sufficient testing regimes established, but they clearly recognized the need. Besides uncertainty about the prevalence of the pathogen, poor testing necessitates that public health measures must be more intrusive across a broader swath of the population and last longer. This was precisely the experience in both South Korea and New Zealand, which could and did return to normal life while lockdowns in the United States were only intensifying. Poorly rolled-out testing infrastructure cost America money, time, and trust, expenses only heightened by poor communications about the disease more generally.

Communications Calamity

A long-running trend in American society is a deeply ingrained distrust of institutions, especially those at the Federal level. A series of Gallup surveys shows clearly that responses indicating "a great deal" or "quite a lot" of trust in fourteen institutions have not risen above an average of 36% in the last fifteen years (Brenan, 2021). This project, which began in the wake of the Watergate scandal of 1973, shows that confidence across many institutions spiked (to the soaring heights of 33%) during 2020 as organizations leapt to respond to the pandemic, but have decreased in the year since (Brenan, 2021). A major Pew research project in 2015 found that only 19% of respondents trusted the government "always" or "most of the time" (Doherty et al., 2015). These findings have obvious implications for situations like 2020 – or future pandemics – when government experts recommend unpopular, uncomfortable measures in the name of public health.

Rooted in this anti-institutionalism is America's fondness for conspiratorial thinking. Pandemics, being naturally mysterious, frightening, and emerging from murky circumstances, lend themselves well to this, and the previous chapter examined several conspiracy theories. These vary widely in believability and content, but share two commonalities. First, they feed on doubt in institutions: Someone who lacks faith in the ethics and competence of government agencies is not going to believe them when they attempt to debunk conspiracies, and will interpret any efforts in that vein in the most sinister way possible. Doubt is thus air to the fire of conspiracies, their necessary precondition, and pushes a negative feedback loop of doubt feeding conspiracy theories which instill further doubt. Second, they undermine efforts to combat the collective danger. Someone who believes the virus is a hoax will not cooperate in efforts to fight it; one who thinks it is a "plan-demic" or active conspiracy might struggle, even violently, against the measures in place to contain it like lockdowns or mask mandates. The comprehensive responses executed in South Korea, New Zealand, and Senegal examined earlier depended on civic engagement and cooperation from citizens and would have been much less effective or impossible without this collective effort. Greater public participation requires fewer and less heavy-handed government intervention, which intrudes less on political freedoms and sensibilities.

The exact cause of this traditional anti-institutionalism is murky, and irrelevant to this project. What matters is that it exists and that it shapes popular perceptions of national events, and through these perceptions, changes how citizens at large react.

In 2020 the soil of institutional distrust, anti-intellectualism, and science denialism, once watered by poor communications, bore terrible fruit. Nowhere was this

more obviously visible than in the case of masks. In January and February, the persistent message from the Centers for Disease Control (CDC) was that masks were likely to be of little help, and should not be pursued by the general public (Wetsman, 2020). On February 29, tweets by Surgeon General Jerome Adams advised the public not to buy masks, saying that they were "NOT effective" (Breslow, 2020). This was a deception, a lie by omission at best: The truth was that medical-grade masks are highly effective, in desperately short supply, and needed to be used by healthcare workers who had the highest level of exposure to infected patients in the course of their work (Wetsman, 2020). By April, the message had changed – responding to new information about asymptomatic but infectious individuals who could spread the virus without showing any signs that might lead to self-isolation, the CDC started recommending universal mask-wearing (Breslow, 2020). States began to enforce this mandate in law, requiring masks in public, and many businesses followed suit. By late June, that same Surgeon General would publish a tweet stating that, "I show my patriotism by wearing a face covering in public!" even as his boss, the President, refused to wear a mask in public (Madhani, 2020).

When dealing with a novel pathogen, much is going to be learned as scientists study the virus and people infected with it. Guidance must and will change, as the threat becomes better understood. But the reserve of public trust that the administration and government agencies more generally enter a situation with is a precious currency, easily depleted and extremely hard to regain over the short term. As shown above and in the comparisons to other countries, this trust is a scarcer resource in the United States than elsewhere, and more precious for it. Confusing messaging and mandates applied in

uneven fashion, varying from State to State, county to county, and company to company deplete that reservoir more quickly and make some types of swift, coordinated action demonstrated by New Zealand or South Korea more difficult or impossible.

The Hole Truth

As detailed above, the United States did worse – *much* worse – in responding to the 2020 coronavirus pandemic than it ought to and was expected to. The threat was real, known, and prepared for…and yet millions of Americans died who ought to have lived. Pandemics are not a new threat, and while SARS-CoV-2 was a novel pathogen from a comparatively-rare family of viruses, it was fundamentally neither unprecedented nor unexpected. There is no reason – absolutely *none* – not to expect similar pandemics in the future, and the trends that drive the spread of zoonotic disease – population growth, habitat destruction, urbanization, greater and more rapid transportation – are still present worldwide, and increasing across much of the globe. There will be another pandemic, and another after that, and yet more coming on, like waves crashing ashore. The preceding sections have detailed that the physical and social infrastructure of America's healthcare system will strain to meet the demands of a major heath emergency like a pandemic, that other countries have demonstrated a variety of successful tactics and techniques for responding to this exact same emergency, and that the United States failed to match the performance of these other nations, despite billions invested in planning and preparedness. What are we to learn from these examples?

First, that preparedness, preparation, and planning was wholly insufficient. This is a remediable problem, and will almost certainly be overhauled in the near-future. Certainly, a vast amount of institutional energy and funding is currently and will shortly

be spent on “lessons learned” projects from every imaginable angle. Historically, great changes in policy are often stimulated by crises, and there’s no reason to suppose differently in the case of 2020. Second, and visible mostly by its absence, is the uncomfortable truth that there’s a hole in pandemic planning and a lack of institutional capacity to respond to the home health care population and their caregivers.

One of the famous Sherlock Holmes stories is the mysterious “case of the dog in the night-time.” The crucial clue for the great detective is not anything that happened, but something that didn’t: specifically, a guard dog that did not bark, revealing that it must have known the intruder. Sometimes an omission in the data is the signal in the noise. It is notable that even as planning centered on potential influenza pandemics, known for increased lethality among the elderly, that when a novel pathogen emerges that is similarly dangerous to that vulnerable population, there is no plan specifically to address this population. This, then, is the “hole truth”, the dog that didn’t bark. What goes unplanned for goes unaddressed when plans become reality.

Chapter IV.

Known Unknowns

When setting out to understand a complex topic, it is essential to include, and ideally begin with, an assessment of what exactly is known about it already, what is unknown but knowable, and what are, in the words of the late Dick Cheney, the "known unknowns". It is, after all, of little value to produce a hypothesis that cannot be tested, or to promote policies that cannot be evaluated for success or failure, let alone efficiency and effectiveness. Unfortunately, the community of homecare workers – those providing services to people in their homes, rather than in an institutional setting – is hard to pin down and describe accurately, which obviously makes targeting them for interventions difficult. As this chapter will demonstrate, interventions here are absolutely necessary, because demand for homecare workers is surging with the aging of the American population – estimates predict that by 2030 seventy-three million Americans (one-fifth of the population) will be over the age of 65 and needing more than a million more home-care workers than today (HRSA, 2018). This chapter will establish context by laying out some history of long-term care in the United States, including the evolution of homecare; explain the different service delivery models currently in use today; and examine the "known unknowns" about the homecare workforce, and the limitations on what we as researchers currently know and can know about them and conclude with what predictions are currently being made for the near future.

A Brief History of Long-Term Care

Long-Term Care (LTC) refers to services provided to individuals with chronic, ongoing illness or disability that needs treatment equal to that found in a nursing facility (*What Is Long Term Care?*, 2020). LTC is often referred to as Long-Term Services and Supports (LTSS), especially in the Medicaid context, and it appears in legislation like the Affordable Care Act (Forman, 2012). When one cannot perform "activities of daily living" without assistance, they can no longer live independently. The Centers for Medicaid and Medicare Services define this term as "Activities you usually do during a normal day such as getting in and out of bed, dressing, bathing, eating, and using the bathroom." (*Glossary*, 2006) These are, as the name implies, the basic essentials of survival, but services often extend to improving quality of life and allowing someone to engage with their community, creating a broader category of Instrumental Activities of Daily Living, or IADLs (*What Are IADLs or the Instrumental Activities of Daily Living?*, 2017). These include activities like daily household chores, shopping, and transportation, and a 2014 survey by the Centers for Disease Control found that of respondents over the age of 75, 11% needed help with ADLs and more than 18% with IADLs ("QuickStats," 2016).

To quote one former senior Pennsylvania official, "We should all hope to live long enough to need some form of care." This care might take the form of an institution like a nursing facility, but increasingly it is provided in the individual's home and/or community, hence Home and Community Based Services (HCBS) (*Home & Community Based Services | Medicaid*, n.d.). Long-Term Care has nearly a century of history in the United States, briefly summarized below. HCBS is centered on allowing someone to stay

in their home as long as possible and so includes both services provided in someone's home, i.e., with home-care workers coming into the home, or with local non-institutional services like senior centers, home modifications or adult daycare (*Home- and Community-Based Services | CMS*, n.d.).

In 1935 with the passage of the Social Security Act, Federal money is made available to the States to fund old age homes; this specifically excludes public institutions – i.e., State-funded ones – and thus creates the private nursing home industry ("Long-Term Care in the United States," 2015). In 1965 the Social Security Act is amended to include Medicare and Medicaid (public health insurance programs for elderly and low-income citizens, respectively); the former does not include LTC, and the latter only includes it in institutions rather than the home; governments swiftly become the primary payers of LTC, creating a sharp rise in nursing home utilization and a bias towards institutions and away from HCBS ("Long-Term Care in the United States," 2015). In 1974, the pendulum starts to swing the other way, as amendments to the Social Security Act allow for Federal grants to States that pay for social services programs; this accelerates in 1981, when the waiver programs are enacted, which allow for States to offer HCBS that is broader than medical care alone and paid for through Medicaid ("Long-Term Care in the United States," 2015). In 1990 the Americans with Disabilities Act is passed, and its focus on integrating people with disabilities into their communities synergizes with the HCBS movement; this broadens still further in 1999 with the Supreme Court Olmstead decision ("Long-Term Care in the United States," 2015). In 2010 the Affordable Care Act makes numerous provisions that give States more options and funding for LTSS; this is appropriately timed, because the first of the 'baby boomer'

generation start turning 65 in 2011 (“Long-Term Care in the United States,” 2015). The baby boomers are the second-largest demographic in the United States, estimated at 73 million strong, and are rapidly aging with around 10,000 turning 65 every day until 2030 (2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers, 2019).

Fee For Service, Managed Care, and Delivery Models

The provision of LTC has evolved over time in America, as demonstrated by the brief history included above. As the country has aged and the population seeking to remain in their homes has grown, the systems to provide that care have changed in tandem. More recently, the model of service delivery has changed as well, which offers new opportunities to synergize efficient service provision and cost management. It also offers some new avenues for preparedness and response to health emergencies and research into the same.

Traditionally, HCBS that were paid for via a Medicaid waiver (so called because it waived the general requirement for services to be provided in an institution) were provided through a delivery model called Fee For Service (*What Is a Medicaid Waiver?*, 2017). In short, a participating service provider (home care agency, nursing service, therapist, or so forth) provides the service to the recipient as detailed on their individual service plan, and then bills the State for reimbursement (“What Is Fee-for-Service?,” 2021). This delivery model is very straightforward, but prone to creating perverse incentives, because no one is actual paid for minimizing the amount of care the person receives. It’s in everyone’s best interests – except the State’s, and the taxpayers’ – to find any justification to provide more services to the recipient.

An alternative gradually emerged: the application of managed care (services managed or primarily provided by an entity incentivized to keep down costs) to long-term services and supports. The first of these programs is as old as this author, first rolled out in Arizona in 1987, as an alternative to the Fee For Service model (*Appendix B. A Brief History of Managed Care*, 2015). Such programs gradually propagated, and by the end of 2020, 25 States had implemented some form of managed long-term services and supports (MLTSS) ("Managed Long-Term Services and Supports," n.d.). This includes Pennsylvania, which implemented its own version, Community HealthChoices, regionally over 2018-2020 (*CHC-Main*, 2021). Because the central feature of these programs is the inclusion of a responsible entity that is incentivized to control costs rather than provide the maximum number of services, they offer a new actor to be concerned with preparedness for and response to major health crises. The original qualitative research interviews presented in the following chapter will address these entities as both actors and information channels to and from State and Federal government during 2020.

What We (Think) We Know About the Home Care Workforce

The best data available regarding specific occupations in the United States is provided by the Bureau of Labor Statistics (BLS), a division of the Department of Labor. Through a laborious process detailed below, BLS collects and publishes comprehensive estimates about the number and nature of almost every segment of the American workforce. Their numbers for the occupation classifications "Home Health Aides" and "Personal Care Aides" are startling. The Occupational Employment and Wages data estimates a workforce of 3,211,590 in the United States, earning a mean wage of $13.49 hourly and $28,060 annually (*Home Health and Personal Care Aides*, 2021). These

numbers fall well below the mean wages reported for all jobs for the same time period, $27.07 per hour and $56,310 per year (*May 2020 National Occupational Employment and Wage Estimates*, 2021).

BLS also produces an Occupational Outlook Handbook that uses estimates derived from the Occupational Employment and Wages data to make predictions about the future of the workforce, in order to guide career decisions. These estimates for the same jobs forecast growth of 33% over the next ten years, adding 1,129,900 to the workforce (*Home Health and Personal Care Aides Occupational Outlook Handbook*, 2021). This is explosive growth, because the very same page predicts that the entire US workforce as a whole will grow 8% over the same time period, meaning these specific occupations will outpace the rest of the labor market four times over.

Other indicators broadly align with more precise data of the BLS. Census data concurs with these predictions, as their County Business Patterns dataset indicates that healthcare had the highest employment of any sector of the economy in 2018, noting that "…there are also over two million nonemployer health care businesses, such as home health care providers and other ambulatory health care services, which reported over $71.6 billion in revenue in 2018" (Dowell, 2020).

The Health Resources and Support Administration (HRSA), part of the Department of Health and Human Services, released its own forecast of the demand for direct care workers over the period 2015-2030 in 2018. They defined "direct care workers" as those employed in LTSS occupations that included nursing assistants, home health aides, personal care aides, and psychiatric assistants/aides, or around 71% of the LTSS workforce in their LTSS Direct Care Worker Demand Projection (HRSA, 2018).

Like the BLS, they call for around 1.1 million more direct care workers to be needed in LTSS settings by 2030 to serve an elderly population (65 or older) of almost 73 million, or about one fifth of the American population (HRSA, 2018).

Nongovernmental analyses are in consensus, too. PHI National is an advocacy group that describes itself "As the nation's leading authority on the direct care workforce, PHI promotes quality direct care jobs as the foundation for quality care" ("About Us," 2020). Their "US Homecare Workers: Key Facts" report describes homecare workers as being overwhelmingly female (89% to 11%), disproportionately minority (more than half of the workforce), and less well-educated (more than half with no completed education past high school) (Key Facts, 2017). It also estimates more than 800,000 individuals are employed directly by consumers through publicly-funded programs and are not captured in labor statistics as employees (Key Facts, 2017).

Unfortunately, the beautifully comprehensive statistics above come with some caveats. Per the BLS' Handbook of Methods, they collect information on more than 800 occupations through annual surveys of businesses and local governments. The most recent report, from May 2020, is pulled from six semiannual surveys over three years, mostly conducted by State Workforce Agencies across the country over more than 580 areas, and so is mostly pre-pandemic data that includes only part of the impact of the 2020 pandemic, averaged into previous year data (*JTechnical Notes for May 2020 OES Estimates*, 2021). These laboriously captured statistics, though comprehensive in other ways, do not include the self-employed, estimates by the size of establishment, or information on existing vacancies (*Frequently Asked Questions*, 2021). Definitions vary and there is no universal terminology, even when comparing data from multiple Federal

agencies, which adds a layer of confusion to meta-analyses. And of course, any survey of businesses cannot possibly collect information on services provided informally, paid or unpaid. Friends and family – particularly women – still carry an enormous share of the burden of caring for ill and/or aging people in the United States (Sharma et al., 2016). These omissions, particularly that of the self-employed, mean that the BLS estimates must be taken as practical minimums, the lower bound of a still larger workforce whose true dimensions remain unknown.

What Comes Next

It is clear that there is a superabundance of research into the home care workforce and equally-ample predictions for how it is growing. The projections by different Federal agencies from disparate datasets all broadly align, which suggests strongly that there is an underlying truth: As the American population ages, homecare agencies are trying to grow to meet the coming demand. Whether there will be sufficient supply of workers to do that remains in doubt. Given the low pay cited above, it should not be surprising that advocacy groups and journalists have repeatedly noted a looming shortfall in staffing for all homecare occupations.

In 2017, an article by PHI National warned that "the shortage in direct care workers has become a crisis," stating that the aging of the American population and concomitant growing demand for care workers, the much slower growth of the primary labor pool for care workers (who are almost universally women), and departure of many existing care workers (PHI National suggests that one in two leaves the job within 12 months of starting) has led to surging demand that simply cannot be met without serious intervention ("8 Signs the Shortage in Paid Caregivers Is Getting Worse," 2017). The

article continues that these issues are worst in rural areas of the country, which already suffer from a dearth of healthcare resources, and that despite concern expressed in surveys by home care agencies, intervention to alleviate the issue is hampered by a lack of data on the direct care workforce, particularly at the local or municipality level ("8 Signs the Shortage in Paid Caregivers Is Getting Worse," 2017).

A 2019 CNBC article didn't warn that a crisis in homecare workers was imminent, it stated bluntly that the crisis was already ongoing, with skyrocketing demand for all types of home health-care workers (Woods, 2019). American spending on home healthcare was estimated at $103 billion in 2018, and projected to hit at least $173 billion by 2026, none of which includes the $470 billion worth of unpaid labor added by family caregivers estimated by an American Association of Retired Persons (AARP) report in 2016 (Woods, 2019). Executives at home health-care agencies and advocacy groups have even begun carefully advocating for easing immigration restrictions in the hopes of expanding the labor pool for homecare workers (Woods, 2019).

The effects of high demand for homecare workers have spread beyond the struggles of home care agencies owners and operators to recruit staff. As of June 2021, Maine's home care program had a waitlist 925 people long, applicants who need services, have payment for them arranged, and simply cannot get the services provided, which puts them at increased risk (Galewitz, 2021). One provider in Maine, SeniorsPlus, reported that they were constantly recruiting, "because we have over 10,000 hours a week of personal care we can't find workers to cover." (Galewitz, 2021) To put those numbers in context, MaineCare, the State's program for citizens who are elderly, disabled, or with low incomes, had 21,688 members who used any kind of LTSS in fiscal year 2014 (Snow

et al., 2014). They are hardly alone in this, as Leading Age, an advocacy group that represents aging services providers, reports that this staffing shortage was first forecast twenty years ago, has only worsened since, and has been worsened by the effects of the 2020 pandemic, with senior vice president Robyn Stone commenting that, "COVID-19 uncovered the challenges of older adults and how vulnerable they were in this pandemic and the importance of front-line care professionals who are being paid low wages." (Galewitz, 2021)

A series of focus groups of direct care workers conducted by the Kaiser Family Foundation in mid-2021 confirmed that the COVID-19 pandemic had exacerbated these existing stresses, with respondents describing increasing and even "overwhelming" mental demands of caregiving, uncertainty over work scheduling and hours, hesitancy about getting vaccinated as a job requirement and potential employer mandate, and universal agreement that wages were too low and insufficient to support a household (Musumeci et al., 2021).

The Price of Ignorance

This chapter began by stating forthrightly that shaping policy or even research in the absence of a clear understanding of the lives one intends to affect is unwise at best and actively unhelpful at worst. There's a great deal that we know about homecare workers and more specifically home health aides and personal care workers. BLS data especially allows for a startling degree of specificity by state or area. But as knowledge illuminates ignorance, it casts the things we still do not know into greater relief. The first and most obvious of these is obviously whether there will be enough staff to meet the demands for these services. Current indicators suggest not, and predict shortages unless

drastic changes are made. More relevant to the specific topic of this research project is another question: How vulnerable are homecare workers in a health emergency?

BLS data does not specify between full-time and part-time employment, does not collect information on benefits, and does not gather demographic information (*Frequently Asked Questions*, 2021). This means that research like PHI National's into the financial security and insurance status of homecare workers must be less precise. What data they do have is depressing, predictable, and depressingly predictable. In short, homecare workers are mostly part-time, about a quarter lack health insurance (and other full-time benefits), and large percentages of the workforce are under the poverty line and/or receiving some form of State or Federal assistance (Key Facts, 2017). Combined with the low salaries established by the BLS occupational report earlier, this paints a picture of a workforce perched in precarity, essential to providing life-maintaining care for others but at profound risk of financial peril if subjected to job disruptions. And of course, to satisfy rising demand by aging baby boomers these occupations must grow at least four times faster than the rest of the economy.

Without changes, over the near future, the United States will be more and more dependent on daily care being provided by a poorly-paid and poorly-treated workforce, an ever-greater weight suspended from an ever-thinner string. Before any changes can be considered, let alone evaluated, a concerted research effort needs to be mounted not into the demands upon this workforce or their expected growth, but the needs of the individuals employed here, how to support them in times of strain, and how to make these essential occupations rewarding enough to attract sufficient employees for the coming decades.

Chapter V.

Voices Heretofore Silent

It is a basic principle of logic that any analytical process is only as good as the raw data that is fed into it – garbage in, garbage out. One of the most common places for bias to complicate the data is when it enters the scientific process in the selection of data sources. If there's a selection bias at play there, then all the statistical methods and qualitative techniques known to science together might not be able to fill the hole. Worse, an implicit bias at the very outset of research is likely to blind researchers into not seeing the hole in the first place. Addressing such a gap is one of the core purposes of this research project. To do so, a series of one-on-one, semi-structured interviews were conducted with participants who have professional experience as current or former senior staff with Pennsylvania Medicaid (specifically, the Office of Long-Term Living, a branch of the Department of Human Services) and Managed Care Organizations. This chapter will introduce the participants, their roles, and the depth and applicability of their experience, identify parallel insights from their responses to the common survey instrument (available for reference as Appendix 3), and then draw together a common conclusion in support of this thesis; that there exist significant vulnerabilities in the home and community-based services populations that can be addressed, and must be in order to prepare for the next global pandemic.

The interview participants represent a set of voices that do not appear in existing literature on the subject of pandemics and preparedness. On the one hand, this is understandable, as pandemics are inherently transnational and multi-domain, cutting

across traditional boundaries of field and research. They are public health crises with medical, scientific, social, economic, and national security dimensions – practically any field can have valuable input to contribute. On the other hand, it is baffling – the elderly constitute a rapidly-growing population in the United States and are well understood to have comorbidities or other predispositions that put them at risk to health crises. This work attempts to start clearing this gap in the research by collecting the input of Kevin Hancock, Randy Nolen, and Jennifer Burnett who agreed to be interviewed on the record for this project. From March 2020 to June 2020, Kevin Hancock was Deputy Secretary for the Office of Long-Term Living, before he moved into a role at Health Management Associates, a consulting firm. Randy Nolen was Director of the Bureau of Coordinated and Integrated Services, which includes directly overseeing the operations of the three contracted Managed Care Organizations in Pennsylvania. Jennifer Burnett, a former Deputy Secretary of the Office of Long-Term Living, spent 2020 as Senior Director at PA Health & Wellness, one of the Managed Care Organizations contracted with the Commonwealth of Pennsylvania to provide Managed Long-Term Services and Supports (MLTSS).

Several themes recurred repeatedly during these interviews. First, that planning was inadequate; that the structural weaknesses of the workforce raised in the previous chapter are not only real but understated; and that the service delivery systems and their administrators were able to innovate and adapt to challenging new conditions more rapidly than anyone expected.

Planning and the Lack Thereof

The first of the themes is that there was a lack of specific planning or preparation for the pandemic that addressed the community of citizens receiving services in their homes and their caregivers. The "biggest lesson learned was how there was an overemphasis on protecting hospital capacity while ignoring the real vulnerabilities of long-term care settings," said Kevin Hancock, who was Deputy Secretary during the first half of 2020. Misjudgment of these vulnerabilities, he said, led to a disastrous rate of infection in long-term care settings before corrective measures started to be put in place by May 2020. "There was no guidance targeted to the Home and Community-Based Services (HCBS) population," he continued, and in-home care followed the same guidance as for the public at large, like the use of personal protective equipment (PPE), and out of fear, "individuals often elected not to receive services." Other interview participants reinforced this point, Burnett saying bluntly that, "the informal supports infrastructure is super important to the continuity of services in a pandemic or some sort of emergency situation," and that "people completely reliant on the formal paid network are set up for a failure." For context, informal supports are family and friends providing care rather than professionals. These are the unpaid supports identified earlier, an effort overwhelmingly provided by women. In the case of a pandemic the need to provide these supports would obviously cause a ripple of disruption to other sectors and areas of life beyond those directly infected with the virus.

Randy Nolen added that there was "no playbook to deal with a pandemic that was as contagious and difficult to get a handle on as this one is" and that there was "no capacity in the system to treat this community." He elaborated that there was no way to

isolate potentially-infected individuals in nursing facilities, no capacity and knowledge base to handle this type of pandemic, and crucially a lack of trust. Previous chapters have examined in some detail the crucial resource of public trust, how governments in other countries carefully husbanded it and employed it to great effect, and how the absence of it hampered others, including the United States. It shouldn't be surprising – but should be alarming – that the same trend emerges in this context. Nolen contributed that the one thing he wished more people knew about the HCBS communities was "how people reacted to this [the pandemic] based on their socioeconomic, racial, cultural status, how large the inequalities in our medical system are, [like] rural areas not having access to medical care. People don't trust the medical system, hospitals, doctors, researchers/CDC." He continued that authorities underestimate hesitancy to vaccines and guidance and the level of knowledge gap that exists among these communities. That underestimation by government officials is itself a knowledge gap, a lack of understanding that hampered and continues to hamper outreach and response efforts. It should go without saying that the trials of 2020, including the pushback against lockdown efforts, masks, and vaccines, have not increased this reserve of confidence in public health institutions and have very probably depleted it, maybe permanently.

Structural Weaknesses

All interview participants also agreed overwhelmingly that there were significant structural issues present in the workforce, though interestingly these responses tend to focus on different aspects of this issue. Kevin Hancock was particularly blunt: The "workforce itself is getting a lot of attention – [a] significant portion of these individuals left and haven't come back" and there simply "aren't enough people." He agreed

unreservedly that the workforce is viewed as being in crisis, and that most States are looking to increase their rates to increase the wages of homecare workers in hopes of making the work more attractive. “In the current context,” he said, “there is no slack.” This strain might go partially obscured by the substitution of informal supports: “anecdotally, strong evidence says yes, that informal supports usage went up…more working from home, more home-based, greater availability for informal support.” This is obviously unsustainable and, in any case, not available to everyone, and is a disturbing echo of Burnett’s comments on informal supports infrastructure.

Hancock added that the limits of knowledge about this workforce extend much further than just how many there are – it extends even to what they do. Electronic Visit Verification, mandated under the 21st Century Cures Act of 2016, means that there is at least transparency that people have entered the home, but there’s no other transparency about the services provided. He was candid: There is “no evaluation of quality, prevention of fraud, waste, and abuse,” and he agreed that the community of private pay recipients – individuals who are paying for home care services out of pocket – remains a total blank, with only very broad estimates across the United States. Getting a truly complete number is probably impossible, because the only reporting that could be collected would be by agencies and even that would not be fully comprehensive because some people – no one knows how many – pay caregivers directly, formally or informally, without any agency involved. The total number of caregivers and their contact info is a “giant black hole” and even the staff members of agencies that contract with Medicaid can take hours or days to reach.

Hancock had a few final comments on the pandemic as a whole. He noted that "it's probably too soon" to find lessons learned from the whole pandemic and that "anything that policymakers can do at this point is throw money at the problem" that "might paper over the problem in the short term" but is not going to be a sustainable long-term solution. The bigger issues of staffing, lack of transparency, and the limitations of facility-based care are going to require some time to figure out a long-term solution.

Randy Nolen agreed that there was substantial disruption in service provision during 2020. "People getting COVID, or their families getting COVID, [had a] direct impact on workforce," he said, continuing that "individuals who need eighty hours a week were maybe getting fifty" and "home modifications getting delayed six months or more" because contractors couldn't get the materials. This extended to nursing facilities: there were no available beds in nursing facilities because of a shortage in the system of the ability to provide adequate staffing. This was worst in skilled nursing facilities, those that provide highly staff-intensive services like ventilator or tracheostomy care; it was "next to impossible to fill those service needs because of a shortage of skilled nursing facilities." These comments align neatly – terrifyingly so, for those people or families searching desperately for life-sustaining care and could not find it – with Chapter III and its descriptions of a healthcare infrastructure that is drastically overextended and devoid of slack or spare capacity.

Nolen added that these disruptions extended beyond the actual provision of homecare. The basis of Pennsylvania's Home and Community Based Services program is the person-centered service plan itself dependent on the person-centered assessment. The program needs to know exactly what a recipient's capabilities are, what the barriers are in

their home and what their needs are. Service coordinators conduct that assessment, but there was a moratorium on the process for about four months during 2020. Service coordination is an administrative function for the MCOs, essential to their management responsibilities, either done internally or contracted out. Central to this are the assessments. When the moratorium was lifted, Nolen continued, they offered recipients the choice of participating either in person in their home or via electronic means, mostly by telephone. According to Nolen 80% to 90% of assessments now are by telephone, which offers coordinators less information, no nonverbal cues, and no information on the home environment, all of which makes appropriate service planning much more difficult. This is now the primary barrier to service delivery – "how to determine needs."

Burnett echoed concerns about staffing shortages, contributing that homecare has "a very fragile workforce to work with – very low skilled, very dedicated." She was quick to note that there was "a lot of resilience and in many cases the bond or concept is that people who are strongly connected with their workers and the workers felt a sense of duty towards participants." But her primary point was a broader, societal one: that dealing with homecare and the population it serves, there is a deep and abiding stigma.

"It is a difficult population," she said, "literally hidden years ago, not in the public's eye – there's still a stigma about this population, people don't really want to care or know about people with disabilities, including senior citizens, it's not until family members are exposed to someone" that they come to care about it. "When the media does cover this," she added, "it's often couched in how heroic the caregiver is – human interest story pulling at heart strings, rather than a story of everyday life." She continued that the workforce is not just undervalued, in that it's not paid as much as it should be, despite its

dedication, but that it's underutilized as well. "The nature of this work is that they're in the person's life every day and if there was some way to use that workforce for recognizing depression and so forth, collect information on the day-to-day life of that person, it would help the MCOs tremendously." Her two points are synergistic – a broader, more important role for caregivers with greater recognition and respect would demand a commensurate increase in pay, and likely increases in training and a proper career path.

Burnett's comments suggest strongly that addressing the causes of the structural weakness demonstrated during the 2020 pandemic is going to require more than simply increasing funding. As Hancock said, that would only serve to "paper over" the problem. A true fix for these staffing shortages – and the surging demand predicted over the near future, as described in Chapter IV – is going to demand a new concept of homecare services and their place in society. Existing stereotypes and misconceptions about the Medicaid population and their caregivers are going to need to be addressed. As America ages and more care is demanded in homes and communities, changing not only how that care is provided, but how it is thought about, seems not only essential but inevitable.

Adaptations

The Office of Long-Term Living and its contracted partners had to dramatically change and adapt over the tumultuous year of the pandemic, like businesses and governmental agencies of all stripes at every level across the United States and the globe. Adaptation and adjustment under challenging circumstances is often difficult, especially in cases that combine fear and limited information, and there were both failures and successes in the world of home and community-based services in 2020. This is especially

true in the case of Pennsylvania in 2020 because Community HealthChoices, Pennsylvania's new Managed Long-Term Services and Supports program, was still in implementation phase until June 2020, not yet fully rolled-out even as the pandemic hit. Nolen described the implementation of the program as only reaching "steady-state," that is, fully deployed and running, several months into the pandemic. Likewise, Burnett agreed that 2020 was "still in a nascent state of managed care," and that there were stresses in trying to respond to the pandemic while having to reach out to more than a thousand homecare agencies across Pennsylvania. Other interview participants agreed, adding that as a large and diverse State that includes both urban and rural communities, Pennsylvania faced geographical disparities in both resource availability and demand. Southeast Pennsylvania around Philadelphia, they said, was a particular hotspot.

The transition to a managed care model offered some opportunities that would have been otherwise missed, according to Nolen. The Pennsylvania MCOs were able to experiment with innovative new responses to the disruption caused by the pandemic that simply weren't possible otherwise – he particularly notes their efforts to distribute both PPE and later vaccines to the community. Burnett added that her efforts during 2020 included a national experiment on creating a worker bank of emergency staff to fill in for staff shortages caused by the pandemic, what she called a "heroic group of workers in Philadelphia to go out in emergency cases" that ensured service availability for individuals who caught COVID themselves. The individual service plans for every recipient of services are mandated to include backups if care workers are unavailable, but under the stresses of the pandemic, many backups failed. This measure "grew organically out of the need, and became a lesson learned" and should serve as a pilot program for

creating more formalized emergency backup systems. Her efforts also included setting up vaccine rollouts via a partnership with RiteAid across Pennsylvania and noted that the economic logic of the MCOs was closely aligned with the interests of the State: "[an] entity like an MCO has a ton of skin in the game, responsible for keeping participants as healthy as possible – the healthier they are, the less care they need, the less cost for us, great incentive for us to motivate heroic efforts to keep people safe and healthy." Hancock concurred, agreeing that the MCOs were "particularly effective" with vaccine distribution and getting PPE to homecare workers and that they shone in communications with the beneficiaries and made for much more consistent messaging to the program participants.

The successes of the managed care model, particularly the greater flexibility of an MCO to respond to new challenges in innovative ways, offer one of the few bright spots agreed on by all participants. This is especially valuable because managed care programs are in many States, but not all, and if they have proven as successful in other States, that's another powerful argument for their continual deployment. Because many MCOs, including both PA Health & Wellness and AmeriHealth Caritas in Pennsylvania, are part of larger, multi-state companies, they potentially offer a reserve of institutional knowledge and experience that can prove invaluable during a major health crisis that transcends State borders. That was the experience of Burnett, who added, "Centene (PA Health & Wellness' parent company) had weekly meetings across State lines" and was able to feed information back to the State. She continued that research projects like Mind at Home, focused on Alzheimer's care and sponsored by Johns Hopkins University and

the Center for Medicare and Medicaid Innovation could benefit her office because a Centene unit in Texas was participating.

These experiences suggest that further research is required to validate that these successes of vaccine and PPE distribution, innovative techniques to ensure service provision, and communication with participants under the managed care model are not anomalous. There's reason to suggest not, but the proposition would need to be tested more rigorously on a wider scale. If they were found to be general, however, that would imply strongly that best practices and recommendations from MCOs across the country should be collected and disseminated and that the transition to a managed care model be encouraged in States that don't already offer it. Even without the economic logic that has driven adoption so far, improved outcomes in a pandemic or other health crisis should further encourage this.

Takeaways

In conclusion, there are several things to take away from the interview results presented above. At the first, initial level of analysis, these individuals, and by extension, those like them in Pennsylvania and other States, are clearly a source of intensely relevant knowledge and experience on the subject of this research, and should appear in broader and deeper future research into the interlinked populations of individuals receiving services in their homes and the caregivers who provide those services. At the second level of analysis, the value of these contributions – and the absence of their input in existing literature – means that further research is merited on related subjects using this new source. Such a rich vein of knowledge on the subject should not go untapped any longer. To do otherwise is to handicap our collective understanding of two large and fast-

growing segments of the American populace. Finally, a tertiary level of analysis incorporating both of the above and the contents of the preceding chapters suggests very strongly that there is truly something here, a serious and unappreciated vulnerability that is not accounted for nor even acknowledged in publicly-available pandemic planning and response documents. Truly, no one would have been happier than this researcher to find that all the implications of the preceding chapters were void in practice, that 2020, the year of pandemic, had proven us more resilient than predicted. That the consensus opinion of the interview participants swings so overwhelmingly the other way on every question shows that optimistic suggestion to be wrong and should be a source of dismay for everyone. More, it should be a clamor, an alarm bell ringing loudly to encourage us as researchers, policy-makers, and concerned citizens to do more research, gather further data, and take drastic action to change the systems discussed here. That another pandemic will come is a certainty. Whether America will be ready is in doubt, unless we can prepare for these suddenly-exposed vulnerabilities and repeat these successes rapidly and at-scale.

Chapter VI.

Conclusion

This project opened by bluntly stating its intention to address a simple question: Are the two communities of people receiving services in their homes and the homecare workers providing those services more vulnerable to a major health crisis like a pandemic? It has sought to answer this by examining the pandemic of 2020, both from a social care and the individual experience perspective, investigating the structural weaknesses and lack of capacity in different parts of the American health care infrastructure, comparing the experiences of 2020 with that of other countries, digging into the limits of existing knowledge and research on the population of homecare workers in particular, and finally by presenting the results of interviews with senior staff at the Pennsylvania Medicaid agency and the Managed Care Organizations they contract with, individuals whose experience and institutional knowledge does not appear in the existing literature. All of the above has come to a simple conclusion to the simple question: Yes, they are.

It Could Have Been So Much Worse

For all that this project has discussed in great depth the SARS-CoV-2 virus and the COVID-19 disease it produces, there's one thing that has thus far gone unspoken. It seems almost profane given the still-rising death toll, but America and the world got off easy with SARS-CoV-2. If it's uncomfortable to read that, good. It should be; millions of people are dead. No one really knows how many millions; at the time of writing this,

some detailed estimates count more than ten million, and the disease is hardly eliminated ("There Have Been 7m-13m Excess Deaths Worldwide during the Pandemic," 2021). There are places where it's growing faster than ever, even, and some speculate not without merit that SARS-CoV-2 or some variant will become a recurring issue for years or generations to come, endemic in the human population for the foreseeable future (Anita & Halloran, 2021).

And yet, America and the world got off easy with COVID-19. It could have been much worse, because for all the misery and havoc it's created, SARS-CoV-2 is not the most dangerous pathogen medical science has ever encountered. It's not as infectious as measles, nor as lethal as either of its close cousins, SARS or MERS (Yong, 2020), let alone Ebola, deadlier than either and not yet airborne. In the words of Zeynep Tufekci, an infectious disease expert, the story of 2020 is an answer to "how does America handle a starter pandemic*"* (Yong, 2020).

The trends that have changed the world so profoundly between the 1918 flu pandemic and the global outbreak of SARS-CoV-2 – population growth, urbanization, and ever-greater and faster transport of people, goods, and information – are still with us and they're not going away. The world population is forecast to reach more than 9.7 billion by 2050, with nearly 70% of them living in cities, up from 56% in 2020 (*World Population Projections - Worldometer*, n.d.). International transportation is unlikely to go away either, and even if it did isolation is not a sufficient answer to pandemics. Yes, island nations like Australia and New Zealand were able to delay and mitigate the early effects of this pandemic by promptly imposing travel restrictions, but that wasn't a

panacea. Even if it were, the majority of the world's population doesn't live on easily-isolated islands.

As the qualitative research presented above demonstrates through its interviews of a previously-unexamined community of health program professionals, this paper raises more questions than answers. Exactly how many people are receiving services in their homes today in the United States is unanswered because it is unanswerable. But allowing people to remain in their homes for as long as possible, to receive services there with dignity – that's a long-running trend and certainly not going away. Likewise, no one anywhere can say for sure how many people are providing those services, let alone how to reach them all and provide them with the resources necessary for their safety. Estimates have been provided, certainly, and more estimation is likely in the coming years, but they are only estimates. What this project aimed to establish is not these quantities, but their quality, and one specific, addressable quality in particular: vulnerability. These communities, however large they are and fast they're growing, are going to succumb to the next pandemic, whatever it is and wherever it comes from, and a failure to plan for them is a plan to fail them. If the surprise of this new pandemic and the still-rising mortality count it has racked up teaches us anything, it should be this: what we don't know *can* hurt us, all of us, and almost certainly *will*.

A project that attempts to address a topic of this scope and scale needs to make conservative limitations on what it intends to cover and what must be left unsaid. Entire books can and certainly will be written about the COVID-19 experience on the Indian subcontinent, for instance, and a putative global oral history of the pandemic would be both fascinating reading and an incredible research project. Whole libraries remain to be

written about the SARS-CoV-2 pandemic from every imaginable angle – it has affected every sphere of human life across the whole planet, and this project makes no attempt at being comprehensive. If all it does is raise concerns and prompt questions in the hope of provoking further, more detailed research, that is a success.

Ultimately, any discussion on pandemics has to root down to the practical and acknowledge that they are a public health issue. Like all public health issues great and small, the accountability here is a matter of life and death. Good or successful public health programs prevent needless deaths; bad or absent ones fail to prevent those deaths. When pandemic planning, or response, or mitigation, or whichever component fails, people die. Given that the subject of this entire paper has been on the United States and that means these programs are operating at substantial scale, failure means lots of people die. The stakes really are high, high enough to demand that they be taken seriously. If this research and these interviews establish anything, it is that there are real vulnerabilities here that need addressing.

"A Pandemic of the Unvaccinated"

The coronavirus pandemic of 2020, still ongoing as of the time of this writing, is unique in several ways, one of them being that this is the first such global pandemic of the social media age. In many ways, the effects it's had on global perceptions and culture are unprecedented. The most notable, and costliest, of these is clearly the 'infodemic" of misinformation that has led many Americans into poor medical choices. This is nowhere more apparent than in regards to vaccination.

As this project is being completed in January of 2022, confirmed cases of and deaths from COVID-19 are rising in the United States, even as safe, reliable vaccines are

available to anyone in the country at no cost to them (*COVID-19 Vaccines*, 2020). The Biden Administration set an aggressive goal to have 70% of American adults receive at least one vaccine shot by July 4, and just missed its target (Kaul, 2021). This news was not greeted as a national tragedy but as a bit of political theater, provoking cheers from major politicians (Holmes, 2021). Combined with a new and more contagious variant of the virus, deaths are again rising, particularly among the younger cohorts (Fox et al., 2021). Testing confirms that as many as 99% - or more – of deaths are among those who did not receive a vaccine, and given the availability of vaccines to American citizens at no cost (and indeed in some States at negative cost, given the various incentive programs offered) almost all of these deaths are preventable (Sullivan, 2021).

Diagnosing the source of vaccine hesitancy is a complex and weighty project outside the scope of this thesis and it was briefly addressed earlier. Nonetheless, this is now a premier public health issue: people are dying, and more to the point, putting the lives of others at risk, because they will not get vaccinated, a refusal that is largely tied to misinformation about the nature of the vaccine, its effects, and conspiracy theories. This leads to a two-tiered public health response between these two communities and a pandemic of the unvaccinated. If this is a struggle today, it can only be expected to be worse in the future if left unaddressed.

Never Let a Crisis Go to Waste

An ancient proverb of political wisdom goes, “never let a crisis go to waste.” Despite the Machiavellian implications, the essential truth is sound. In democracies that are often institutionally resistant to change, the best and sometimes only opportunity to radically reshape a system is in the midst of a crisis. The New Deal would not have been

politically feasible without the preceding chaos of the Great Depression, and the Civil Rights Act would not have come about without the foment of the civil rights movement. It's perhaps too early to say with certainty that the aftermath of 2020 is another such moment waiting to be seized, but recommendations abound about what to do in the 'coronavirus Chernobyl moment' (Powell, 2021). At the time of this writing, nearly a million Americans have died of COVID-19 (*US COVID-19 Cases and Deaths by State*, 2022). That's more deaths than suffered in four years of World War II (Stone & Feibel, 2021). Certainly, that was out of a smaller population base, but that statistical truth, however accurate, is surely a cold comfort to the millions of Americans who lost someone they cared about in the last two years. If this many deaths (and still rising) is not enough to motivate radical, essential reform, what possibly could be? After all, the tragic events of 9/11 profoundly reshaped American society and government, and this slow-motion disaster took place across all of America for two years and claimed more than *one hundred times* as many lives in *the first year alone* (Stone & Feibel, 2021). As this project is completed, the 7-day average of confirmed deaths due to COVID-19 is over 2,000 – that's two-thirds of 9/11, every day, for weeks (*US COVID-19 Cases and Deaths by State*, 2022).

The question of "what, therefore, should we do" looms large here. It is a deep and vitally important question, and truthfully lies outside the scope of this work, but the author would be remiss if he didn't at least attempt to address it. Bluntly, in an interconnected world a county as large and populous as the United States is always going to be in the path of pandemics, and stopping them at the shore is a naïve dream. Prevention of pandemics is impossible, and response to them can never be swift enough

to shield the entire country – by the time we can see it, it's already among us. Addressing it incrementally on a city or State level is wasteful and counterproductive – the States might be fine laboratories for democracy, but they are much worse at virology – and Federal leadership needs to be coherent, consistent, and current.

It remains to us, as scholars, academics, and public officers of every kind and rank from civil servants to concerned citizens to learn from the things that went right (swift vaccine development and deployment, the value of Managed Care Organizations) and the ones that went poorly because the one certainty in pandemics is that we will get hit again…and we might not get off so easily next time.

Appendix 1.

Definition of Terms

Several of the terms central to this work are medical in origin but are defined below as they are used in this thesis, when that use is narrower and more specific than that of the medical field as a whole. These are working definitions and reflect how terms with multiple overlapping scientific, medical, and/or colloquial definitions will be used consistently within the context of this thesis.

Coronavirus	A virus of the Family *Coronaviridae*, a type of large single-stranded RNA viruses characterized by a lipid envelope studded by club-shaped spike proteins that infect birds and other mammals. This family are the causative agents of MERS, SARS, and COVID-19 (*Definition of CORONAVIRUS*, n.d.). In common usage, refers specifically to COVID-19. For reasons of specificity, this term will be used only in this work to refer to the entire Family of coronaviruses rather than a specific one.
COVID-19	Coronavirus Disease 19, the disease that has killed more than 500,000 people in the first six months of 2020 (*Coronavirus Pandemic (COVID-19) – the Data*, n.d.). This name was issued by the World Health Organization, the agency of the United Nations that coordinates international efforts to contain, mitigate, or combat major virus epidemics and pandemics, which includes a responsibility to name disease(s) caused by new human viruses ("The Species Severe Acute Respiratory Syndrome-Related Coronavirus," 2020). If SARS-CoV-2 is the cause, COVID-19 is the effect, and therefore the proximate but not ultimate cause of death. Accordingly, this will be the primary term used in this work.

SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2. The name, issued by the *Coronaviridae* Study Group of the International Committee on Taxonomy of Viruses recognizes this disease as a sister clade of previously-identified coronaviruses causing severe acute respiratory syndrome ("The Species Severe Acute Respiratory Syndrome-Related Coronavirus," 2020). Though this is the causative agent of COVID-19, for reasons of simplicity and accessibility, this paper will primarily use the latter term, as defined here, unless specifically referring to the virus and not its symptoms.
Eclipse Phase	The eclipse phase or eclipse period is the stage of a viral infection where a bacteriophage or other virus has infected a cell but the mature virus has not yet emerged (Venes, 2013). This is a period where a body has a disease, but is asymptomatic – no progeny virus is found in the cell (Venes, 2013). It has been chosen as the title for this thesis because it serves as a metaphor for the infection of vulnerable members of the community by a pandemic: Under the right – or more appropriately, wrong – circumstances, specific vulnerable populations can be sick and even dying without the body politic as a whole knowing.
Epidemic	As an adjective, a disease spreading rapidly across an area or population by infection; as a noun, an outbreak of disease spreading widely and quickly ("Epidemic," n.d.). For purposes of this thesis, it refers to influenza.
Pandemic	An epidemic that is both occurring across a wide geographic area and affecting large segments of the population. ("Pandemic," n.d.) For the purposes of this work, it will be used interchangeably with "epidemic", there being little practical difference in effect. When used with a date (e.g. "2009 flu pandemic") it will refer to a specific pandemic that was formally declared as such by the World Health Organization.

Influenza/Flu	An acute, contagious viral infection, primarily characterized by inflammation of the respiratory system (*Influenza | Taber's Medical Dictionary*, n.d.). Influenza viruses come in a wide variety of strains, including "avian flu" or "swine flu." While these terms will occur in referenced and quoted works, the modifiers will not be used within this text and "influenza" or "flu" is intended to mean all strains and varieties of the influenza virus complex.
Preparedness	The US Department of Homeland Security defines preparedness as "a continuous cycle of planning, organizing, training, equipping, exercising, evaluating, and taking corrective action in an effort to ensure effective coordination during incident response" (*Plan and Prepare for Disasters*, 2012). In short, making individuals, institutions, and the nation as a whole as ready as possible to mitigate serious negative events as completely as possible; in the context of this thesis, preventative actions taken or intended to minimize casualties and disruption resulting from a pandemic.

Definition of Terms as used in this Thesis

Appendix 2.

Interview Participants

Kevin Hancock	Deputy Secretary, Office of Long-Term Living, then Consultant, Health Management Associates
Randy Nolen	Director, Bureau of Integrated and Coordinated Services, Office of Long-Term Living
Jennifer Burnett	(Former Deputy Secretary, Office of Long-Term Living), Senior Director, PA Health & Wellness
Kimberly Barge	Division Director, Provider Operations Division, Office of Long-Term Living

Interview Subjects by Date Interviewed

Appendix 3.

Survey Instrument

ECLIPSE PHASE QUESTIONNAIRE

Please note that unless you request otherwise, this interview will be recorded and the recording maintained securely. Please refer to the invitation email that you received for details regarding protection of your identity or contact me directly if you have any questions.

Heading: Time, Date, Interviewer, Interviewee.

Icebreaker: For the year Jan 1, 2020 to Jan 1, 2021, please describe your job title and responsibilities briefly in your own words. Because researching an ongoing pandemic is a moving target, all questions are going to focus on the period of January 1, 2020 to January 31, 2021. Please feel free to consult datebooks, calendars, or other reference material if you have them available. Before we begin, please state for the record that you reviewed the statement of your rights that was included in the email to you, that you consent to this interview, and that you consent to being recorded.

Question One
What have you learned in your professional capacity about the home and community-based services community over the course of the 2020 pandemic?

Follow-ups:
What do you wish your agency had or knew when the pandemic started that it didn't? In other words, looking back with perfect hindsight, what didn't you have that you needed? If you did have a need, was it fulfilled promptly? What are you glad that you got? Do you think that you were well-informed about the nature of the challenge, as new information arrived? Was guidance from State and Federal agencies tailored for your communities?

If you're willing to comment, what do you wish people knew about these two communities (recipients and home health care workers) that you think they don't?

Question Two
What experiences can you talk about in ensuring provision of services throughout 2020?

Follow-ups:
In your personal experience, how much disruption was there, day to day, from the pandemic? How much of this was indirect, from altered work environments,

and how much was direct from impacts on providers and recipients? Were there recommendations or advice from State and Federal agencies specific to your population of recipients and/or caregivers? Over the course of 2020, did you feel well-informed about how the pandemic was affecting your specific population?

Question Three
How much do you or anyone at your agency know about the homecare/home healthcare workforce?

Follow-ups:
Does anyone at the State or Federal level know more? What about the number of people receiving services in their homes, including private pay clients? Do you know how to get these numbers? Does anyone? If you wanted to communicate to these communities, how would you do it? What proportion of these populations do you think you could reliably reach, and how long would it take you/your agency to do, in your professional opinion?

Question Four
Like many states, Pennsylvania is now operating primarily through managed-care organizations (MCOs). In your experience, how did this service model work during the 2020 pandemic?

Follow-ups:
Were there specific parts that worked better or more efficiently? Service coordination is a core responsibility of MCOs – to your knowledge, were there disruptions in service coordination during 2020 caused directly or indirectly by the pandemic? How did the MCOs coordinate across state lines? Were MCOs able to "ramp up" staffing for the duration? Was that a concern in communications with the State?

Question Five
Do you think that the home health care community – either or both of participants receiving services in their homes, home care aides providing those services – is more vulnerable to a pandemic or other health crisis?

Follow-ups:
Have your experiences over 2020 changed your opinion? In your experience, what is the level of informal supports usage? In other words, when professional supports fall through, what is the capacity of informal supports? For how long could informal supports suffice? As far as you're aware from your professional experience, what is the spare capacity of homecare workers? In your experience, how quickly can homecare or home healthcare agencies recruit, hire, and train staff?

Question Six
Finally, is there anything else you wish to discuss that I may have missed during our interview?

Thank you very much for your time and attention. Your voice is critical in helping to delineate the vulnerabilities in your role and I hope it will help our community be prepared for the next pandemic. If you have any questions or concerns about this research or your participation, or if at any point you wish to retract your permission to use your interview in my research, please do not hesitate to reach out to me directly through my contact information listed in the email you received.

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