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BENO

BIO QUARTERLY

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Removing the Veil: Health Care Disparities during the Covid-19

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"When you're in the middle of a crisis, like we are now with the coronavirus, it really does …ultimately shine a very bright light on some of the real weaknesses and foibles in our society."

-Dr. Anthony Fauci,
Director of the National Institute of Allergy and Infectious Diseases, White House Coronavirus Task Force. [Gray]

The impact of the Covid-19 pandemic is far reaching and still unfolding. The stress of a life-threatening illness confronting health care providers and the public daily, the terrible loss of life and resulting grief, and the isolation and controversy of Covid-19 restrictions have given many of us lots to consider as the virus takes its toll. While the virus impacts all of us in some way, it is increasingly apparent that this burden is not equally shared. The National Academies of Sciences, Engineering and Medicine

continued on page 3...

CONTENTS

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Submissions

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Greetings
FROM THE PRESIDENT

Greetings from Northeast Ohio!

It was great to "see" everybody virtually at our conference in April! I want to thank the many members of our board who worked so tirelessly to put together such a wonderful learning opportunity! If you missed it, look for some recaps coming to the BENO website in the future!

It's hard to believe another academic year is coming to an end. We are always looking for new members with new ideas to join our board. If you have a commitment to the field of bioethics, enjoy collaborating with others, and want to have fun in the process, please consider running for a position on the board. Elections are typically held in late June/early July. The commitment is attendance at 2 in-person meetings per year and two virtual meetings per year and participating in activities to help further BENO's mission. The commitment is minimal, but the rewards are great!

Now that this year's conference is behind us, we will again continue to look toward other ways we can further bioethics education throughout Ohio. We are trying to develop activities that are easily accessible and will fit into our member's busy schedules. As these become available, we will share them with our members. If you have ideas for things you think would be particularly helpful, please reach out. We would love to hear what YOU need!

Wishing you all a safe and relaxing summer!

Warm regards,
Cassandra

FOLLOW BENO ON:

Removing the Veil *continued from page 1...*

define health equity as "a state in which everyone has the opportunity to attain full health potential, and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstance" [Kullar]. Data collected to date, within Ohio and nationally, reveal disparities in how racial, ethnic, and cultural minorities are faring in the pandemic. Studying Covid-19 hospitalizations in 14 states, the CDC found that while 18% of those states' population identified as African American, African Americans comprised one third of hospitalized patients [Kullar]. A CDC study of 1500 COVID-19 hospitalizations in 14 states found that one third of the hospitalizations were African Americans, which exceeded their representation in population percentage of 18% in the areas studied, and their population percentage of 13% in the US [Kullar]. The Washington Post reported that counties where African Americans comprised a majority of the population had three times the rate of infection of majority white counties. [Kullar]. The CDC found that Hispanic Covid-19 cases account for 28.4% nationally despite being only 18% of the US population. In 87% of the 31 states reporting data about Hispanics, the percentage of cases identified as Hispanic exceeded their population percentage in that state [Gil].

African American, Latino, Asian American, and other smaller racial and ethnic populations including immigrants and refugees constitute 21% of Ohio's population. Ohio is also a part-time home for about 5,700 migrant workers. As of June 2020, the Ohio Department of Health Covid-19 Ohio Minority Health Strike Force reported that African Americans comprise 13% of the state population, but 26% of Covid-19 cases, 31% of hospitalizations, and 19% of deaths. Latinos comprise 4% of Ohio's population, but 8% of cases, 7% of hospitalizations and 2% of deaths. Whites, by comparison, comprise 82% of state population, but only 50% of cases, 55% of hospitalizations, and 78% of deaths [ODH Strikeforce]. It should be noted that both the national and Ohio data change frequently as the pandemic is ongoing. It should further be noted that this data may be subject to refinement; not all states collect data based on race or ethnicity, and not all respondents share that information willingly.

While health inequities are not new, the pandemic has made them glaringly apparent.

Appalachians and those living in rural areas also suffer from health inequities. Appalachian and rural populations are more likely than average to suffer from many comorbidities that complicate COVID-19 infection, including COPD, cardiovascular disease, diabetes, chronic kidney disease, and obesity. Appalachian and rural regions are often under-resourced in terms of beds, medical staffing, ventilators and other supplies needed in a pandemic scenario [Razzaghi, Roberts]. Jobs in rural areas, such as poultry and meat production, may not offer health insurance. Rural hospitals struggle to remain open in the face of high costs of care and a significant population of uninsured or underinsured patients, particularly in 14 states that have declined to expand Medicaid [Van Dorn]. All these factors create decreased access to emergency and intensive care for rural inhabitants.

Health inequities made apparent during the pandemic also afflict the LGBTQ+ community. Research done in late 2020 reveals that LGBTQ+ individuals experienced gaps in receipt of timely and effective treatment due to financial barriers, lower rates of insurance, medical mistrust, and discrimination at the point of care [Ruprecht]. Studies also documented significant increases in anxiety, worry, and exacerbation

continued on page 4...

Removing the Veil *continued from page 3...*

of mental health conditions in this population already disproportionately affected by negative mental health outcomes, ties to loss of employment and limited access to mental health services [Wallach].

While health inequities are not new, the pandemic has made them glaringly apparent. Rollston and Galea note that health in the United States is worse than it should be, leaving our population more vulnerable to Covid-19 and its complications. In 2018, the US spent 17.7% of its Gross Domestic Product (GDP) on health care, twice as much as the average nation in the Organization for Economic Cooperation and Development (OECD). Even though the US spends a far greater proportion of its GDP on health care, 28% of Americans struggle with chronic diseases, while only 17.5% of residents of all OECD member nations do. Before the Covid-19 pandemic, American life expectancy was 2.1 years shorter than the overall OECD average; US infant mortality was 71% greater than the OECD average. The mismatch of spending and outcomes is explained by lack of investment in forces that shape health, often called the Social Determinants of Health (SDOH). SDOH include supportive housing, education, early childhood care, and public health practice. The US spends more on acute medical care and less on SDOH, contributing to conditions that allowed for easier spread across the US population [Rollston]. Examples of the limitations of directing spending to curative, rather than SDOH, are not hard to find. The urban setting of Boston has the highest density of physicians in the country and world class hospital care just a stone's throw from concentrations of poverty and poor health. Some Boston neighborhoods have a chronic disease burden three times higher than other neighborhoods. Social and economic circumstances shape health, and research shows that investment in social services is needed to improve health outcomes [Rollston].

One of the slogans Ohio has used to help people cope with the stress of the pandemic is "We are all in this together". As a result of the pandemic, our awareness of the ways in which we are not yet all together has increased.

D. M. Gray and colleagues offer a useful classification of SDOH. Upstream social determinants include racism, discrimination, social policies, and poverty, and are seen as root causes at the population level. Midstream SDOH are the result of upstream determinants, and include educational attainment, employment status, safety of housing and quality of living conditions, stability of income, food security and quality of diet, exposure to toxins, medical mistrust, access to high quality health care, access to Covid testing and care, ability to physical distance during the pandemic, and access to masks during the pandemic. Compromises in these determinants impact development of comorbidities, ability to social distance and ease of Covid transmission, and access to health insurance coverage and care. Downstream health outcomes, the health endpoints impacted by social determinants, include heart disease, asthma and lung disease, obesity, Type 2 diabetes mellitus, cancer, and Covid-19 cases, hospitalizations, and death. All three categories must be addressed to accomplish effective health outcome improvements [Gray].

Persons of color, immigrants, refugees, and other minority groups are disproportionately represented in lower income and less educated groups, leading to poorer housing, less healthy food choices, poorer access to coverage and care, and higher risk for Covid transmission and complications [Rollston]. Multigenerational family dwellings, employment demanding in-person presence rather than the option to work from home, use of public transportation, fear of loss of income, and lack of paid sick time all increase risk of exposure and transmission and make social distancing difficult. Families often have to choose between exposure at work or staying home without income. Additionally, a disproportionate percentage of African Americans are also at increased risk in the overcrowded penal system [Kullar]. In 2018, Hispanics had the lowest rates of medical coverage (19.8 uninsured compared to 5.4% of non-hispanic whites); other formidable barriers include language barriers and mistrust surrounding immigration status [Gil].

Resolving health care inequities requires a multidisciplinary effort with dedication to overcoming longstanding diverse barriers. Public health has a fundamental role to see that our future is more just and equitable [Van Dorn]. Indeed, all health care professionals have a role to play in this goal.

continued on page 5...

Gray, Van Dorn, Kullar, Gil, Razzaghi and the Ohio Department of Health have issued recommendations to begin the journey. I will list their suggestions, combining those that overlap. Some of these are already beginning in Ohio:

Engage community leaders to disseminate information about transmission and prevention, promote EBP, avoid cultural stigmatization.

Leverage technology to optimize communication for patients and health care providers.

Make information available through social media and all messaging platforms, in multiple languages, in a culturally acceptable format.

Provide equitable, accessible testing.

Establish consistent collection and reporting of accurate, detailed national data on race, ethnicity and SDOH.

Declare racism a public health crisis. Twenty-five counties, cities, and boards of health in Ohio have done this. State of Ohio has a bill pending; five other states have declared such. This enables deployment of resources to address inequities. Franklin County has created the Center for Public Innovation; The State of Ohio has assembled experts to form the Covid-19 Ohio Minority Health Strike Force) [ODH strikeforce].

Workforce diversity in health care and science must increase. Encourage African American and other minority participation in research as researchers and subjects.

Pursue federal, state, and local support for health disparities research; research team must look beyond data for interventions to address inequities. Data must include testing availability and accessibility. In rural areas, data regarding prevalence of comorbidities may help predict resource needs and develop resource allocation plans.

Improved funding for NIH Institute on Minority Health and Health Disparities (one of the lowest funded initiatives at NIH up to this point).

Mandating implicit bias training for grant review committee members.

Strengthen public health infrastructure and crisis response; dismantle discriminatory policies.

Give voice to those most affected by inequity to propose and implement solutions. Partnerships public, private civic organizations, local grassroots initiatives: build social capital, foster resilience, cultivate political will to challenge discrimination.

National Medical societies must be invested in above. Encourage collaboration of government, pharmaceutical industries, academia, medical societies for thoughtful understanding of disparities and actions to counter them related to COVID-19.

Support Medicaid expansion in all states. Support/create programs to decrease food, financial, childcare and job insecurities and increase primary health care access.

We are now faced with the challenges listed here to create a more just and equitable health care system. As health care professionals, we have before us a "call to action", in which each of us reflects upon our own work, as well as our collaborative initiatives, to incorporate some of these suggestions. The BENO Bioquarterly would be pleased to share any Ohio initiatives with our readership as they come to fruition.

April is National Minority Health Month per the Ohio Department of Health, a designation begun in 1915 with Booker T. Washington, and recognized by the United States Congress in 2002. As I write this article, it is April, and I am aware of how many of the suggestions made by these authors are beginning to be put in place. I hope that we will celebrate further progress in the 2022 National Minority Health Month.

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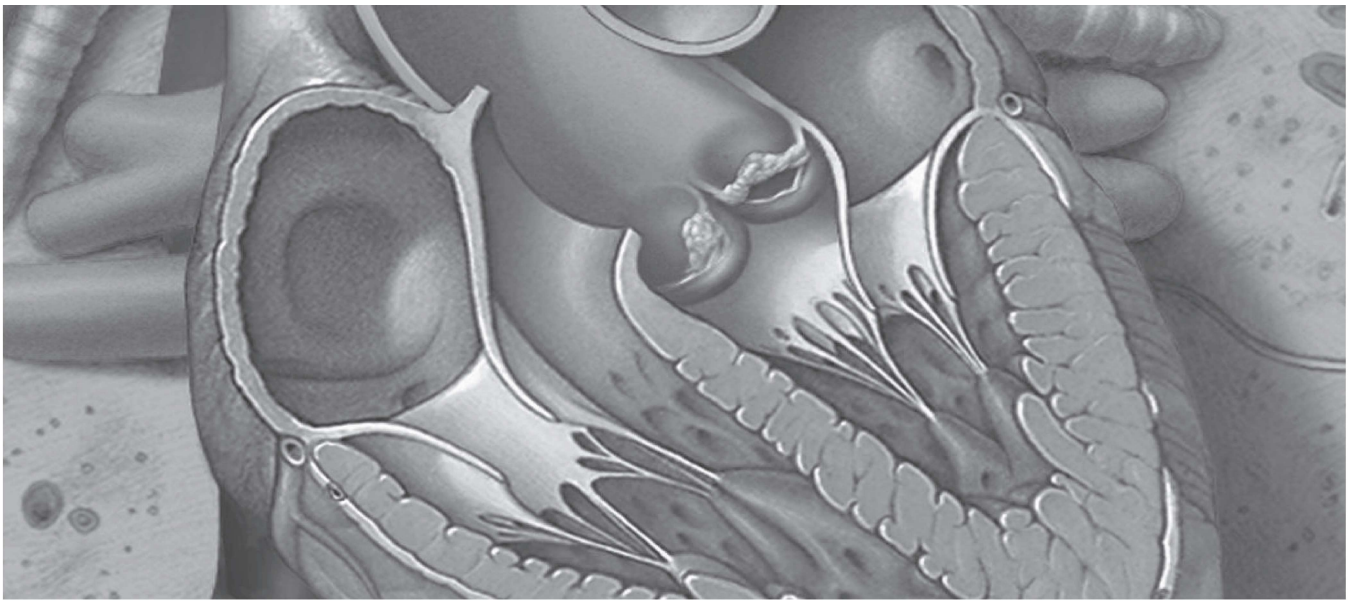
The Practice of a Disease: Ethical Quandaries with Infective Endocarditis in Substance Users

Keren Tanguay is a clinical ethicist at OhioHealth and a PhD candidate in Comparative Studies at the Ohio State University, where her dissertation research focuses on the ethical challenges associated with caring for patients with substance use disorders. Keren earned her Bachelor of Arts in theology from Southern Adventist University and her Master of Divinity from Fuller Theological Seminary.

As a condition that was discovered 350 years ago, infective endocarditis is by no means the "new kid on the block" in the field of medicine's infectious diseases [1]. Infective endocarditis (IE) is a condition in which bacteria enters the blood stream causing an infection that often settles itself in the inner layer of the heart (the endothelium), heart valve, or blood vessel. Patients presenting with IE often have dental disease or degenerative heart structures that come with age [1]. However, in recent years, increased syringe use in the context of the opioid epidemic in the United States has caused intravenous drug users (IVDUs) to become one of the most prominent patient demographics for IE. IE accounts for up to 20% of substance users' hospitalizations and up to 10% of their deaths [2]. The standard of care for patients presenting with IE consists of replacing the infected heart valve with a prosthetic valve and an intensive regime of numerous weeks of intravenous antibiotics. However, the rapid and recent increase in IVDUs is changing the standard of care. Many question whether the better treatment option is to require sobriety before offering valve replacements [3]. Additionally, concerns emerge regarding what kind of antibiotics are most beneficial in the context of non-adherence deciding between oral vs. intravenous antibiotics [4]. As a result, IVDUs with IE are creating significant ripples in what has otherwise been an unremarkable disease and an accepted standard of care.

This particularity in substance users with IE warrants further understanding and assessment. By examining the interplay between healthcare providers' perceptions, available treatment options, and the practice of the disease, I study how infective endocarditis is enacted in unique ways that often results in exceptions within the standardized treatment plan and serves to redefine a disease that is centuries old. This study operates on the belief that disease is not something that is merely *discovered* or *diagnosed* as much as it is something that is done. Disease is not merely a science, but most importantly a practice, "brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices. [5]"

To date, research has focused on the efficacy of medical interventions weighing risks vs. benefits, mortality rates post-surgery, and rates of re-presentation of infection to acute care hospitals [6, 7, 8, 3]. However, none of these studies have studied the social production of the disease itself. This gap leaves important questions unanswered: How do the practices of medicine shape the way IE materializes as scientific knowledge? How do these practices collaborate, coexist, or contend with one another? How do clinicians come to understand the way



substance users create exceptions in otherwise normative standards of medical care for IE? How does patient lifestyle choices, views of responsibility, socioeconomic status become clinical factors that contribute to a provider's judgment and perceptions of treatment plans? How do such judgements and perceptions get narrated and documented?

I am working to bridge this gap in scholarship with an ethnographic qualitative study that includes interviewing care providers and a narrative analysis of electronic medical records for patients who have previously been diagnosed with IE. As an ethnographic study, my inquiry into the "doing" of infective endocarditis among substance users allows me to critically reexamine everyday encounters, conversations, and events that often pass by as "normal" or routine [9].

There is much at stake in the treatment of IVDUs with IE. When one considers that the treatment options up for debate are life-sustaining in nature, the stakes could never be higher. However, these debates on treatment options are nuanced, complicated by the perceptions and various practices surrounding infective endocarditis that are socially constructed and produced. Considering and better understanding the social realities of this condition can contribute not only exploring more optimal treatment options for IE in substance users, but also treating IE in a way that results in greater respect for this vulnerable patient demographic.

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2021 ANNUAL BENO CONFERENCE REVISITED

Theory in Action

Thursday, April 22
& Friday, April 23rd

Our annual conference was held virtually this year to respect pandemic safety recommendations. Lively discussion centered around the topics of moral distress, barriers to surrogate decision making, ethics education in health care, adolescent rights, complex discharges and ethical dilemmas for patients in the margins, and DNR updates. BENO also paid tribute to two accomplished health care professionals we lost recently: Dr. Robert Taylor and Dr. Lynn Maitland.

Dr. Robert Taylor

Dr. Robert (Bob) Taylor was a man of great intelligence, integrity, spirituality, and humanity, who devoted his life to caring for others, including those at the end-of-life. Sadly, he passed away of pancreatic cancer on January 15, 2021. Bob had been very involved in BENO over the years, developing and leading the organization, having served in many capacities including as board president. He was a neurologist and a palliative care physician as well as a medical ethicist.

From 2001-2006, Bob was Medical Director of the Palliative Care Program at Mount Carmel Health System in Columbus, Ohio. He was the founding Director of The Ohio State University (OSU) Palliative Care Program from 2007 to 2015, and also established the OSU Hospice and Palliative Medicine Fellowship program. Bob was at the OSU College of Medicine and The OSU Wexner Medical Center until 2017, where he was an Associate Professor of Neurology, Associate Professor of Clinical Medicine, and Director of Clinical Ethics. Then he left Columbus to serve as the Associate Medical Director at Care Dimensions Hospice House in Waltham, Massachusetts.

During his distinguished career as a physician, he was a friend and mentor to many students and colleagues who greatly benefited from his teaching and guidance. BENO will be honoring Bob by having a student-centered session at the BENO conference each year in his name. The Ohio State University is developing the Robert M. Taylor, MD Lecture in Ethics and Palliative Care. Anyone is welcome to honor Bob by contributing to these initiatives. We are grateful for the opportunity to have worked with and learned from our friend, colleague and mentor, Dr. Bob Taylor, and we are better people for having known him.

2021 BENO Founder's Award – Dr. Lynn Maitland

The recipient of the 2021 Founder's Award is Dr. Lynn Maitland, who died in 2019 and was involved with BENO as a fledgling organization. She was a social worker at Lutheran General Hospital when her interest in ethics started. Lynn went on to earn a Masters in Medical Ethics and a Doctorate (PhD) in Moral Philosophy and work at The Park Ridge Center for Health, Faith, and Ethics in Chicago as Director of Ethics and Education, Mount Carmel Health System in Columbus as Director of Ethics, and Trinity Health as Vice President of Mission and Ethics. She also served as an adjunct associate professor for Georgetown University's Graduate School of Nursing and Vice President of Mission and Ethics at UH St. John Medical Center, and was only a few weeks out into retirement when she died.

Most in ethics will remember Lynn for her pragmatic, consistent, meaningful, and narrative approach to the practice of ethics, which she embodied and advocated in her scholarly work as well as in her dissertation using narrative ethics as a framework for patients in the margins.

Below is a summary of one of the breakout sessions from our recent annual conference. Individual BENO members soon will be able to access recordings of this and other annual conference presentations through the BENO website!

Margot Eves and Alan Murphy presented on revisions to the State of Ohio's Do Not Resuscitate (DNR) regulations. BENO participated in stakeholder meetings with the Ohio Department of Health (ODH) from 2017 into 2019 as ODH considered changes to Ohio Administrative Code 3701-62, the regulations that specify the details of the state's DNR framework. With the 2019 revisions, ODH clarified that the DNR protocol allowed for non-invasive mechanical ventilation and IV access for comfortmedications, points that were ambiguous before 2019. Ohio Administrative Code 3701-62-10 was completely rewritten to clarify the priority among DNR orders, Living Wills, and Health Care Powers of Attorney. Margot and Alan discussed these changes and common issues related to DNR orders that healthcare organizations need to attend to in policy, including reducing customized in-hospital code status orders to the State of Ohio DNR form and consent to inpatient code status changes.

WELCOME OUR NEW BENO MEMBERS IN 2021

Amanda Booher, PhD
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Winslow Homer, The Veteran in a New Field, oil on canvas, 1865, Metropolitan Museum of Art, New York, https://www.metmuseum.org/art/collection/search/11145.

As the US begins to emerge from the COVID-19 pandemic, the gulf between the crisis we have been through and the relaxed summer we hope for can seem almost insuperable. Winslow Homer's "Veteran in a New Field" (1865), a jewel in the collection of the Metropolitan Museum of Art, visually collapses the distance between recent tragedy and a brighter future. A farmer works in the center of the painting with his back to the viewer. His jacket and canteen, cast aside in the lower right corner, identify him as a veteran of the Union Army that had only recently won the US Civil War when Homer executed the painting. The farmer's scythe, anachronistic even in 1865, suggests the Grim Reaper and, by extension, the Civil War's staggering toll of suffering and death [1]. But in the present the farmer reaps instead a seemingly endless harvest of wheat beneath a brilliant, mostly clear sky. Popular American illustration in 1865 frequently juxtaposed parallel scenes of the Civil War with the peace that followed, thereby highlighting the discontinuity between America's bloody past and happy future [2]. "The Veteran in a New Field" instead depicts a more hopeful future that has not pretended to efface the suffering that preceded it.

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