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A Research Paper submitted to the Department of Engineering and Society

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

The global impact of COVID-19 warranted a united research front on the international scale for countries to share data on the pandemic as people continue to reel from its effects. As countries also sought to quickly develop vaccines and new ways to deal with the pandemic, there was a boom in research publishing about COVID-19 from 2020 to the present, 2023. In 2020 alone, over 100,000 articles on COVID-19 were published and submissions to Elsevier's journals saw an increase of 58% between February and May as compared to the same period in 2019 (Else, 2020).

With this surge in research <u>came an</u> ever more alarming surge in patients being admitted into hospitals and the subsequent overwhelming of medical systems both nation and worldwide. With little available information at the onset of the pandemic about the transmission pathways of COVID-19, the disease spread rapidly throughout entire communities and hospitals would face waves of patients at a time. The manner of the pandemic and quarantine measures such as social isolation and public advisories for personal protective equipment (PPE), however, also led to severe resource shortages. Most hospitals reported overcrowding of emergency departments (EDs) and intensive care units (ICUs), PPE shortages, facility closures, and resource scarcity during COVID-19 that impacted patient care delivery (Sandhu et al., 2022).

In the face of such scarcity, many hospitals had to implement rationing protocols to determine which patients would be administered ventilator care. These rationing protocols prioritized "saving the most lives and saving the most life-years" (Kerr & Schmidt, 2021, p. 133). These protocols would be categorized as utilitarian in its approach where "outcomes determine the means" and is society-centered, which serves as a shift from more ordinary practices of patient-centered care, or a deontological approach (Mandal, Ponnambath, & Parija,

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2016). In emergency situations and as observed during the COVID-19 pandemic, the guiding ethical framework for decision-making is shifted to utilitarianism (Vearrier & Henderson, 2021). In this framework, the greatest good for the greatest number, is the guiding principle for making decisions and this is often quantified in numbers such as number of life-years saved or factors such as quality of life improved (Dolan, 2001).

When creating resource allocation guidelines (RAGs) with such criteria, although there is an attempt to be as equitable as possible, certain patient populations become inevitably disadvantaged. This is not to say that it is wrong to use utilitarian-based RAGs during a national crisis, but it is simply to acknowledge that certain prioritizations disproportionately affected certain groups. Such groups include and are not limited to elderly populations, children, and people with disabilities or pre-existing conditions that lead to more severe symptoms.

Furthermore, the redistribution of resources and personnel did not simply occur within a vacuum of COVID-19 resource reserves that affected only COVID-19 patients. Rather this was a system-wide reshuffling that also impacted non-COVID-19 patients, particularly those with non-communicable diseases (NCDs).

NCDs are chronic diseases primarily resulting from environmental or lifestyle factors, "chiefly cardiovascular diseases, cancers, chronic respiratory diseases and diabetes," and contribute to 63% of all deaths globally, disproportionately affecting low- and middle-income countries but are a prominent health issue in all countries (Bloom et al., 2012). People with NCDs require frequent interactions with the medical system as well as increased risks associated with contracting COVID-19. These downstream effects have also been called the "spill-over" effect, which is used to describe the indirect impact of interventions that the individual themselves did not receive, but are still affected by (Mak et al., 2022).

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Despite this effect being established, I propose there is still one area and scale of study that remains insufficient considering its significance on public health and patient outcomes. In order to fully understand how COVID-19 affected the medical system, it is important to look beyond COVID-19 patients themselves, but to also consider all of the other patients that were in the hospital facing the same resource shortages and concerns of lack of appropriate care. It is through this that medical institutions and governments alike will be able to get a more holistic view of the far-reaching ripples of COVID-19.

In this paper, I cover how COVID-19 RAGs were implemented, how these RAGs and COVID-19 as a whole disproportionately affected the care of NCDs, and the scale with which this impact has been studied. An analysis using completed research, mainly surveys, that detail NCD patient outcomes as affected by COVID-19 will be conducted. Data on the obstacles that patients with NCDs faced in accessing care as well as how resource allocation decisions have affected them will also be presented. This research synthesis helped identify at what scales the current state of research is insufficient or lacking.

Largue that the downstream effects of COVID-19 RAGs on the care for non-communicable diseases only exist on a national/global scale but further work is needed on a regional/state-level to capture nuances seen only on these smaller scales and that there is significant value in doing so. Through my analysis, I found that regional/state level data and research on how patients with NCDs have been affected by COVID-19 RAGs is severely lacking. I also found that non-COVID-19 patients with specialized care needs are disadvantaged by RAGs and that system-wide policies do not consider the particular medical needs of a region, for example, regions with many pediatric care centers. In conclusion, this lack of understanding on a regional level has negatively affected the patient outcomes of those with NCDs and it is

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crucial that these effects are effectively studied and understood. In doing so, patients stand to benefit from a system that more holistically considers their needs and existing strain on a medical system can more effectively and equitably be distributed such that certain groups are not disadvantaged.

Literature Review

COVID-19 overwhelmed medical systems, Jeading to the development of new utilitarian emergency RAGs. With rapid transmission rates and no vaccines developed in 2020, hospitals struggled to meet the demands of inpatient surges in both resources and manpower. 63% and 61% of hospitals reported alerts of ED and ICU overcrowding, respectively, from March 7, 2020 to April 30, 2021 (Sandhu et al., 2022). In the face of resource limitations, it is difficult for medical institutions and health professionals to provide the utmost care to each individual patient, such that conventional standards of care would typically necessitate, and this Jed to the "progression of serious conditions among some persons who would have benefitted from earlier diagnosis and intervention" (French, 2021, p. 1613). When resources are limited such that individual patients cannot be put at the forefront, public health is prioritized and a utilitarian framework is used in order to "focus on promoting the health of communities and populations" while creating new RAGs (Vearrier & Henderson, 2021, p. 45).

These RAGs disproportionately affected non-COVID-19 patients with NCDs and specialized care needs because of resource and medical personnel redistributions. The World Health Organization (WHO) conducted a survey with its 163 member countries and 75% reported disruptions in NCD prevention and treatment services due to the pandemic (Devi et al., 2021). This survey found that the most common reasons for these disruptions were from "cancellations of planned treatments, closure of population-based screening programs, decrease

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in public transport availability, and a lack of staff because of health workers being reassigned to support COVID-19 services" (p. 2), Furthermore, in a different survey with 4,831 patient participants conducted in the USA and Europe both during and after strict lockdown orders, "50% of the patients reported a worsening of their medical condition, and 17% developed a new disease" as well as "26% of the respondents reported an impact of the pandemic on regular/long-term treatment intake" (Pécout et al., 2021, p. 1). Even from the perspective of published research, "a study of 11 medical journals in the first half of the [2020] year found that they published coronavirus papers much faster than normal, but at the expense of publishing other research more slowly" (Else, 2020, p. 553). This demonstrates the shift in the focus of the medical world to COVID-19 due to its new and immediate consequences.

As shifts in care priorities were observed, this had an adverse effect on patient outcomes.

Many NCD patients reported a worsening of their medical condition during the pandemic, as well as disruptions to their treatment plans that may have led to this. These disruptions to care are so significant because a majority of care for NCDs is long-term and constitutes repeated visits to health institutions to monitor condition, progression, and treatment of the disease (World Health Organization, 2020). When considering the RAGs as well, when physicians looked at patients with the same medical condition, they had to then begin looking at other factors to determine who would benefit the most and these factors include "age, comorbidity, gender and severity of the disease" (Mannelli, 2020, p. 364). In order to maximize patient outcomes, physicians are forced to consider these characteristics when allocating scarce resources. So, in the face of RAGs that prioritize factors such as number of life-years saved when deciding resource distributions, people with NCDs who are more likely to have poor patient outcomes

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when exposed to COVID-19 found themselves disadvantaged by a system that is supposed to be equal for all.

STS Framework

My analysis of NCDs and COVID-19 draws on Star's (1999) "Ethnography of Infrastructure" framework (Star, 1999). Star defines infrastructure as an essentially invisible and relational system that supports the function of other systems and has the following eight properties: embeddedness, transparency, reach or scope, learned as part of membership, links with conventions of practice, embodiment of standards, built in an installed base, becomes visible upon breakdown, and is fixed in modular increments instead of all at once (Star, 1999, p. 380-382). Of these properties, the ones of most relevance to this analysis are embeddedness, transparency, reach or scope, and becoming visible upon breakdown. Embeddedness refers to how infrastructure is sunk into other structures, in a manner where the different coordinated infrastructures may not be distinguishable anymore within a larger system (Star, 1999, p. 381). Infrastructure is transparent in that it invisibly supports each task without having to be reinvented each use (Star, 1999, p. 381). The reach or scope of the infrastructure refers to both spatial and temporal influence beyond a single event or moment of use (Star, 1999, p. 381). Becoming visible upon breakdown refers to the idea that the original "invisibleness" of the infrastructure is negated when the infrastructure breaks because the tasks/functions originally supported no longer work as intended (Star, 1999, p.381). Star further makes the argument that there is a need to develop more adequate tools to study such infrastructures because of how deeply infrastructure permeates the visible systems. You can't judge the quality of water in a pond without first looking at the soil that lines it.

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This framework will be used to examine how COVID-19 responses were embedded in the larger infrastructure of the medical system and how these systems have scopes reaching both throughout and beyond independent medical institutions. The transparency of the emergency response infrastructure will be examined and how it was designed to handle the pandemic while maintaining prior functions. As an infrastructure that exists across different spatial/geographical scales, this framework helps examine how the infrastructure became visible upon breakdown at these different scales. The breakdown of infrastructure in this case refers to the resource and personnel shortages experienced during the pandemic that have disproportionately affected NCD patients. The lack of research and understanding of these effects in specific regions contributed to the perpetuation of them, ultimately resulting in negative patient outcomes, which is how the infrastructure becomes visible upon breakdown. In looking at how and why the infrastructure broke down, this framework is also useful in identifying exactly what aspects of the infrastructure became visible and how these newly revealed components manifested themselves as downstream effects for NCD patients. Star's theory of infrastructure best embodies the interconnectedness of the medical system while also acknowledging that it is still composed of independent systems with their own needs and obstacles which is why this framework will be used in this analysis.

Methods

An extensive literature search, analysis, and synthesis was conducted using the following online databases: SpringerLink, PubMed, and medRxiv, as well as a more general literature search using Google_Scholar. The search was limited to only include articles published from 2020 to 2023. The following keywords were used: COVID-19, non-communicable diseases, downstream effects, United States, states, and regional. The geographically related search words

were included in the later part of the search. This analysis helped determine the state of the field and its breadth of research at different geographical scales in examining the spill-over impact of COVID-19 on care for NCDs.

To determine if there was a need for regional/state-specific research, a search was conducted to see if there were studies that demonstrated notable differences in NCD presentation across different states in the United States that proved geographical relevance. Through literature analysis, potential reasons for the lack of region-specific research were identified. To examine how different regions have different medical needs, a literature search was done on the specific needs of different NCDs that have different prevalence rates across the US.

Analysis

The negative effects of COVID-19 and the resulting RAGs on the care of patients with NCDs has been established, but mostly on a nationwide/global scale. After conducting a literature search across three different major online databases for medical research publications, no studies conducted nor data collected/organized/analyzed on a regional or statewide level were found. All the studies that were found and any referenced in this paper were conducted or pulled data from either the entire US, Europe, both, or were a meta_analysis of data from entire databases with research from different countries and continents. Some may argue that data on NCDs on the state/regional level has been lacking even before the pandemic due to inconsistencies in metrics used to quantify cases and no standardization of data. However, with the surges of data now available due to extensive COVID-19 studies, it is more important than ever to begin examining and investigating the data and relationships that may be uncovered at these regional levels.

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How the Lack of Understanding Can Hurt

The lack of understanding of the downstream effects RAGs have had on specific regions resulted in negative patient outcomes that are visible due to the breakdown of existing infrastructure. For example, research has found that there existed a "direct competition for mechanical ventilators between patients with critical COVID-19-related respiratory failure and patients with severe exacerbations of chronic lung disease without COVID-19 infection" (Chang, Cullen, Harrington, & Barry, 2021, p. 455). One of the most common chronic lung diseases in the US is chronic obstructive pulmonary disease (COPD), and in 2017, the prevalence of this disease differed across states ranging from 13.8% prevalence in West Virginia to 4% in Minnesota ("Chronic Respiratory Diseases," n.d.; "Prevalence of COPD U.S. by State 2017," n.d.). In states where chronic lung diseases are more common, it can be assumed that during COVID-19 the "competition" for mechanical ventilation, which also requires significant medical personnel to administer and maintain amidst staffing shortages nationwide, may be tighter than states where this is not the case. With patients suffering from lung-related NCDs facing more severe complications from COVID-19 and poorer prognosis, COVID-19 RAGs may push for mechanical ventilation to be prioritized to patients with better chances of full and speedy recoveries so that the resources can then be directed towards another patient. In failing to consider NCD patients such as those with chronic lung disease, the infrastructure can no longer properly support the care for those patients and the consequences arise in the form of poorer patient outcomes.

The representation of end-stage renal/kidney disease (ESRD or ESKD) in specific communities is another example of how the spillover effect of COVID-19 and RAGS has negatively affected existing infrastructure that could have potentially been avoided with more

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region-specific preparation. Patients with ESRD or ESKD who required hemodialysis in 2021 had an increased risk of COVID-19 exposure because the frequency of their treatment did not allow for long-term self-isolation (Chang et al., 2021). These patients are often incapable of transporting themselves to dialysis centers either, so both the patient and their transporter/caregiver had an increased risk of exposure and spreading it to communities.

According to the United States Renal Data System 2020 Annual Data Report, "for every white person who develops ESKD, 3 Black people develop ESKD". For communities with a higher Black population, this could have resulted in complications for both the patient that may have had to delay or cancel dialysis appointments and faced complications as a result, and the community they resided in for increased transmission risks. Medical staff shortages or reassignments to COVID-19 care centers would also have introduced disruptions to care that could have manifested itself in worsening conditions in patients. Dialysis facility closures would also cause patients to travel further to get dialysis and wait longer, further increasing community transmission risks.

Why Only National Studies?

The only existing research on the connection between COVID-19 and NCD care being on a national scale could be due to multiple factors such as national image concerns, the solidification of the US as a major global player, as well as the unprecedented amount of data being collected nationally and globally. In a survey across thirteen countries, not including the US, a median 15% said the US had done a good job of dealing with the pandemic compared to the 37% that said China, the 57% that said the European Union (EU), and the 64% that said the WHO (Greenwood, 2020). With a plummeting reputation, scientific discovery and technological

innovation in efforts to fight the pandemic may have been one of the few ways the US had left to uphold its image as a significant player on the global stage.

As the US government continued to face backlash from its own citizens on the COVID-19 responses, new emphasis on medical innovation and research can be seen; however, this revamped effort has yet to be reflected on local scales despite mass funding initiatives. Almost \$4.9 billion had been given to the National Institute of Health (NIH) to fund COVID-19 research, reflecting the urgency and desire for scientific breakthroughs to be made ("COVID-19 Funded Research Projects," n.d.). In attempts to gather as much data as possible and to cover as many populations as possible, many of the studies looking at the spillover effect of COVID-19 on NCDs have been through country-wide surveys, with particular emphasis on low- and middle-income countries (Devi et al., 2021). Every study referenced thus far in this paper, except for the one specifically investigating regional-level variations in NCD representation in the US which was also before the COVID-19 pandemic, has been conducted on a national and/or global level.

Specific Regions and Specific Needs

Region/state-specific research is necessary because nation-wide policies and larger scale mandates are not able to adequately serve the unique needs of a specific region and its community. NCD programs that are more specifically tailored to individual regions have a higher chance of being implemented and followed by the community, which is key in preventing NCDs.

COVID-19 can affect different NCDs differently, and in a nation-wide survey conducted in two waves, in Europe and then the United States, using the international online patient community Carenity with adult respondents, "59% of the respondents wished to have received additional information regarding the risks associated to their medical condition during the

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pandemic" (Pécout et al., 2021, p. 1). Such additional info would only be possible if there were an existing understanding of the prevalent medical conditions in each community. Also, despite over 60% of countries surveyed by WHO reporting partial or complete disruptions to services for NCDs, only about 17% of high-income countries allocated funding for NCD services into their national COVID-19 plan (Mak et al., 2022). In light of this, it is even more apparent that national policies are not specific nor comprehensive enough to support NCD programs. In this way, one can see how despite the focus of the COVID-19 response on a national level, these medical infrastructures exist at various levels and among other systems that are also deserving of attention.

Without a proper way to understand the reach and embeddedness of newly developed COVID-19 responses in relation to pre-existing infrastructure, the services that once seemed to adequately support NCD patients are visibly broken down and these weaknesses have long-standing effects on this patient population. Research has supported the idea that NCD mortality rates are correlated with "regional-level or system-related factors such as socioeconomic status, demographic composition, health care access, and environmental features" (Song et al., 2020, p. 2). This demonstrates the evident variability in NCDs across the country and that this variability also has implications for mortality rates. As the US and the world begins to tackle the aftereffects of the pandemic, it is critical for the sake of these patient populations that we work to understand the resulting disproportionate impacts these crisis standards caused. This will allow health systems and governments more effectively support communities in need and to mediate the poor patient outcomes that already occurred as a result.

Conclusion

The US health system experienced strain at all levels during the COVID-19 pandemic, and yet there is a focus seen only on the national level of how this system-wide strain has affected care of NCDs. This is an issue because research has demonstrated that regional differences in NCD presentation exist and these differences are also reflected in state-wide mortality rates. The glaring lack of research/region specific data has consequences found in more negative patient outcomes and inadequate support post-pandemic. By developing a better understanding of the unique obstacles faced by those with NCDs on a smaller scale, it is possible to better understand these regional nuances and present patients with better options, alternatives, and result in more positive patient outcomes. In this way, I urge state governments, COVID-19 related philanthropic organizations, medical research centers, and even regional universities with medical research programs to fund/aid in this research effort and help create an infrastructure that more equitably serves patients with NCDs or specialized care needs.

This research seeks to understand and improve upon the understanding of how, people with NCDs have been disproportionately affected by COVID-19. This has implications for more systems-wide research at multiple breadth-scales and potentially guide improvements upon existing infrastructure. There is also potential to use such research to inform future emergency responses that may include more tailored information about how certain public emergencies affect certain individuals differently and appropriate courses of actions or resources for support. To help avoid the need for RAGs during times of crisis, a deeper understanding of local needs can also help direct resource stockpiles and funds in a way that maximizes community benefit. Future research could be done to determine what frameworks or methods are best suited to begin to actually sort through the data already collected to look for relationships between other areas as

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well as propose new ways to collect relevant data. This includes the development of new data-sorting programs that can help parse through the pools of existing research for patterns in things like patient morbidity rates from COVID-19 complications in communities with high morbidity rates due to other health complications and so forth and so on. The limitations of this study include that although the significance of further research is highlighted and demonstrated, actual methods for data collection and analysis are not addressed. Given that it is already acknowledged that people with NCDs had to face more challenges during the pandemic due to a myriad of factors, now it is time to work our way to understanding how best to help this population and that although this focus is on regional scales, the implications for NCD care and infrastructure are system-wide.

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