# Social Determinants of Health

*Exploring factors that influence health disparities*

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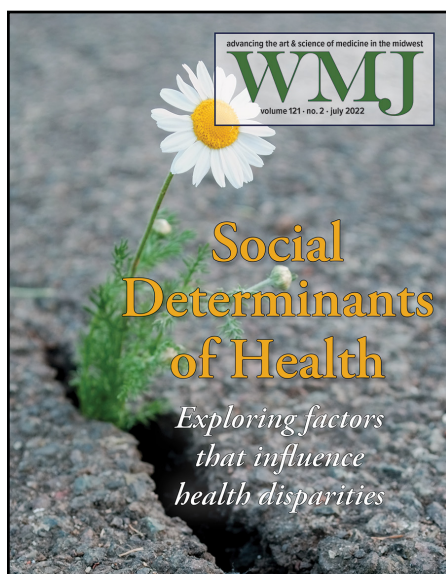
## COVER THEME
### Social Determinants of Health

*Access to health care is just one of many factors that influence health and well-being. Others include our communities, housing, education, social support, family income, employment, and childhood experiences. In this issue of* WMJ, *authors explore several of these influences and some of the ways they lead to health disparities among patients.*

Cover design by Kendi Neff-Parvin

# WMJ

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### EDITORIAL & NEWS

### ORIGINAL RESEARCH

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*\*Denotes online only content. Visit www.wmjonline.org to access these papers.*

# Expanding the Pipeline of Rural Students Interested in Medicine

Dear Editor:

I remember sitting in class my sophomore year of high school wondering what my future would hold. The thought of becoming a physician had just begun to smolder in the back of my mind, but whether a career in medicine or even going to college was possible made me doubt myself. As an aspiring first generation college student from a rural community, the odds seemed stacked against me. What I needed was a source of inspiration that becoming a physician was possible.

During my undergraduate studies, I found a spark of inspiration: the Advocates in Medicine Pathway (AMP) through the Medical College of Wisconsin-Central Wisconsin and North Central Wisconsin Area Health Education Center (AHEC). As part of the program, I was connected to mentors and provided with tools to help make me a more competitive medical school applicant. Surrounded by a group of diverse premedical students like myself in AMP, I felt empowered and galvanized to pursue a career in rural medicine.

There are other programs in Wisconsin focused on creating a pipeline of rural and underrepresented students into medical school. However, these programs target individuals who have already demonstrated an interest in medicine by having students apply or register. But what about the students who don't know they have an interest in medicine or are lacking a source of inspiration?

To help expand the pipeline of rural students matriculating into medical school and ultimately increase the number of physicians practicing in rural Wisconsin, programs should be developed to inspire rural high school students that becoming a physician is possible. One potential way to achieve this is by presenting workshops during class periods so that all students are targeted—not just those with a demonstrated interest in medicine. From there, programs like AMP can assist scholars in crafting competitive medical school applications. A similar model in New Hampshire was developed where a medical student went to a high school and presented on rural medicine, possible careers, and personal stories. An initial trial of this program showed promising results in inspiring high school students.[1]

As the shortage of rural physicians continues to impact our communities, new initiatives are needed to increase the number of physicians in rural Wisconsin. It is my hope that programs like the New Hampshire model can be implemented in Wisconsin to help inspire more students to enter the pipeline to medical school.

*Jakob Anibas, University of Minnesota Twin Cities, Minneapolis, Minnesota; email aniba009@umn.edu*

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# What Is the Clinician's Role in Advocating for Social Issues?

Sarina Schrager, MD, MS, *WMJ* Editor-in-Chief

Health outcomes are predicted by a complex interplay between genetics, health care, and social factors. Outside of genetics, the factors that contribute to health are called social determinants of health and account for up to 80% of health outcomes.[1] The University of Wisconsin Population Health Institute's County Health Rankings and Roadmaps measured the effects of different social determinants of health throughout the country and found that health behaviors account for 30% of the variation in outcomes, clinical care accounts for 20%, social and economic factors account for 40%, and physical environment (ie, where you live) accounts for 10%.[1]

It follows, then, that medical care alone has a relatively small impact on overall health and health outcomes.[2] Other social determinants of health—such as access to insurance, poverty, food insecurity, and healthy neighborhoods—account for a large variation in overall health, and government policies can influence these factors.[2,3] A recent systematic review and meta-analysis of 38 randomized controlled trials found that there are health benefits from interventions to affect early childhood experiences, improved health insurance, and income support; but most of the trials included in the review were underpowered to detect changes in health outcomes.[3]

So, where does this leave clinicians? We work in hospitals and clinics, but to most effectively improve our patients' health, it makes sense for us to also work to influence policy. The idea of clinician advocacy is not a new one, but it is unclear for many where to start—how to learn advocacy skills and how and where to apply them.[4] However, there are many opportunities for those who wish to get involved. Common forums for clinicians to hone their advocacy skills include affiliations with medical societies, many of which have professionals on staff to offer guidance and support; leadership roles within health systems; and membership on boards of directors for local organizations.[4]

> We work in hospitals and clinics, but to most effectively improve our patients' health, it makes sense for us to also work to influence policy.

Clinicians can advocate at different levels as well, ranging from helping a patient get a disabled parking permit to advocating for patients and polices within organizations and health systems, or talking to legislators about issues like Medicaid expansion.[5]

Several papers in this issue of *WMJ* discuss issues related to social determinants of health and highlight topics where clinicians could advocate on behalf of their patients, including health of refugee populations, firearm safety, proximity to coal-fired power plants and more

The paper by Petrassi et al describes an educational intervention to improve knowledge of factors that influence the health of refugees and cultural competence.[6] The intervention, which included a lecture and 3 small-group sessions, improved clinician knowledge but did not affect cultural competence. The authors conclude that further work is needed. Balza et al conducted focus groups with refugees to assess their barriers to care.[7] Unsurprisingly, access to transportation, language barriers, and not feeling respected were obstacles hindering refugees' ability to receive excellent care. At the system level, clinicians could advocate for improved health care for this population.

In their excellent commentary, Stiles et al present ways health systems and hospitals can advocate for reduction of firearm-related deaths and injuries.[8] The authors outline several different approaches clinicians and health systems can use to decrease the number of people injured or killed by guns. A Florida law banned physicians from asking patients about firearms. The law was repealed in 2017, but a subsequent survey of Florida physicians found that only 40% routinely asked about firearms during clinic visits.[9] A national survey of family physicians suggested that formal training in firearm safety improved clinicians' comfort level when asking about firearm safety during clinic visits.[10] These examples suggest that clinicians should advocate for more firearm safety education.

Advocating for health equity for vulnerable populations is another area where clinicians can effect change. In their review article, Ellis et all suggest that professionals must work across disciplines and social sectors to address the effect of racism and discrimination on the health of Milwaukee's African American population.[11] The study by Schiefelbein et al evaluated all adults diagnosed with pancreatic cancer in Wisconsin between 2004 and 2017.[12] They found that non-Hispanic Black patients were significantly less likely to receive treatment or have surgery than non-Hispanic White patients—inequities that affect survival. In another study, Lor et al conducted a chart review looking at documentation of pain treatment and found significant differences between

the way White patients are treated for pain compared to Spanish- and Hmong-speaking patients.[13] These papers provide examples of clinical and community settings that may benefit from policy change.

For those who wish to get involved in advocacy efforts, there are resources available locally, in specialty-specific arenas, and nationally. For example, the AMA has available curated resources for physician advocacy (www.ama-assn.org/health-care-advocacy), and the Wisconsin Medical Society (www.wismed.org/wisconsin/wismed/Advocacy/) and the Wisconsin Pharmacy Society (www.pswi.org/Advocacy) are two organizations that provide resources for those who wish to advocate on behalf of specific legislation. These are just a few resources and guides available to clinicians to help them learn about advocacy and find a venue for their advocacy goals.

If we wish to optimize health and health care for our patients beyond the clinic, working to impact policies that affect social determinants of health is a great place to start.

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# Fahad Aziz, MD, named new *WMJ* Editor-in-Chief

The publishing board for the *Wisconsin Medical Journal* (*WMJ*) named Fahad Aziz, MD, FASN, Editor-in-Chief in June for a three-year term effectively immediately. Dr Aziz succeeds Sarina Schrager, MD, MS, who stepped down to assume the editorship of *Family Medicine*, the official journal of the Society of Teachers of Family Medicine.

Doctor Aziz is an assistant professor of medicine in the Division of Nephrology at the University of Wisconsin (UW) School of Medicine and Public Health, where he also serves as director of the

**Fahad Aziz, MD, FASN**

nephrology fellowship program. He has extensive editorial experience, having authored and edited books, published over 70 peer-reviewed manuscripts and seven book chapters, and served as a peer reviewer for more than 10 academic journals. He is also a member of the editorial board of *Kidney360*, the official publication of the American Society of Nephrology.

"When faced with the challenging task of finding a replacement for Dr Schrager, the *WMJ* publishing board had the good fortune of interacting with Dr Aziz—an accomplished author, reviewer, and editorial board member," said publishing board chair Jonathan Temte, MD, PhD, MS, associate dean for public health and community engagement at UW School of Medicine and Public Health. "We were also impressed with his vision for the *WMJ*—to produce cutting-edge research in all the fields of medicine, promote the success of medical trainees and young professionals, and to extend knowledge and its applications beyond the boundaries of any institution. We are excited to welcome him to the *WMJ* team."

A graduate of King Edward Medical College in Lahore, Pakistan, Dr Aziz completed his residency in internal medicine at Jersey City Medical Center, a fellowship in nephrology at the University of Missouri, and a fellowship in transplant nephrology at UW Hospital and Clinics. He is board certified in internal medicine and nephrology and is a member of the American College of Physicians, the American Society of Nephrology, and the American Society of Transplantation. As a medical educator, he has presented clinical research at national medical conferences and provided classroom instruction to physician assistant students and nephrology fellows, as well as continuing medical education presentations to clinicians.

Dr Schrager became *WMJ* editor-in-chief in 2020 and served as interim editor-in-chief in 2019. Prior to that, she was associate editor and a member of the *WMJ* editorial board for several years.

"Seamlessly filling the big shoes left by previous *WMJ* editor John Frey, III, MD, Dr Schrager skillfully guided the transition of *WMJ* from its home within the Wisconsin Medical Society to co-ownership by the Medical College of Wisconsin and the UW School of Medicine and Public Health, as well as the development of a successful special issue on the impact of race and racism on health," said Dr Temte. "We wish her well in her new role—a wonderful professional opportunity for her—and we are grateful for her extraordinary service to *WMJ*."

# Preventing Firearm-Related Death and Injury: A Call to Action for Wisconsin Health Systems and the Wisconsin Hospital Association

Melissa Stiles, MD; Stephen Hargarten, MD, MPH; Mary Lauby; Nan Peterson MS, RN; James Bigham, MD, MPH

Deaths and injuries related to firearms in the United States have reached epidemic proportions and continue to rise. Approximately 40,000 people die in the US, and an estimated 100,000 people are injured from firearms annually. In 2021, Wisconsin firearm injuries increased by 11% over 2020; 2020 firearm injuries reflected a 71% increase over 2019. The number of people killed with firearms in Wisconsin increased in 2020 by 48% over 2019; and 2021 fatalities from firearms increased by 34% over 2020.[1]

Although injuries from motor vehicle crashes and falls outnumber all other patient injuries in Wisconsin adult trauma centers, it is the lethal nature of firearms (high case fatality ratio) that distinguishes them from other causes of injury. Firearms account for less than 10% of suicidal acts but 50% of deaths—the highest case fatality ratio of any other method. It is well documented that access to firearms increases

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the risk of death by suicide by 3 times. With a reported 64% increase in gun purchases (22 million) in 2020 over 2019 and a 30% increase in unintentional shooting deaths of children between March and December 2020 over 2019, the forecast is dire.[2] Despite these alarming trends, as most firearm injuries are intentional, there are opportunities for intervention and prevention utilizing a comprehensive public health approach to address this epidemic.

Our nation's health care systems manage the care of patients with violent injuries, most notably injuries from bullets. Our health systems also care for these patients long after the initial injury has occurred. We also care for and mobilize resources for the countless indirect victims – the family members and friends of victims and the witnesses of violence. The trauma system/regional trauma systems in Wisconsin initially and definitively manage the biology of firearm injuries and continue to make progress in saving lives, minimizing physical disabilities, and preventing death. Rather than sitting back and treating the downstream impact of growing gun violence in our communities, we are

calling on health systems to create training and leverage resources to prevent these injuries from occurring.

**In Wisconsin, we can and need to do more.** Recently, with support from the Kaiser Permanente health system and the American

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Hospital Association, the National Academy of Medicine published a workshop that identifies ways health care systems can actively engage in firearm injury prevention. More recently, the Association of American Medical Colleges president and the chief executive officer of the Ascension health care system have opined about the importance of health care systems in preventing gun violence. Finally, Northwell Health and several other health care systems across the United States have begun to commit to violence prevention—specifically gun violence prevention (Northwell Center for Gun Violence Prevention).[3]

There is a unique opening for hospital emergency departments (ED) and inpatient care providers to intervene at a moment when patients who have suffered firearm injuries may be particularly responsive to options and interven-

tions. A highly successful approach to hospital-based firearm injury interventions engages community partners with lived experience who provide culturally proficient peer support to patients and family members beginning in the hospital and continuing with community-based intensive case management. The first hospital violence intervention programs (HVIP) were established in the 1990s.[4] They embrace a public health approach to prevention and have been evaluated and proven effective at reducing intentional firearm injury.

In addition, primary care physicians—along with other health care professionals providing care in ambulatory care settings—have a crucial role to play in screening for all forms of injury prevention. The American Medical Association, American Academy of Family Physicians, American Academy of Pediatrics, and American Public Health Association all recommend that clinicians screen their patients for firearm injury prevention and safe storage.[5,6] To save the lives of hundreds of Wisconsinites per year, Wisconsin's health care systems should encourage primary care providers and other physicians and clinicians to perform brief screening for firearm ownership followed by counseling on firearm injury prevention. This intervention is crucial for patients at risk for self-harm and intimate partner violence and patients with mental illness (including dementia and depression), as well as homes with children or adolescents.[7] A comprehensive firearm-related injury prevention program is centered on strengthening patient care, genuine community engagement, and advancing research, education, and policy.

Principles to address and reduce gun violence and achieve gun safety in all Wisconsin communities through a comprehensive approach include the following:

- Employ a public health approach (define the problem, identify risk and protective factors, develop and test prevention strategies, assure widespread adoption) in partnership with other sectors of civil society, including public health agencies, community-based violence prevention organizations, law enforcement, fire department, schools, faith-based organizations, and businesses (including gun shop owners).
- Provide trauma-informed care for all patients and families: inpatient/outpatient/community.

- Consider vicarious trauma prevention strategies for staff treating patients with firearm injuries.
- Involve all aspects of the health care systems in genuine community engagement initiatives to help make our communities healthy and safe for everyone.
- Educate, communicate, and collaborate within your health care organization and your community.

## COMMUNITY-BASED APPROACHES

Community-based approaches include the following:

- Be an active and essential partner in genuine community engagement initiatives.
  - Address upstream social determinants of health and structural racism that underpin the cycle of violence and establish programs to address these obstacles to achieve health and safety.
  - Partner with public health, law enforcement, hospital EDs, and community leaders to implement the Cardiff Model (which has been shown to reduce violence/injuries by 30% to 40%) across cities in Wisconsin.[8] The Cardiff Model combines and maps anonymous hospital and law enforcement data (location, time, date, mechanism of injury) to help create and evaluate local place-based solutions for preventing violent injuries.[9]
  - As an extension of biopsychosocial care of patients who are injured from bullets, employ behavioral interrupters with lived experience in real time that continue trauma-informed care into the community, linking patients to resources that can address safety, food, housing, employment insecurity, cognitive behavioral therapy, and other needs that can reduce the risk of future violence.
  - Create opportunities for system-wide health care and community conversations about preventing firearm injuries. Partner with gun shop owners to establish safe gun storage programs and help in identifying and implementing realistic strategies for preventing firearm injuries in your communities.
  - Consider sponsoring Stop the Bleed[10] training in communities.
  - Empower or dedicate a portion of a staff

position to focus on firearm injury prevention.
- Use your voice and experiences to inform local, regional, and state organizations and policy leaders on evidence-based gun safety programs and policies.[11]
- Work in partnership with community-based organizations and academic leaders to provide health care professionals education and staff training on community-based interventions, including effective screening strategies for assessing firearm injury risk and trauma (eg, acute, historical, adverse childhood experiences).
- Partner with academic resources/centers to advocate for resources to advance research through rigorous evaluation of community-based firearm violence prevention interventions.
- Contribute to, and actively participate in, regional, state, and national coalitions of health system-based organizations working on firearm violence prevention efforts, such as HAVI and Northwell's Gun Violence Prevention initiative.[3]
- Strengthen health systems' participation in the state's trauma care system.[12]

## DIRECT PATIENT-CARE APPROACHES

Direct patient-care approaches include the following:

- In the hospital and ED settings, employ the biopsychosocial model to strengthen discharge planning of patients with partnerships with and referrals to community resources (eg, trauma treatment, sexual/domestic/community violence and child abuse prevention programs, suicide prevention, basic needs).
- Strengthen the care of patients with trauma-informed care throughout the spectrum of care.
- Strengthen staff/clinician education (inpatient/ED/outpatient) on best practices for screening/counseling on safe firearm storage, identifying high-risk patients, and lethal means restriction training.[13] During clinical encounters, clinicians should do the following:
  - Inquire about firearms in the home; ask about the plan to keep the gun and ammunition safe and away from unintended users.[14,15]

- Clinicians should also screen to ensure high-risk individuals are safe with firearm(s) in the home. This includes screening for mental health concerns or suicidal ideation, intimate partner violence, or children/adolescents in the home. Certain higher-risk patients may wish to have a voluntary transfer of their firearm to a trusted individual so their firearm can be held during a period of increased risk for injury from the firearm.[16,17]
- Exam rooms can include handouts or posters with QR codes that highlight the key elements of safe firearm storage.
- Consider providing gun locks for patients and information about resources for local gun shops that offer safe storage programs.
- Strengthen staff/clinician education (inpatient/ED/outpatient) on trauma-informed care and the range of community resources that address gun injury prevention (eg, trauma treatment, sexual/intimate partner/community violence and child abuse prevention programs, suicide prevention).
- Leverage the electronic medical record capabilities to streamline universal screening questions regarding gun access and safety and link to local resources.

## COLLABORATION/ADVOCACY/RESEARCH

- Join the Gun Violence Prevention Learning Collaborative for Health Systems and Hospitals that is committed to learning from other health care organizations with the "intention of developing and implementing best practices for firearm safety and gun violence prevention."[18]
- Engage gun owners within your health care system to help identify strategies for addressing firearm injury prevention in the community and strategies for health care providers.
- Advocate for appropriate research funding as part of the federal budget for firearm-related injury and violence prevention research.[19]
- Collaborate across health care organizations to foster evidence-based public policy and programs to decrease gun violence. These might include Extreme Risk

Protection Order (ERPO)[20] policies, means restriction training, and other strategies to reduce violence.

## THE TIME TO ACT IS NOW

Deaths and injuries from firearms only continue to increase in Wisconsin. There is clear evidence to guide what can be done and how to focus efforts to reduce both intentional and unintentional firearm injuries through a multifaceted approach grounded in public health. Wisconsin health care organizations and the Wisconsin Hospital Association can play a vital role in advancing and implementing this gun injury/violence prevention model for Wisconsin and its health care systems.

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# WMJ

# Treatment Inequity: Examining the Influence of Non-Hispanic Black Race and Ethnicity on Pancreatic Cancer Care and Survival in Wisconsin

Andrea M. Schiefelbein, MSPH; John K. Krebsbach, BS; Amy K. Taylor, MD; Jienian Zhang, MS; Chloe E. Haimson, MS; Amy Trentham-Dietz, PhD; Melissa C. Skala, PhD; John M. Eason, PhD; Sharon M. Weber, MD; Patrick R. Varley, MD, MS; Syed Nabeel Zafar, MD, MPH; Noelle K. LoConte, MD

## ABSTRACT

**Introduction:** We investigated race and ethnicity-based disparities in first course treatment and overall survival among Wisconsin pancreatic cancer patients.

**Methods:** We identified adults diagnosed with pancreatic adenocarcinoma in the Wisconsin Cancer Reporting System from 2004 through 2017. We assessed race and ethnicity-based disparities in first course of treatment via adjusted logistic regression and overall survival via 4 incremental Cox proportional hazards regression models.

**Results:** The study included 8,490 patients: 91.3% (n = 7,755) non-Hispanic White, 5.1% (n = 437) non-Hispanic Black, 1.7% (n = 141) Hispanic, 0.6% Native American (n = 53), and 0.6% Asian (n = 51) race and ethnicities. Non-Hispanic Black patients had lower odds of treatment than non-Hispanic White patients for full patient (OR, 0.52; 95% CI, 0.41-0.65) and Medicare cohorts (OR, 0.40; 95% CI, 0.29-0.55). Non-Hispanic Black patients had lower odds of receiving surgery than non-Hispanic White patients (full cohort OR, 0.67 [95% CI, 0.48-0.92]; Medicare cohort OR, 0.57 [95% CI, 0.34-0.93]). Non-Hispanic Black patients experienced worse survival than non-Hispanic White patients in the first 2 incremental Cox proportional hazard regression models (model II HR, 1.18; 95% CI, 1.06-1.31). After adding insurance and treatment course, non-Hispanic Black and non-Hispanic White patients experienced similar survival (HR, 0.98; 95% CI, 0.88-1.09).

**Conclusion:** Non-Hispanic Black patients were almost 50% less likely to receive any treatment and 33% less likely to receive surgery than non-Hispanic White patients. After including treatment course, non-Hispanic Black and non-Hispanic White patient survival was similar. Increasing non-Hispanic Black patient treatment rates by addressing structural factors affecting treatment availability and employing culturally humble approaches to treatment discussions may mitigate these disparities.

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## BACKGROUND

Pancreatic ductal adenocarcinoma (PDAC) remains one of the deadliest cancers in the United States, with a 5-year survival rate of 9%.[1] It accounts for an estimated 3% of new cancer cases nationally for both sexes yet is responsible for an estimated 8% of cancer deaths in both sexes.[1] PDAC incidence and death rates are both increasing[2] and, in the absence of early detection screening, clear symptoms of early-stage disease, and curative treatments for regional and distant disease, these trends are likely to persist.

Siegel et al note that 5-year PDAC survival rates are similar for Black and White patients.[1] However, disparities in PDAC overall survival, treatment, and stage at diagnosis between Black and White patients are well documented. Studies have shown that non-Hispanic Black patients are less likely than non-Hispanic White patients to receive an oncology consultation of any kind.[3,4] Additionally, chemotherapy receipt is lower among non-Hispanic Black patients than non-Hispanic White patients, for both regional and distant disease and when paired with surgical resection.[5-8] Surgical resection—the only curative treatment for pancreatic cancer—is offered to, accepted by, and performed on non-Hispanic Black patients at lower rates than their non-Hispanic White counterparts.[5,6,8-13]

An estimated 950 Wisconsinites died from PDAC in 2020, making it the second most common cancer-related cause of death in the state.[1] Wisconsin ranks in the top quarter of states for pancreatic cancer mortality.[1] Additionally, Wisconsin has the worst death rate ratio—1.30 (95% CI, 1.18-1.42)—between non-

Hispanic Black and non-Hispanic White cancer patients of all states.[1] This death rate ratio climbed to 1.78 (95% CI, 1.56-2.02) between non-Hispanic Black and non-Hispanic White patients under age 65.

We investigated race- and ethnicity-based disparities in PDAC treatment and survival among Wisconsin patients. We also investigated the relationship between race and ethnicity and other social factors that impact cancer outcomes, including insurance status, rurality, and treatment. Our 2 primary outcomes of interest were (1) whether race- and ethnicity-based disparities existed in terms of receipt of any treatment versus no treatment, and (2) for those patients who received any treatment, whether disparities existed in terms of surgical receipt—either with or without chemoradiation—versus definitive chemoradiation. Secondary to these treatment outcomes, we examined whether race- and ethnicity-based survival disparities existed amongst Wisconsin PDAC patients.

## METHODS

This study was approved by the University of Wisconsin – Madison Institutional Review Board.

### Patient Cohort

Data were provided by the Wisconsin Cancer Reporting System (WCRS), which requires facilities to record the first course of treatment after diagnosis for each cancer. Patients diagnosed with PDAC between January 1, 2004, and December 31, 2017, were selected for analysis. We defined PDAC using the appropriate ICD-0-3 codes for site of origin (C25.0, C25.1, C25.2, C25.3, C25.7, C25.8, or C25.9) and histology (8140 and 8500). Patients with missing sex, rurality, first course treatment, or survival time were excluded from analysis. The 1.1% of patients who were missing data were spread across race and ethnicities, and we assumed missing data would not alter our findings.

### Individual-Level Variables

We categorized first course treatment 3 ways to utilize in different analyses. First, we created "any treatment," a binary variable differentiating between patients with a documented first course treatment of chemotherapy, radiation, or surgery—in combination or individually—versus patients with no documented first course treatment.[14] Second, we created "treatment type," a binary variable differentiating between patients who had a documented first course treatment of chemotherapy or radiation ("definitive chemoradiation") versus surgery, alone or in combination with chemotherapy and/or radiation. Finally, we created "treatment course" to categorize patients based on those who had no documented first course treatment, those who had documented chemotherapy and/or radiation as the first course of treatment, and those who had surgery with or without chemotherapy and/or radiation as their first course of treatment.

The race/ethnicity variable was consolidated to include Non-Hispanic White, Non-Hispanic Black, Native American, Hispanic, Asian, and patients with unknown or Pacific Islander race and ethnicity (Other). We further consolidated the Native American, Asian, and Other race and ethnicity categories in some tables to preserve patient confidentiality when few patients were present for specific categories.

Insurance categories were consolidated such that 1 "Private" insurance category included patients with managed care, health maintenance organization, preferred provider organization, and fee-for-service insurance. Patients with Tricare, Veterans Administration (VA), or military insurance also were categorized together. Patients with Indian Health insurance were included in the "Insurance, NOS" category, and patients with unknown insurance status, no insurance, or self-pay were categorized together.

Patient rurality status was assigned at the county level using the US Department of Agriculture's 2013 Rural-Urban Continuum codes (RUCC).

### County-Level Variables

Wisconsin county-level education status and median household income were accessed from Social Explorer (SocialExplorer.com, accessed May 10, 2021). American Community Survey 5-year estimates for 2009-2013 were used since these years represented the midpoint of the WCRS registry data. The percent population of individuals 25 years and older with a high school degree or equivalent was calculated for each county. The counties were ranked and assigned a quartile based on that percent. The counties also were ranked by their median income and assigned a quartile. These county-level variables were assigned to each case based on the case's county of residence at diagnosis.

### Statistical Analysis

We summarized patient characteristics across the variables of interest and potential confounders by race and ethnicity categories. Categorical variables were summarized by number and percentage, and continuous variables were summarized by mean and 95% confidence interval. We used a chi-square test to evaluate differences between the categorical and continuous variables by race and ethnicity.

We conducted multivariable logistic regression to evaluate the odds ratios (OR) of any versus no treatment for first course treatment (Any Treatment model) and definitive chemoradiation versus surgery (Type of Treatment model) for those patients who had any treatment documented for their first course of treatment. We analyzed a basic model, which included patient age, sex, rurality, and race and ethnicity, and a comprehensive model, which included basic model variables and SEER (Surveillance, Epidemiology, and End Results) stage at diagnosis and insurance for both the Any Treatment and Type of Treatment models. We incorporated county-level education attainment and median

**Table 1.** Characteristics of Pancreatic Cancer Patients by Race and Ethnicity, Wisconsin Cancer Reporting System, 2004-2017

| Variable | Non-Hispanic White (n=7,755) | | Non-Hispanic Black (n=437) | | Native American (n=53) | | Hispanic (n=141) | | Asian (n=51) | | Other (n=53) | | Total (n=8,490) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Count | % of Total | Count | % of Total | Count | % of Total | Count | % of Total | Count | % of Total | Count | % of Total | Count | % of Total |
| Age (years) | | | | | | | | | | | | | | |
| Mean and SD | 69.4 | 11.3 | 64.6 | 11.2 | 63.3 | 11.2 | 65.3 | 12.3 | 64.6 | 11.0 | 73.5 | 12.5 | 69.1 | 11.4 |
| Sex | | | | | | | | | | | | | | |
| Male | 4113 | 53.0% | 216 | 49.4% | 28 | 52.8% | 91 | 64.5% | 20 | 39.2% | 27 | 50.9% | 4495 | 52.9% |
| Female | 3642 | 47.0% | 221 | 50.6% | 24 | 45.3% | 50 | 35.5% | 31 | 60.8% | 26 | 49.1% | 3994 | 47.0% |
| SEER stage | | | | | | | | | | | | | | |
| Localized | 741 | 9.6% | 54 | 12.4% | | | 15 | 10.6% | 6 | 11.8% | | | 819 | 9.6% |
| Regional | 2735 | 35.3% | 147 | 33.6% | 23 | 43.4% | 39 | 27.7% | 17 | 33.3% | 17 | 32.1% | 2978 | 35.1% |
| Distant | 4115 | 53.1% | 232 | 53.1% | 28 | 52.8% | 84 | 59.6% | 28 | 54.9% | 20 | 37.7% | 4507 | 53.1% |
| Unstaged | 147 | 1.9% | | | | | | | | | | | 169 | 2.0% |
| Rurality (RUCC) | | | | | | | | | | | | | | |
| Mean and SD | 3.1 | 2.1 | 1.3 | 0.7 | 4.9 | 2.7 | 1.7 | 1.1 | 2.4 | 1.5 | 3.4 | 2.2 | 3.0 | 2.1 |
| Treatment course | | | | | | | | | | | | | | |
| No treatment | 2221 | 28.6% | 156 | 35.7% | 16 | 30.2% | 44 | 31.2% | 19 | 37.3% | 30 | 56.6% | 2486 | 29.3% |
| Definitive chemo-radiation | 3877 | 50.0% | 206 | 47.1% | 26 | 49.1% | 63 | 44.7% | 20 | 39.2% | 8 | 15.1% | 4200 | 49.5% |
| Surgery, with or without definitive chemoradiation | 1599 | 20.6% | 72 | 16.5% | 11 | 20.8% | 32 | 22.7% | 11 | 21.6% | 9 | 17.0% | 1734 | 20.4% |
| Insurance | | | | | | | | | | | | | | |
| Private | 1755 | 22.6% | 72 | 16.5% | 13 | 24.5% | 27 | 19.1% | 15 | 29.4% | 0 | 0.0% | 1882 | 22.2% |
| Medicare | 4699 | 60.6% | 207 | 47.4% | 24 | 45.3% | 76 | 53.9% | 20 | 39.2% | 13 | 24.5% | 5039 | 59.4% |
| Medicaid | 257 | 3.3% | 92 | 21.1% | 7 | 13.2% | 16 | 11.3% | 9 | 17.6% | 0 | 0.0% | 381 | 4.5% |
| VA/Tricare/Military | 233 | 3.0% | 21 | 4.8% | | | | | | | | | 264 | 3.1% |
| Insurance, NOS | 483 | 6.2% | 20 | 4.6% | 6 | 11.3% | | | | | | | 520 | 6.1% |
| Self-pay/not insured/unknown | 328 | 4.2% | 25 | 5.7% | | | 12 | 8.5% | | | 32 | 60.4% | 404 | 4.8% |
| Overall survival (months) | | | | | | | | | | | | | | |
| Mean and SD | 9.6 | 12.6 | 8.6 | 9.6 | 10.7 | 14.2 | 8.3 | 10.2 | 8.3 | 10.2 | 3.5 | 4.3 | 9.5 | 12.4 |

Abbreviations: SEER, Surveillance, Epidemiology, and End Results; RUCC, Rural-Urban Continuum Codes; VA, Veterans Administration.

household income into these models to assess whether these social factors impacted the results. We conducted this analysis on the full patient cohort, including testing for an interaction between race and ethnicity and insurance, the subset of Medicare patients, and the subset of Medicare patients with supplemental insurance. The latter 2 cohorts were analyzed to minimize insurance as a potential effect modifier.

We also conducted a survival analysis with multivariate Cox proportional hazards regression to assess risk of death. Here, we completed stepwise analysis starting with a basic model that included age, sex, rurality, and race and ethnicity. We repeated the analysis 3 times as we individually added insurance, SEER stage at diagnosis, and treatment course to the regression. We incorporated county-level education attainment and median household income into these models to assess whether these social factors affected the results. We again repeated this series of analyses on the full patient cohort, the subset of Medicare patients, and the subset of Medicare patients with supplemental insurance.

## RESULTS
### Patient Characteristics

We identifiedFT 8,490 patients with PDAC, of which 437 were of non-Hispanic Black race/ethnicity and 7,755 were of non-Hispanic White race/ethnicity. Table 1 illustrates the distribution of patient characteristics by race and ethnicity. Non-Hispanic Black patients were diagnosed at a younger mean age (64.6 years; 95% CI, 63.6-65.7) compared to non-Hispanic White patients (69.4; 95% CI, 69.1-69.6) (P<0.001). Non-Hispanic Black patients had a higher percentage of localized disease diagnoses than non-Hispanic White patients (12.4% vs 9.6%, respectively), though 53.1% of both groups were diagnosed with distant disease (P=0.09). Non-Hispanic Black patients tended to be from metropolitan counties with a mean RUCC code of 1.3, while non-Hispanic White patients had a mean RUCC code of 3.1 (P<0.001). A higher percentage of non-Hispanic Black patients had no documented first course of treatment (35.7%) compared to non-Hispanic White patients (28.6%) (P=0.01). Fewer non-Hispanic Black patients

**Figure.** Adjusted Odds Ratios (OR) of Intended First Course Treatment by Race and Ethnicity and Insurance Subsets

**A**
**Any Treatment vs No Treatment**
Full Patient Cohort (n=8,416)

**D**
**Surgery vs Definitive Chemoradiation**
Full Patient Cohort (n=5,933)

**B**
**Any Treatment vs No Treatment**
Medicare Patient Cohort (n=5,005)

**E**
**Surgery vs Definitive Chemoradiation**
Medicare Patient Cohort (n=3,217)

**C**
**Any Treatment vs No Treatment**
Medicare Supplement Patient Cohort (n=2,743)

**F**
**Surgery vs Definitive Chemoradiation**
Medicare Supplement Patient Cohort (n=1,812)

ORs for patients of Asian and Other race/ethnicity were omitted from (F) for low sample size (n≤5). Full patient cohort models (A and D) are adjusted for age, sex, race, ethnicty, rurality, SEER stage, and insurance. Medicare patient cohort models (B and E) and Medicare Supplement patient cohort models (C and F) are adjusted for age, sex, race/ethnicity, rurality, and SEER stage. Odds ratios are shown on a log scale.

Abbreviation: SEER, Surveillance, Epidemiology, and End Results.

**Table 2.** Sequential Models of Adjusted Cox Proportional Hazards Regression for Overall Survival[a]

| All Patients | Model I | | | Model II | | | Model III | | | Model IV | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | HR | 95% CI | *P* value | HR | 95% CI | *P* value | HR | 95% CI | *P* value | HR | 95% CI | *P* value |
| **Age** | | | | | | | | | | | | |
| Continuous | 1.03 | 1.02–1.03 | <0.001 | 1.03 | 1.03–1.03 | <0.001 | 1.03 | 1.03–1.03 | <0.001 | 1.01 | 1.01–1.01 | <0.001 |
| **Sex** | | | | | | | | | | | | |
| Male | ref | | | ref | | | ref | | | ref | | |
| Female | 0.97 | 0.93–1.02 | 0.223 | 0.98 | 0.94–1.03 | 0.405 | 0.99 | 0.94–1.03 | 0.532 | 0.94 | 0.90–0.99 | 0.015 |
| **Race/ethnicity** | | | | | | | | | | | | |
| Non-Hispanic White | ref | | | ref | | | ref | | | ref | | |
| Non-Hispanic Black | 1.12 | 1.01–1.24 | 0.038 | 1.18 | 1.06–1.31 | 0.002 | 1.11 | 0.99–1.23 | 0.065 | 0.98 | 0.88–1.09 | 0.706 |
| Native American | 1.09 | 0.83–1.45 | 0.528 | 1.14 | 0.86–1.51 | 0.352 | 1.10 | 0.83–1.46 | 0.496 | 1.10 | 0.83–1.45 | 0.527 |
| Asian | 1.02 | 0.76–1.39 | 0.881 | 0.97 | 0.71–1.31 | 0.834 | 0.91 | 0.67–1.23 | 0.525 | 0.66 | 0.48–0.90 | 0.008 |
| Hispanic | 1.03 | 0.86–1.24 | 0.713 | 1.01 | 0.78–1.49 | 0.887 | 0.98 | 0.82–1.17 | 0.830 | 0.95 | 0.79–1.14 | 0.575 |
| Other | 1.20 | 0.87–1.66 | 0.270 | 1.08 | 0.78–1.49 | 0.638 | 0.87 | 0.62–1.21 | 0.408 | 0.57 | 0.41–0.80 | 0.001 |
| **Rurality (RUCC)** | | | | | | | | | | | | |
| Continuous | 0.99 | 0.98–1.00 | 0.171 | 0.99 | 0.98–1.00 | 0.249 | 0.99 | 0.98–1.00 | 0.154 | 1.00 | 0.99–1.01 | 0.773 |
| **SEER stage** | | | | | | | | | | | | |
| Localized | | | | ref | | | ref | | | ref | | |
| Regional | | | | 1.05 | 0.97–1.15 | 0.225 | 1.06 | 0.97–1.16 | 0.193 | 1.31 | 1.20–1.43 | <0.001 |
| Distant | | | | 2.72 | 2.50–2.96 | <0.001 | 2.73 | 2.51–2.97 | <0.001 | 2.48 | 2.28–2.71 | <0.001 |
| Unstaged | | | | 2.20 | 1.85–2.62 | <0.001 | 2.09 | 1.75–2.49 | <0.001 | 1.32 | 1.10–1.57 | 0.002 |
| **Insurance** | | | | | | | | | | | | |
| Private | | | | | | | ref | | | ref | | |
| Medicare | | | | | | | 1.04 | 0.97–1.12 | 0.297 | 1.07 | 1.00–1.15 | 0.052 |
| Medicaid | | | | | | | 1.41 | 1.25–1.59 | <0.001 | 1.25 | 1.11–1.41 | <0.001 |
| Tricare/VA/Military | | | | | | | 1.16 | 1.01–1.34 | 0.036 | 1.09 | 0.94–1.25 | 0.250 |
| Insurance, NOS | | | | | | | 1.08 | 0.98–1.20 | 0.133 | 1.01 | 0.91–1.12 | 0.858 |
| Not insured, self pay, unknown | | | | | | | 1.49 | 1.32–1.69 | <0.001 | 1.16 | 1.02–1.31 | 0.020 |
| **Treatment course** | | | | | | | | | | | | |
| No treatment | | | | | | | | | | ref | | |
| Definitive chemoradiation | | | | | | | | | | 0.33 | 0.31–0.34 | <0.001 |
| Surgery, with or without neoadjuvant and/or adjuvant treatment | | | | | | | | | | 0.16 | 0.15–0.18 | <0.001 |
| Unknown | | | | | | | | | | 0.47 | 0.36–0.61 | <0.001 |

[a]Model I included age, sex, race/ethnicity, and rurality. Model II included age, sex, race/ethnicity, rurality, and SEER Stage. Model III included age, sex, race/ethnicity, rurality, SEER stage and insurance. Model IV included age, sex, race/ethnicity, rurality, SEER stage, insurance, and treatment course. 91 patients were excluded for missing survival time, sex, and/or rurality. County-level education status and median household income were added to each model, and the results remained consistent with those shown here.

Abbreviations: HR, hazard ratio; SEER, Surveillance, Epidemiology, and End Results; RUCC, Rural-Urban Continuum Codes; VA, Veterans Administration.

(16.5%) had surgery included in their first course of treatment than non-Hispanic White patients (20.6%) (*P* = 0.01). A lower percentage of non-Hispanic Black patients had private (16.5%) and Medicare (47.4%) insurance compared to non-Hispanic White patients (22.6% and 60.6%, respectively). A higher percentage of non-Hispanic Black patients had Medicaid insurance (21.1%) than non-Hispanic White patients (3.3%) (*P* < 0.001).

## Any vs No First Course of Treatment

Non-Hispanic Black patients had a significantly lower OR of receiving any versus no treatment compared to non-Hispanic White patients (OR, 0.52; 95% CI, 0.41-0.65) when controlling for age, sex, race/ethnicity, rurality, SEER stage, and insurance (Figure A). This remained consistent after adding county-level education status and median household income to the analysis (OR, 0.58; 95%

CI, 0.45-0.74). This was also true for Asian patients (OR, 0.47; 95% CI, 0.38-0.59) and patients with a race/ethnicity categorized as Other (OR, 0.48; 95% CI, 0.23-0.98). We also found that patients with Medicare (OR, 0.79; 95% CI, 0.65-0.95), Medicaid (OR, 0.40; 95% CI, 0.29-0.53), TRICARE/Military/VA (OR, 0.44; 95% CI, 0.32-0.61), Insurance NOS (OR, 0.66; 95% CI, 0.50-0.88), and Self Pay/Not Insured/Unknown (OR, 0.27; 95% CI, 0.20-0.36) insurances all demonstrated significantly lower ORs for receiving treatment compared to patients with private insurance.

Non-Hispanic Black Medicare patients had an OR of receiving any versus no treatment of 0.32 (95% CI, 0.23-0.45), while non-Hispanic White Medicare patients had an OR of 0.78 (95% CI, 0.64-0.94) compared to non-Hispanic White private insurance patients. Likewise, non-Hispanic Black Medicaid patients

**Table 3.** Sequential Models of Adjusted Cox Proportional Hazards Regression for the Subset of Medicare Patients for Overall Survival[a]

| Medicare Patients | Model I | | | Model II | | | Model IV | | |
|---|---|---|---|---|---|---|---|---|---|
| Variable | HR | 95% CI | *P* value | HR | 95% CI | *P* value | HR | 95% CI | *P value* |
| Age | | | | | | | | | |
| Continuous | 1.03 | 1.03–1.04 | <0.001 | 1.03 | 1.03–1.04 | <0.001 | 1.01 | 1.01–1.02 | <0.001 |
| Sex | | | | | | | | | |
| Male | ref | | | ref | | | ref | | |
| Female | 1.00 | 0.94–1.06 | 0.994 | 1.03 | 0.97–1.09 | 0.363 | 0.96 | 0.91–1.02 | 0.186 |
| Race/ethnicity | | | | | | | | | |
| Non-Hispanic White | ref | | | ref | | | ref | | |
| Non-Hispanic Black | 1.12 | 0.97–1.30 | 0.128 | 1.18 | 1.02–1.37 | 0.029 | 0.93 | 0.80–1.08 | 0.351 |
| Native American | 0.88 | 0.58–1.34 | 0.550 | 1.04 | 0.68–1.59 | 0.848 | 1.12 | 0.73–1.70 | 0.601 |
| Asian | 1.05 | 0.67–1.65 | 0.820 | 0.90 | 0.57–1.41 | 0.641 | 0.82 | 0.52–1.29 | 0.395 |
| Hispanic | 1.10 | 0.87–1.39 | 0.442 | 1.11 | 0.87–1.40 | 0.403 | 1.15 | 0.91–1.46 | 0.243 |
| Other | 0.90 | 0.47–1.74 | 0.760 | 1.70 | 0.57–2.11 | 0.779 | 1.00 | 0.52–1.92 | 0.998 |
| Rurality (RUCC) | | | | | | | | | |
| Continuous | 0.99 | 0.97–1.00 | 0.104 | 0.99 | 0.98–1.00 | 0.122 | 0.99 | 0.98–1.01 | 0.375 |
| SEER stage | | | | | | | | | |
| Localized | | | | ref | | | ref | | |
| Regional | | | | 1.00 | 0.91–1.11 | 0.935 | 1.25 | 1.13–1.39 | <0.001 |
| Distant | | | | 2.50 | 2.26–2.76 | <0.001 | 2.32 | 2.09–2.56 | <0.001 |
| Unstaged | | | | 1.91 | 1.53–2.38 | <0.001 | 1.32 | 1.06–1.64 | 0.014 |
| Treatment course | | | | | | | | | |
| No treatment | | | | | | | ref | | |
| Definitive chemoradiation | | | | | | | 0.32 | 0.30–0.35 | <0.001 |
| Surgery, with or without neoadjuvant and/or adjuvant treatment | | | | | | | 0.16 | 0.14–0.18 | <0.001 |
| Unknown | | | | | | | 0.49 | 0.34–0.69 | 0.001 |

[a]Model I included age, sex, race/ethnicity, and rurality. Model II included age, sex, race/ethnicity, rurality, and SEER stage. Model III was not completed since all patients had Medicare insurance. Model IV included age, sex, race/ethnicity, rurality, SEER stage, and treatment course. Thirty-three patients were excluded for missing survival time, sex, and/or rurality. County-level education status and median household income were added to each model, and the results remained consistent with those shown here.

Abbreviations: HR, hazard ratio; SEER, Surveillance, Epidemiology, and End Results; RUCC, Rural-Urban Continuum codes; VA, Veterans Administration.

had an OR of 0.20 (95% CI, 0.12-0.33) and non-Hispanic White Medicaid patients had an OR of 0.37 (95% CI, 0.26-0.52) compared to non-Hispanic White private insurance patients. Privately insured and uninsured non-Hispanic Black patients had similar ORs of treatment as their non-Hispanic White counterparts, respectively.

We repeated this analysis on the 5,039 patients with Medicare insurance to minimize insurance as a potential mediating factor to treatment. We found that non-Hispanic Black Medicare patients had a significantly lower OR of any versus no treatment compared to non-Hispanic White Medicare patients (OR, 0.40; 95% CI, 0.29-0.55) (Figure B). Again, this result remained consistent when education status and median household income were added to the analysis (OR, 0.44; 95% CI, 0.31-0.61). No similar difference was noted between non-Hispanic White Medicare patients and patients of Asian or Other race/ethnicities. The Medicare model also showed that female patients had a lower OR of any versus no treatment than male patients (OR, 0.85; 95% CI, 0.75-0.96). Restricting this analysis to only Medicare patients with supplemental insurance did not affect these findings (Figure C).

### Survey vs Definitive Chemoradiation as First Course of Treatment

Controlling for age, sex, race/ethnicity, rurality, SEER stage, and insurance, the OR of receiving surgery versus definitive chemoradiation in non-Hispanic Black patients remained significantly lower than non-Hispanic White patients (OR, 0.67; 95% CI, 0.48-0.92) (Figure C) and remained significantly lower after county-level education status and median household income were added to the model (OR, 0.66; 95% CI, 0.47-0.93). Patients with a race/ethnicity categorized as Other had a higher OR of receiving surgery versus definitive chemoradiation compared to non-Hispanic White patients (OR, 3.21; 95% CI, 1.19-8.65), though only 17 patients were in that subgroup. Patients with TRICARE/Military/VA (OR, 1.51; 95% CI, 1.01-2.26) and Insurance NOS (OR, 1.36; 95% CI, 1.03-1.79) had a higher OR of receiving surgery versus definitive chemoradiation compared to privately insured patients. Patients with Medicare, Medicaid, and Self Pay/Not Insured/Unknown insurance no longer had a difference in first course treatment of surgery or definitive chemoradiation compared to privately insured patients. We did not see an interaction between race and ethnicity and insurance status or resectable

**Table 4.** Sequential Models of Adjusted Cox Proportional Hazards Regression for the Subset of Medicare Patients With Supplemental Insurance for Overall Survival[a]

| Medicare Patients | Model I | | | Model II | | | Model IV | | |
|---|---|---|---|---|---|---|---|---|---|
| Variable | HR | 95% CI | P value | HR | 95% CI | P value | HR | 95% CI | P value |
| **Age** | | | | | | | | | |
| Continuous | 1.04 | 1.03–1.04 | <0.001 | 1.04 | 1.03–1.05 | <0.001 | 1.01 | 1.01–1.02 | <0.001 |
| **Sex** | | | | | | | | | |
| Male | ref | | | ref | | | ref | | |
| Female | 0.96 | 0.89–1.04 | 0.371 | 1.00 | 0.92–1.08 | 0.990 | 0.94 | 0.87–1.01 | 0.108 |
| **Race/ethnicity** | | | | | | | | | |
| Non-Hispanic White | ref | | | ref | | | ref | | |
| Non-Hispanic Black | 1.01 | 0.75–1.35 | 0.963 | 1.03 | 0.77–1.38 | 0.849 | 0.86 | 0.64–1.15 | 0.314 |
| Native American | 0.86 | 0.48–1.57 | 0.630 | 0.95 | 0.52–1.73 | 0.871 | 1.17 | 0.65–2.13 | 0.599 |
| Asian | 1.03 | 0.46–2.30 | 0.944 | 0.72 | 0.32–1.60 | 0.415 | 1.03 | 0.46–2.31 | 0.935 |
| Hispanic | 0.97 | 0.67–1.41 | 0.879 | 1.11 | 0.76–1.61 | 0.587 | 1.34 | 0.92–1.95 | 0.126 |
| Other | 1.48 | 0.662–3.30 | 0.337 | 1.57 | 0.66–3.30 | 0.268 | 1.20 | 0.54–2.68 | 0.651 |
| **Rurality (RUCC)** | | | | | | | | | |
| Continuous | 1.00 | 0.98–1.02 | 0.885 | 1.00 | 0.98–1.02 | 0.819 | 1.00 | 0.98–1.02 | 0.750 |
| **SEER stage** | | | | | | | | | |
| Localized | | | | ref | | | ref | | |
| Regional | | | | 1.03 | 0.89–1.19 | 0.670 | 1.21 | 1.05–1.40 | 0.009 |
| Distant | | | | 2.52 | 2.20–2.90 | <0.001 | 2.27 | 1.97–2.62 | <0.001 |
| Unstaged | | | | 2.28 | 1.70–3.05 | <0.001 | 1.28 | 0.95–1.71 | 0.104 |
| **Treatment course** | | | | | | | | | |
| No treatment | | | | | | | ref | | |
| Definitive chemoradiation | | | | | | | 0.31 | 0.28–0.34 | <0.001 |
| Surgery, with or without neoadjuvant and/or adjuvant treatment | | | | | | | 0.15 | 0.13–0.18 | <0.001 |
| Unknown | | | | | | | 0.52 | 0.35–0.79 | 0.002 |

[a]Model I included age, sex, race/ethnicity, and rurality. Model II included age, sex, race/ethnicity, rurality, and SEER stage. Model III was not completed since all patients had Medicare insurance with supplemental insurance. Model IV included age, sex, race/ethnicity, rurality, SEER stage, and treatment course. Nineteen patients were excluded for missing survival time, sex, and/or rurality. County-level education status and median household income were added to each model, and the results remained consistent with those shown here.

Abbreviations: HR, hazard ratio; SEER, Surveillance, Epidemiology, and End Results; RUCC, Rural-Urban Continuum codes; VA, Veterans Administration.

versus nonresectable stage when studying the odds of receiving surgery versus definitive chemoradiation, though the sample sizes for some race/ethnicity subgroups were small (data not presented).

Within the subgroup of Medicare patients, non-Hispanic Black Medicare patients showed a lower OR of surgery versus definitive chemoradiation as first course of treatment (OR, 0.57; 95% CI, 0.34-0.93) (Figure E). Restricting this analysis to only Medicare patients with supplemental insurance mitigated this disparity, though the confidence interval was wide due to the lower sample size (OR, 0.89; 95% CI, 0.33-2.43) (Figure F).

### Survival Analysis

For patients who were deceased, non-Hispanic Black patients experienced a mean survival of 8.6 months (SD 9.6), and non-Hispanic White patients experienced a mean survival of 9.6 months (SD 12.6). We show the results of sequential adjusted Cox proportional hazards analysis in Table 2 (all patients), Table 3 (Medicare patients), and Table 4 (Medicare patients with supplemental insurance) for risk of death.

Non-Hispanic Black patients had a higher hazard ratio (HR) for risk of death compared to non-Hispanic White patients in the first 2 models (HR, 1.18; 95% CI, 1.06-1.31 in Model II, adjusting for age, sex, race/ethnicity, rurality, and SEER stage). Adding insurance in Model III mitigated some of the survival disparity (HR, 1.11; 95% CI, 0.99-1.23), and adding treatment course in Model IV eliminated the survival disparity between non-Hispanic Black and non-Hispanic White patients (HR, 0.98; 95% CI 0.88-1.09). Including county-level median household income and educational attainment explained some of the survival disparity between non-Hispanic Black and non-Hispanic White patients (HR, 1.10; 95% CI, 0.99-1.23) in Model II when adjusting for age, sex, race/ethnicity, SEER stage at diagnosis, and county-level educational attainment and median household income. Similarly, the survival disparity was minimized by incorporating treatment course (HR, 0.95; 95% CI, 0.85-1.06) when adjusting for age, sex, race/ethnicity, SEER stage at diagnosis, insurance, treatment course, and county-level educational attainment and median household income.

Similarly, for the Medicare patient subgroup, non-Hispanic Black patients had an HR of 1.12 (95% CI, 0.97-1.30) compared to non-Hispanic White patients in the basic model, which increased to 1.18 (95% CI, 1.02-1.37) when we added SEER stage

to the regression (Table 3). This difference in survival was again explained when we added treatment course in the final model (HR, 0.93; 95% CI, 0.80-1.08). County-level educational attainment and median household income had a similar impact on survival in the Medicare patient subgroup as in the full cohort, where it partially explained the survival disparity between non-Hispanic Black and non-Hispanic White patients in Model II (HR, 1.10; 95% CI, 0.94-1.29) and began to reveal a survival advantage for non-Hispanic Black patients when added to the final model (HR, 0.89; 95% CI, 0.76-1.04).

Conversely, we found no survival disparity between non-Hispanic Black and non-Hispanic White Medicare patients with supplemental insurance when restricting the analysis to patients with that insurance in any model (Table 4).

In the final model, which adjusted for age, sex, race/ethnicity, rurality, insurance, SEER stage, and treatment course, Medicare (HR, 1.07; 95% CI, 1.00-1.15), Medicaid (HR, 1.25; 95% CI, 1.11-1.41), and Self Pay/Not Insured/Unknown (HR, 1.16; 95% CI, 1.02-1.31) insurance patients all had higher HRs than patients with private insurance. Female patients had a lower HR (0.94; 95% CI, 0.90-0.99) compared to male patients.

## DISCUSSION

We aimed to identify whether race and ethnicity-based treatment and survival disparities existed amongst Wisconsin PDAC patients. We found that non-Hispanic Black patients were less likely to receive any treatment compared to non-Hispanic White patients. Among those patients who received any treatment, non-Hispanic Black patients were less likely to receive surgery compared to non-Hispanic White patients. This racial disparity persisted in Medicare patients. Additionally, non-Hispanic Black patients experienced higher HRs than non-Hispanic White patients in initial survival models. This survival disparity was primarily mitigated by treatment course, with insurance status and county-level median household income playing smaller roles. This suggests that increasing access to, presentation of, and acceptance of treatment may reduce Wisconsin's non-Hispanic Black PDAC survival disparity.

Non-Hispanic Black patients were the only race/ethnicity subgroup that experienced lower odds of receiving any versus no treatment and surgery versus definitive chemoradiation. Asian and patients of Other race/ethnicities and patients with Medicare, Medicaid, TRICARE/Military/VA, Insurance NOS, and Self Pay/Not Insured/Unknown insurance had a lower OR of any versus no treatment but had similar or higher ORs than non-Hispanic White and privately insured patients of receiving surgery versus definitive chemoradiation. This demonstrates that non-Hispanic Black patients were uniquely disadvantaged compared to patients of other races and ethnicities.

These results are consistent with several studies that found treatment disparities for non-Hispanic Black PDAC patients. Zhu et al[14] found that Black patients experienced lower odds of receiving any treatment compared to White patients. Heller et al[5] found that Black patients were less likely to receive chemotherapy for advanced disease than White patients. Several studies investigating disparities in surgical resection for pancreatic cancer found that Black patients were less likely to be offered[9,11] and undergo surgery.[5,6,8,10-12]

Other studies found that non-Hispanic Black patients presented at a later stage than non-Hispanic White patients.[14,15] In our cohort, however, 53.1% of non-Hispanic Black and non-Hispanic White patients presented with distant disease, and a slightly higher percentage of non-Hispanic Black patients presented with local disease than non-Hispanic White patients. Therefore, contrary to other studies, SEER stage at diagnosis does not explain the treatment disparity non-Hispanic Black patients faced in our study.

We noted an interaction between non-Hispanic Black race/ethnicity and insurance status that, when combined, reduced the OR for non-Hispanic Black patients to receive any versus no treatment. Other studies have not found this interaction. In their study of resectable pancreatic cancer patients, Abraham et al found no interaction between insurance and race.[8] Chang et al[16] and Lee et al[17] found that race did not impact pancreatic cancer treatment or survival in health systems where all patients had equal insurance coverage. Such studies suggest that increasing equity in health insurance may mitigate racial disparities.[16-17] Our data suggest, however, that simply providing the lowest level of insurance coverage will not result in equitable treatment for non-Hispanic Black patients. This is evident from our Medicare cohort results, where non-Hispanic Black Medicare patients were 60% less likely to receive any treatment than non-Hispanic White Medicare patients, and non-Hispanic Black Medicare supplement patients remained 60% less likely to receive any treatment than their non-Hispanic White counterparts.

We performed 4 sequential models of adjusted Cox proportional hazard regression to identify factors that mitigated the survival disparity we found for non-Hispanic Black patients. Non-Hispanic Black patients were at increased risk of death in the first 2 models. Individual-level insurance status and county-level median household income reduced the disparity. In the final model, treatment course explained the disparity for non-Hispanic Black patients, suggesting that appropriate recommendation and communication of treatment benefits to non-Hispanic Black patients—to the end goal of them accepting treatment recommendations—may improve survival and reduce the survival disparity relative to non-Hispanic White patients. Treatment course did not, however, eliminate the survival disparity for patients with Medicaid or no insurance.

A survival disadvantage for non-Hispanic Black patients prior to incorporating treatment has been noted in previous literature. Riall et a[4] found that Black patients had decreased survival relative to

White patients before accounting for resection and similar survival after accounting for resection. Heller et al[5] found a survival disadvantage for Black patients when accounting for demographic and socioeconomic factors and a survival advantage for Black patients when accounting for clinical factors. Alternatively, Nipp et al[18] and Singal et al[19] saw the survival disadvantage for Black patients persist after treatment was included in their analyses.

Our results showing that the survival disparity experienced by non-Hispanic Black patients was mitigated by treatment course suggests that adherence to treatment guidelines can mediate the relationship between non-Hispanic Black race and treatment and survival outcomes. Identifying a patient's prognosis and recommending treatment is based on clinical judgement, and Kirkegard et al[20] found substantial variation in clinicians' assessments of whether a specific patient was a surgical candidate in their European study. Among 19 patients, clinicians from 7 sites only agreed unanimously on 2 patients: 1 resectable and 1 nonresectable. Additionally, the clinicians agreed on whether a patient should undergo potentially curative versus palliative care in fewer than half of the 19 patients. In the United States, several studies have found regional variation, including underutilization, in treatment.[21,22] Finally, treatment at an academic medical center does not mitigate treatment and outcome disparities non-Hispanic Black patients face.[14,23]

Our study, based on registry data from the WCRS, included limitations in terms of the potential biological and social confounding factors available. The WCRS only includes first line of treatment and is not required to include second line treatments. We included age, sex, race/ethnicity, rurality, insurance, SEER stage, and treatment in our analyses, but registry data do not include individual-level socioeconomic status, marital status, educational attainment, income level, or data on comorbidities. Exclusion of comorbidities and individual-level social factors like those stated, as well as others like transportation services and other forms of social capital, may have influenced the racial disparities in treatment and survival. Furthermore, we did not add area-level social factors, such as county level health care access or neighborhood strength or cohesion.[24,25] Additionally, effort was taken to understand if same-type insurance correlated with similar treatment. However, having private insurance or Medicare does not entail the same coverage for all patients, especially across racial lines. As with all registry data, we were also unable to assess recommendations or intent for treatment, only the receipt or lack of receipt of treatment. Finally, even with little missing registry data and a well-powered sample with 8,490 patients, some subgroups had low counts, which resulted in us masking some results.

## CONCLUSION

We found that non-Hispanic Black pancreatic cancer patients face treatment and survival disparities in Wisconsin and that this disparity was primarily explained by treatment, with contributions from insurance status and county-level median household income. Future studies of racial disparities in pancreatic cancer need to focus on how care is presented and provided by clinicians and received by non-Hispanic Black patients at all types of treatment facilities. Studies that continue to focus on lifestyle and biological factors, concluding that these factors do not fully explain disparities experienced by non-Hispanic Black patients, miss a key piece of the pancreatic cancer diagnosis and care cycle. Once diagnosed, treatment offers the ability to extend life. In the absence of novel treatments to improve survival, employing culturally humble approaches, including the incorporation of religious beliefs when appropriate, the use of medical interpreters, ensuring input from patient's preferred support people (family, friends), provider-patient racial congruence whenever possible, use of lay and nurse navigators, community outreach, and engagement around cancer treatment has the potential to increase treatment rates among non-Hispanic Black pancreatic cancer patients with available treatments, improve their pancreatic cancer survival, and reduce disparities.

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# Documentation of Pain Care and Treatment for Limited English Proficiency Minority Patients With Moderate-to-Severe Pain in Primary Care

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## ABSTRACT

**Introduction:** There are 25 million individuals in the United States with limited English proficiency (LEP). Language barriers contribute to poorer patient assessment, misdiagnosed and/or delayed treatment, and inadequate understanding of the patient condition or prescribed treatment. LEP also has been shown to result in inadequate pain control, yet there are significant gaps in our knowledge related to pain documentation and pain management in primary care settings. The objective of this study is to describe and compare pain documentation for LEP racial/ethnic minority patients – Hmong-speaking Asian and Spanish-speaking Latinx – to English-speaking White patients with moderate to severe pain at an academic primary care clinic.

**Methods:** We conducted a retrospective mixed methods electronic health record study of patients age ≥18 with a pain score of ≥6; preferred language of Hmong, Spanish, or English; and evaluation in a primary care clinic. Abstracted data included characteristics of the provider, patient, interpreter, and pain care process. Descriptive statistics, analysis of variance, and chi-square tests were used. Clinician subjective assessment was analyzed using directed content analysis.

**Results:** Three hundred forty-two patient visits were included. Pain score distribution differed by patient language and race/ethnic group ($P < 0.001$), with an average pain score of 7.66 (SD 1.25). Interpreter type varied between the LEP groups ($P = 0.009$). Pain location was documented in a higher percentage of visits overall (87%) and more frequently for English-speaking White and Spanish-speaking Latinx patient visits than Hmong-speaking Asian visits ($P < 0.001$). Pain quality, onset, and duration were documented more frequently in LEP patient visits than English-speaking White patient visits (all $P < 0.001$). While overall opioid prescription rates were low, opioids were prescribed 3 times more frequently to English-speaking White patients than LEP patients ($P = 0.002$). Approximately 20% of patients were prescribed nonpharmacological treatment.

**Conclusion:** Pain care process and treatment documentation varied by patient language and race/ethnicity. Future studies could evaluate the impact of pain assessment and treatment documentation on pain outcomes for LEP patients.

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## INTRODUCTION

While pain is the most commonly reported symptom in primary care, undertreatment of pain continues to persist and may be due to inadequate documentation of pain assessment and treatment. Pain documentation includes electronically produced or written information about a patient's progress, condition, treatments, or care. The prevalence of patients with pain seen in the primary care setting ranges from 5% to 33%.[1,2] Yet, the current research on pain documentation has focused on the hospital[3,4] and long-term care settings.[5,6] Limited research has focused on clinician pain documentation in primary care settings. We found only 1 study focusing on clinician pain documentation in primary care.[7] Krebs and colleagues found that 83% of patient visits had a pain assessment documented, and patients with moderate to severe pain or new pain were significantly more likely to have a pain assessment documented than those with mild pain.[7] The reported racial distribution of patients (n = 237) in this study was as follows: 66.2% White, 29.1% Black, and 4.6% other. All interviews were conducted in English. Therefore, it is unclear whether a difference exists in pain assessment documentation for racial and ethnic minority populations, especially those who have limited English proficiency (LEP).[8,9]

There are 25 million individuals in the United States with LEP, defined as being unable to read, write, and speak English well.[10] The larger body of research on medical care in LEP populations has shown that language barriers contribute to poorer

patient assessment, misdiagnosed and/or delayed treatment, and inadequate understanding of the patient condition or prescribed treatment.[11-15] Likewise, having LEP has been shown to result in inadequate pain control.[16] More research is needed to better understand the effect of language barriers on pain documentation and treatment.

Individuals with LEP are more likely to be from a racial and ethnic minority background. There is extensive evidence that racial and ethnic minorities experience disparities in pain care, including the delivery of pain assessment and management; however, most of the research to date has focused on a specific type of pain[8,17-21] or disparities in analgesic medications.[22] Several studies reported that Black, Asian, and Hispanic patients are less likely than White patients to be prescribed opioids.[23-27] It remains unclear whether other types of pain treatments, including alternative (also called complementary or integrative) medicine, are offered to racial and ethnic minority patients in primary care settings.

Compounding the disparities in health for LEP patients is the varied access and quality of different types of medical interpreters, including both professional or ad hoc (eg, bilingual health care providers, family) interpreters.[28,29] Specific to pain and interpreters, Jimenez et al examined whether interpreter use was associated with the quality of acute pain treatment among Latina patients with LEP.[30] They found that Latina patients who always received interpreters were more likely to report higher levels of pain and timely pain treatment than patients who did not always receive interpreters.[30]

In summary, there are significant gaps in our knowledge related to pain documentation and pain management in primary care settings overall, as well as in racial and ethnic minority populations, including those with LEP. Therefore, the purpose of this electronic health record (EHR), mixed-methods study was to both quantitatively and qualitatively describe and compare pain care process documentation for LEP racial/ethnic minority patients – specifically, Hmong-speaking Asian and Spanish-speaking Latinx – to English-speaking White patients with moderate to severe pain at an academic primary care clinic.

## METHODS

This mixed-methods study is a secondary analysis of clinical and administrative data from a large, Midwestern US primary care clinic collected between November 2019 and September 2020. This study was approved by the University of Wisconsin – Madison's Health Review Board with a waiver of consent.

### Sample

Inclusion criteria for patient primary care clinic visit data were as follows: (a) patient age 18 years or older at time of visit, (b) visit pain score of 6 or greater, and (c) patient preferred language and reported race/ethnicity of Hmong-speaking Asian, Spanish-speaking Latinx, or English-speaking White. To construct the

overall study sample, we identified all Hmong-speaking Asian patient visits (106 visits for 34 patients) and Spanish-speaking Latinx patient visits (126 visits for 39 patients) meeting inclusion criteria. Because the number of English-speaking White patients (n = 10,339) was much greater than the LEP patient groups, we created a comparable English-speaking White patient sample. First, patients were matched by pain characteristics, age, and sex/gender. The matching reduced the number of English-speaking White patients to 3,120 patients. From this group, we generated a random subset of 110 English-speaking White visits (102 patients) that met inclusion criteria.

### Manual EHR Chart Record Abstraction

After Hmong-speaking Asian, Spanish-speaking Latinx, and English-speaking White patients/visits were identified, we conducted a manual EHR chart abstraction to assess pain documentation for each clinic visit. Manual chart abstraction was reviewed based on patients' medical record number and pain visit date. Two coders, a doctoral candidate (ZM) and an undergraduate nursing student (CL), abstracted data from the clinicians' notes and orders into a Microsoft Excel Professional Plus 2019 spreadsheet. A third coder (ML) randomly reviewed the abstracted data for accuracy. Abstracted data included characteristics of the (a) patient, (b) clinician, (c) interpreter, and (d) pain care process.

### Demographic Information

Patient characteristics included (1) sex/gender, (2) age, (3) race/ethnicity, and (4) language preference. Clinician characteristics included (1) type of provider (medical doctor [MD], doctor of osteopathic medicine [DO], nurse practitioner [NP], physician assistant/associate [PA], resident) and (2) sex/gender.

Information about whether an interpreter was present and the type of interpreter (in-person, telephone, family, provider) used for each visit was abstracted. We also abstracted information about whether a family member was present and their relationship to the patient.

Pain care process characteristics included (1) pain assessment, (2) medication(s), (3) treatment ordered, (4) treatment performed, (5) follow-up treatment, and (6) follow-up timeframe (see Table 1). All variables were coded as binary, that is "yes" or "no." In addition, primary diagnosis, medical comorbidity, and the primary reason for visits also were abstracted from the problem list (see Table 1).

### Statistical Analysis

We used IBM SPSS Statistics Version 25 to conduct the statistical analysis and calculated descriptive statistics (ie, counts, percentages) for each variable. We compared continuous patient characteristics by patient language and race/ethnicity group using analysis of variance. We used chi-square or Fisher exact tests, as appropriate, to compare categorical patient, provider, interpreter, and pain care process characteristics by patient language and race/ethnicity group.

**Table 1.** Electronic Health Record (EHR) Data Abstraction Definitions and Examples

| | Definition | Binary Coding Approach to EHR Documentation | Example of Coding Approach |
|---|---|---|---|
| Pain assessment | Were pain location, cause(s), onset, severity score, duration and/or quality documented? | If there was documentation of pain information, it was coded as 1 (yes); if not, it was coded as 0 (no) | Pain severity was documented as 8 out of 10 and was coded as a 1 (yes)<br>Pain severity was not documented and was coded as a 0 (no)<br>Documentation of "element of stiffness in the morning" was coded as a 1 (yes) for pain quality |
| Medications | Were pain medications prescribed? | If there was any medication listed for pain, it was coded as 1 (yes); if not, it was coded as 0 (no) | Documentation of Tylenol and ibuprofen in the medication list was coded as 1 (yes) |
| | Was opioid medication prescribed? | We used the *IT MATTTRs Colorado Opioid* document to classify which medications were considered opioids<br>If an opioid was prescribed, it was coded as 1 (yes); f not, it was coded as 0 (no) | Documentation of Tylenol and ibuprofen were coded as nonopioid, 0 (no)<br>Hydrocodone (Hysingla), morphine (Methadose), fentanyl (Onsolis), oxycodone (Oxaydo), or hydrocodone containing acetaminophen (Anexsia) were coded as opioid, 1 (yes) |
| Treatment orders | Was a treatment order placed (eg, steroid injection, OMT, etc)? | If any treatment order was placed, it was coded as 1 (yes); if not, it was coded as 0 (no) | A treatment order of "therapeutic prophylactic /dx injection subq/im" was coded as 1 (yes) |
| Treatment performed | Was there a pain treatment (eg, steroid injection, OMT, etc) performed during the clinical encounter? | If there was any pain treatment order with document-ation of treatment performed in the clinic, it was coded as 1 (yes); if not, it was coded as 0 (no) | Documentation of "osteopathic manipulative treat-ment of 5-6 body regions" was coded as 1 (yes)<br>Documentation of "triamcinolone acetonide 40 mg injection once in clinic" was coded as 1 (yes) |
| Follow-up treatment | Did the patient follow up with the pain treatment order? | If follow-up treatment was ordered and there was a scheduled and completed visit for that treatment order, it was coded as 1 (yes); if not, it was coded as 0 (no) | Documentation of "x-ray finger ≥2 views left" and date of x-ray was coded as 1 (yes) |
| Follow-up timeframe | Did the patient follow up within the recommended timeframe? | If a follow-up timeframe was indicated, it was coded as a 1 (yes); if not, it was coded as 0 (no) | Documentation of "follow up 1-2 months" was coded as 1 (yes)<br>Documentation of "1-2 months to follow-up on hand swelling and numbness" was coded as 1 (yes) |

## Qualitative Analysis

To provide additional richness to the descriptive quantitative data, we analyzed the subjective assessment of clinicians' documenta-tion using directed content analysis.[31] First, 2 coders (ML, CL) reviewed subjective assessment documentation for 10 patients together to immerse themselves with the EHR data. Then, they came up with codes that were reflected in the narrative. For exam-ple, if a note stated, "depression and anxiety—uncontrolled," we coded it as "mental health problem." Together, the 2 coders cre-ated the following codes: (a) perceived antecedents, (b) perceived causes of pain, (c) pain descriptors, (d) storytelling of pain, (e) per-ceived consequences of pain, (f) mental health problems, and (g) social issues. After the codes were developed, each coder individu-ally reviewed the subjective data in the EHR and entered the pain-related information that reflected each of the pain codes in the Excel spreadsheet. For example, if a note stated, "pain has burn-ing quality," we entered "pain is burning" for the pain descriptors column in the Excel spreadsheet. Both team members gathered weekly to consolidate their coding and entry of information. Any discrepancies in coding were resolved by discussion and referenc-ing the original subjective assessment data in the EHR. The sub-jective qualitative information abstracted from the EHR was used to provide context to quantitative results.

## RESULTS

A total of 342 patient visits were analyzed, including Hmong-speaking Asian (n = 106 visits for 34 patients), Spanish-speaking Latinx (n = 126 visits for 39 patients), and English-speaking White (n = 110 visits for 102 patients).

### Patient Characteristics

The mean age of patients was $52.35 \pm 13.53$ years, with Spanish-speaking Latinx having a younger mean visit age ($47.96 \pm 12.49$) than Hmong-speaking Asian ($55.04 \pm 13.53$) and English-speaking White ($54.79 \pm 12.60$; $P < 0.001$). The overall average pain score was $7.66 \pm 1.25$, with Hmong-speaking Asian ($8.18 \pm 0.99$) hav-ing higher mean visit pain scores than Spanish-speaking Latinx ($7.48 \pm 1.28$) and English-speaking White ($7.37 \pm 1.31$; $P < 0.001$). Approximately 70% of visits were for female patients; gender dis-tribution did not differ by group ($P = 0.952$).

### Clinician and Interpreter Characteristics

Clinician and interpreter characteristics by patient language and race/ethnicity group are reported in Table 2. Clinician type differed by patient language and race/ethnicity group ($P < 0.001$). While MDs and PAs were the first and second most frequently seen cli-nician types in all groups, English-speaking White patients had a visit with an MD (60%) more often than Spanish-speaking Latinx

**Table 2.** Provider and Interpreter Characteristics for Visits by Patient Language and Race/Ethnicity

| | English/White n (%) | Spanish/Latinx n (%) | Hmong/Asian n (%) | P value |
|---|---|---|---|---|
| Provider Type | | | | < 0.001 |
| MD | 66 (60.0) | 56 (44.4) | 35 (33.0) | |
| PA | 27 (24.5) | 41 (32.5) | 24 (22.6) | |
| DO | 9 (8.2) | 23 (18.3) | 21 (19.8) | |
| NP | 8 (7.3) | 6 (4.8) | 26 (24.5) | |
| Resident | | | | 0.223 |
| Yes | 27 (24.5) | 44 (34.9) | 32 (30.2) | |
| No | 83 (75.5) | 82 (65.1) | 74 (69.8) | |
| Clinician sex/gender | | | | 0.105 |
| Male | 30 (27.3) | 39 (31.0) | 20 (18.9) | |
| Female | 80 (72.7) | 87 (69.0) | 86 (81.1) | |
| Interpreter present | | | | 0.062* |
| Yes | - | 111 (88.1) | 101 (95.3) | |
| No | - | 15 (11.9) | 5 (4.7) | |
| Interpreter Type | | | | 0.009 |
| In-person | - | 44 (34.9) | 45 (42.5) | |
| Telephone/iPad | - | 42 (33.3) | 40 (37.7) | |
| Family | - | 6 (4.8) | 11 (10.4) | |
| Provider | - | 18 (14.3) | 7 (6.6) | |
| Declined | - | 16 (12.7) | 3 (2.8) | |
| Family present | | | | < 0.001 |
| Yes | 4 (3.6) | 12 (9.5) | 25 (23.8) | |
| No | 106 (96.4) | 114 (90.5) | 80 (76.2) | |

Abbreviations: MD, medical doctor; PA, physician assistant/associate; DO, doctor of osteopathic medicine; NP, nurse practitioner.
*P* values from chi-square tests, except where noted (*) as a Fisher exact test. Visit sample size varies by characteristic.

**Table 3.** Pain Characteristic Documentation for Visits by Patient Language and Race/Ethnicity

| | English/White n (%) | Spanish/Latinx n (%) | Hmong/Asian n (%) | P value |
|---|---|---|---|---|
| Pain location | | | | < 0.001 |
| Yes | 103 (93.6) | 116 (92.1) | 77 (72.6) | |
| No | 7 (6.4) | 10 (7.9) | 29 (27.4) | |
| Pain quality | | | | < 0.001 |
| Yes | 28 (25.5) | 63 (50.8) | 53 (50.0) | |
| No | 82 (74.5) | 61 (49.2) | 53 (50.0) | |
| Pain onset | | | | < 0.001 |
| Yes | 17 (15.5) | 48 (38.1) | 44 (41.5) | |
| No | 93 (84.5) | 78 (61.9) | 62 (58.5) | |
| Pain duration | | | | < 0.001 |
| Yes | 25 (22.7) | 66 (52.4) | 47 (44.3) | |
| No | 85 (77.3) | 60 (47.6) | 59 (55.7) | |
| Pain cause | | | | 0.003 |
| Yes | 34 (30.9) | 66 (52.4) | 42 (39.6) | |
| No | 76 (69.1) | 60 (47.6) | 64 (60.4) | |
| Cause of pain discussed | | | | 0.019 |
| Yes | 33 (30.0) | 59 (46.8) | 36 (34.0) | |
| No | 77 (70.0) | 67 (53.2) | 70 (66.0) | |

*P* values from chi-square tests. Visit sample size varies by characteristic.

(44%) and Hmong-speaking Asian (33%) patients. Spanish-speaking Latinx patients were more likely to see a PA than both other groups or a DO than English-speaking White patients, and Hmong-speaking Asian patients were more likely to see a DO than English-speaking White patients or an NP than both other groups.

Interpreter type varied between the LEP groups (*P* = 0.009). In-person interpreters were the most common for both groups. Hmong-speaking Asian patients more commonly had in-person and family interpreters, while for Spanish-speaking Latinx patients, the clinician served as the interpreter more frequently or patients declined an interpreter. In addition, a family member was present more frequently with Hmong-speaking Asian patients (*P* <0.001).

### Pain Care Process Characteristics

Qualitatively, across all 3 groups, back pain, chest/abdominal pain, and shoulder pain were the most commonly shared reasons for why Hmong-speaking Asian, Spanish-speaking Latinx, and English-speaking White patients sought care. The 3 top pain location complaints observed were lower back, shoulder, and knee for English-speaking White and Spanish-speaking Latinx visits. In contrast, neck, back, and lower back were common among Hmong-speaking Asian visits.

Documentation of every pain characteristic evaluated in the study differed by patient language and race/ethnicity (Table 3).

Pain location was documented in a higher percentage of visits overall (87%) than other pain characteristics, including quality (55%), onset (32%), and duration (39%). Pain location was documented more frequently for English-speaking White and Spanish-speaking Latinx patient visits than Hmong-speaking Asian visits (*P* < 0.001). In contrast, pain quality, onset, and duration were documented more frequently in LEP patient visits than English-speaking White patient visits (all *P* < 0.001).

From the qualitative analysis, the Hmong-speaking Asian patient visits most commonly reported numbness, tightness, tingling, and burning, whereas the Spanish-speaking Latinx patient visits most commonly reported swollen, pressure, sharp, and numbness. The English-speaking White patient visits most commonly reported swelling and numbness and used metaphors, such as "my head is going to blow off" due to headache pain, or "feels leg is 'giving out'" with hip pain.

Cause of pain documentation varied across each group: Spanish-speaking Latinx (52%), Hmong-speaking Asian (40%), and English-speaking White (31%; *P* = 0.003). Cause of pain was more frequently discussed during Spanish-speaking Latinx patient visits than English-speaking White or Hmong-speaking Asian patient visits (*P* = 0.019). The qualitative analysis revealed that the most common cause of pain across the 3 groups was related to falls. Hmong-speaking Asian patients frequently reported causes related to movement (eg, twisted ankle, turned neck), stress, and work, whereas Spanish-speaking Latinx patients reported work- or injury-related causes for their pain. In contrast, English-speaking White patients most commonly attributed weather or seasonal changes as the cause of their pain.

Results for treatment-related pain care process variables are

**Table 4.** Pain Treatment by Patient Language and Race/Ethnicity

| | English/White n (%) | Spanish/Latinx n (%) | Hmong/Asian n (%) | P value |
|---|---|---|---|---|
| Medication prescribed | | | | < 0.001 |
| Yes | 87 (79.1) | 79 (62.7) | 57 (53.8) | |
| No | 23 (20.9) | 47 (37.3) | 49 (46.2) | |
| Opioids | | | | 0.002 |
| Yes | 20 (18.2) | 7 (5.6) | 7 (6.6) | |
| No | 90 (81.8) | 119 (94.4) | 99 (93.4) | |
| Non-steroidal anti-inflammatory drugs | | | | 0.126 |
| Yes | 6 (5.5) | 15 (11.9) | 14 (13.2) | |
| No | 104 (94.5) | 111 (88.1) | 92 (86.8) | |
| Acetaminophen | | | | 0.652 |
| Yes | 6 (5.5) | 6 (4.8) | 8 (7.5) | |
| No | 104 (94.5) | 120 (95.2) | 98 (92.5) | |
| Steroids – oral | | | | 0.425 |
| Yes | 10 (9.1) | 11 (8.7) | 5 (4.7) | |
| No | 100 (90.9) | 115 (91.3) | 101 (95.3) | |
| Type of in-clinic treatments: steroids – injection | | | | 0.679 |
| Yes | 2 (1.8) | 4 (3.2) | 1 (0.9) | |
| No | 79 (71.8) | 92 (73.0) | 83 (78.3) | |
| N/A | 29 (26.4) | 30 (23.8) | 22 (20.8) | |
| Type of in-clinic treatments: OMT[a] | | | | 0.128 |
| Yes | 6 (5.5) | 4 (3.2) | 10 (9.4) | |
| No | 104 (94.5) | 122 (96.8) | 96 (90.6) | |
| Patient prescribed nonpharmacological treatment during visit | | | | 0.683 |
| Yes | 6 (5.5) | 7 (5.6) | 9 (8.5) | |
| No | 76 (69.1) | 87 (69.0) | 65 (61.3) | |
| N/A | 28 (25.5) | 32 (25.4) | 32 (30.2) | |
| In-clinic treatment performed (ie, OMT, steroid injections, acupuncture[b]) | | | | 0.005 |
| Yes | 17 (15.5) | 16 (12.7) | 18 (17.0) | |
| No | 90 (81.8) | 106 (84.1) | 74 (83.7) | |
| N/A | 3 (2.7) | 4 (3.2) | 14 (13.2) | |
| Patient followed up with prescribed treatment | | | | 0.121[a] |
| Yes | 69 (62.7) | 78 (61.9) | 66 (62.3) | |
| No | 14 (12.7) | 13 (10.3) | 15 (14.2) | |
| Refused | 0 (0.0) | 1 (0.8) | 0 (0.0) | |
| No Show | 0 (0.0) | 2 (1.6) | 2 (1.9) | |
| As needed | 0 (0.0) | 1 (0.8) | 0 (0.0) | |
| N/A | 27 (24.5) | 31 (24.6) | 23 (21.7) | |
| Prescribed physical or occupational therapy referral | | | | 0.360 |
| Yes | 12 (10.9) | 17 (13.5) | 8 (7.5) | |
| No | 98 (89.1) | 109 (86.5) | 98 (92.5) | |
| Provider prescribed timeframe for follow-up visit | | | | 0.122 |
| Yes | 72 (65.5) | 72 (57.1) | 74 (69.8) | |
| No | 38 (34.5) | 54 (42.9) | 32 (30.2) | |
| Patient completed follow-up visit within the prescribed timeframe | | | | 0.121 |
| Yes | 40 (36.4) | 40 (31.7) | 41 (38.7) | |
| No | 33 (30.0) | 28 (22.2) | 33 (31.1) | |
| N/A | 37 (33.6) | 58 (46.0) | 32 (30.2) | |

*Abbreviations:* OMT, osteopathic manipulation.
*P* values from chi-square tests.
[a]Treatment orders prescribed by providers.
[b]Acupuncture only performed during 3 visits.

reported in Table 4. There was a statistically significant difference in pain medication prescription by group (*P* < 0.001); specifically, pain medications were most frequently prescribed during English-speaking White patient visits (79%), followed by Spanish-speaking Latinx patient visits (63%), and Hmong-speaking Asian patient visits (54%). While overall rates of opioid prescription were low (~10% of visits), opioids were prescribed approximately

3 times more frequently during English-speaking White patient visits compared to the LEP patient visits (*P* = 0.002). Prescriptions of other pain medications (ie, non-steroidal anti-inflammatory drugs, acetaminophen, and steroids) did not differ by patient language and race/ethnicity. We evaluated clinician type as a potential confounding variable for an opioid prescription because it differed by language and race/ethnicity group. We found that there was a statistically significant difference for opioid prescriptions among clinician type (*P* = 0.019). PAs prescribed opioids at the highest rate (n=16/92 visits, 17.4%) followed by MDs (n = 14/157 visits, 8.9%), NPs (n = 3/40 visits, 7.5%), and DOs (n = 1/53 visits, 1.9%; *P* = 0.019).

Additionally, approximately 20% of patient visits included prescription of a nonpharmacological treatment during the clinic visit. There was a statistically significant difference for nonpharmacological treatment during the clinic visit by patient race/ethnicity (*P* = 0.005). Of these nonpharmacological treatments, osteopathic manipulation (OMT) was featured in 18% of patient visits. Although rates were not statistically different by patient language and race/ethnicity, the Hmong-speaking Asian patient visits received OMT more than the Spanish-speaking Latinx and English-speaking White patient visits. In contrast, the Spanish-speaking Latinx (13.5%) and English-speaking White (10.9%) patient visits received more referrals for physical and occupational therapy than Hmong-speaking Asian patient visits (7.5%).

From the qualitative analysis, we observed more Hmong-speaking Asian and English-speaking White patients requesting OMT during their in-clinic visit. In contrast, Spanish-speaking Latinx patients requested steroid treatment during their in-clinic visits. Compared to the Spanish-speaking Latinx and English-speaking White patient visits, the Hmong-speaking Asian patient visits most frequently reported using cultural or herbal medicine to treat their pain before seeking care.

Finally, follow-up – patient followed-up with prescribed treatment, provider prescribed timeframe for follow-up visit, and patient completed follow-up visit within the prescribed timeframe – did not differ by group. Of the patients who were prescribed a follow-up visit, 54.8% to 58.8%, depending on group, completed a visit within the prescribed timeframe.

## DISCUSSION

This study provides a context to better understand primary care clinician pain care process documentation for LEP patients who reported moderate to severe pain. We found that documentation of the pain care process—both assessment and management/treatment—varied by patient language and race/ethnicity. Most notably, while pain location was more frequently documented for English-speaking White patient visits, documentation of all other pain characteristics (ie, pain quality, onset, and duration) was more complete for LEP minority patient visits. This finding is contrary

to existing research that documentation of pain characteristics is less frequent for racial and ethnic minorities.[7,32]

The discrepancy in pain characteristic documentation between LEP and English-speaking language patients could be due to multiple factors. One factor could be related to the different type of pain episode the patient experienced, ie, acute, chronic, or acute on chronic (also known as a flareup). While diagnosis codes do not drive pain assessment and planning, they may affect clinician documentation and/or our abstraction of type of pain. Currently, in the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) system codes, there is a limited range of options for pain-related codes and no existing code for acute on chronic pain (eg, chronic knee pain flareups). Consequently, it was difficult to differentiate between acute, chronic, and flareup pain diagnoses for some visits, limiting our abstraction to acute versus chronic. Chronic condition "flareup" language does exist within the ICD-10 for other diagnoses, for example, acute on chronic anemia or acute on chronic congestive heart failure. In the setting of chronic pain, flareup is an important differentiation to document from acute as it may affect treatment and prognosis. Without such a diagnosis code option, pain diagnosis documentation is left to clinicians' discretion in the subjective notes, contributing to the existing pain care process documentation challenge. Future research could study ways to classify visits by acute, chronic, and acute on chronic pain in the EHR system.

The limitation of structured pain documentation related to flareups may explain why documentation is less complete for English-speaking patients, who we observed to have more chronic pain. Alternatively, there may be no new information to add. In contrast, the LEP patients were more likely to report acute pain that requires clinicians to document new pain characteristics. Another possible explanation could also be attributed to cultural differences or language discordance between LEP patients and clinicians in discussing pain. A qualitative study of primary care providers found that they have greater difficulty communicating with Hmong patients about pain compared to other LEP patient groups because Hmong patients used few or no qualifiers to describe their pain.[13] This phenomenon also may be reflected in the pain documentation observed in this study.

Consistent with the literature on pain disparities, pain treatment differed by patient language and race/ethnicity.[8,21] Hmong-speaking Asian patient visits had the lowest rates of medication prescriptions overall. Many Hmong patients are fearful of medications being destructive to the body and intolerable side effects; thus, they often do not accept or take medications as prescribed[41] and are more receptive to nonpharmacological treatments, such as OMT. Opioids, while infrequently prescribed overall, were more frequently prescribed for English-speaking White and Spanish-speaking Latinx patients. These findings are as expected. A possible reason for the low rate of opioid prescriptions could be due to clinicians' concerns about opioid misuse, abuse, and addiction.[34]

Documentation for visits where an opioid is prescribed, however, may be more complete due to additional education on pain assessment and treatment motivated by the opioid epidemic.

Treatment also may be related to the location of pain and underlying etiology. Steroids and opioids may be considered a more appropriate treatment for shoulder and knee pain, as seen in the English-speaking White and Spanish-speaking Latinx patients in this study. In contrast, back and neck pain were most commonly treated in Hmong-speaking Asian patients. OMT is commonly used to treat back and neck pain. While not statistically different, it was not surprising that OMT was prescribed more frequently for Hmong-speaking Asian patients compared to other patients. We also found that more Hmong-speaking Asian patients saw DOs, who are trained in OMT and could offer this treatment during their visits. This finding highlights the fact that clinicians at the study clinic are familiar with the Hmong-speaking Asian patients' culture and are sensitive to this population's preferences. Furthermore, referrals to physicial therapy and occupational therapy were seen across the patient language and race/ethnicity groups. This finding illuminates that fact that this clinic is prescribing nonpharmacological treatments to all patients and does not prescribe only medications.

We found that 54.8% to 58.8% of the 3 patient groups completed a follow-up visit within the prescribed timeframe. Our finding of adherence to follow-up visits is similar to existing research on follow-up clinic visits for diabetes (51%).[35] There are many possible explanations for low rates of follow-up visits, from successful pain management and pain resolution to poor access, financial challenges, physician mistrust, and culture.[17,36-41] Reasons for lack of follow-up should be further explored.

For clinician characteristics, we found that English-speaking White patient visits were more frequently with an MD compared to LEP minority patients. This finding is similar to a study by Dill et al, which found that compared to Asian, Black, and Latinx groups, White patients were less likely to report seeing a PA or NP for their most recent medical care.[42] Also consistent with existing research, family members were present more frequently for Hmong-speaking Asian patient visits than Spanish-speaking Latinx and English-speaking White patient visits.[43] One explanation is that Hmong-speaking patients often experience poor quality medical interpretation.[44,45] As a result, they prefer to use their adolescent or adult family members as interpreters.[44] More research is needed to study the effect of family versus professional interpreters on pain communication and documentation.

There are some limitations to this study. Because it used only 1 primary care clinic, focused only on Hmong and Spanish-speaking LEP populations, and was retrospective, the generalizability of the results should be made with caution. This study also was limited by what was documented in the EHR; it is possible that some pain assessment information may have occurred verbally. Because of the nature of EHRs, we do not have access to patients' socioeconomic

and health insurance status. Thus, we were unable to determine the relationship between insurance and prescribed medication. Additionally, we did not examine whether patients' medication was a refill or a new medication. Future research could examine the impact of type of medication and insurance on patient pain outcomes.

## CONCLUSION

To our knowledge, this is the first study to both quantitively and qualitatively describe pain care process and treatment documentation among patients of various language and race/ethnic groups: Hmong-speaking Asian, Spanish-speaking Latinx, and English-speaking White. We found that documentation varied by patient language and race/ethnicity. While pain location was more frequently documented for English-speaking White patient visits, documentation of all other pain characteristics (ie, pain quality, onset, and duration) was more complete for LEP minority patient visits. Likewise, pain treatment differed by language and race/ethnic group, with pain medications most frequently prescribed during English-speaking White patient visits. Nonpharmacological treatments were prescribed in approximately 20% of visits, with OMT performed most frequently during Hmong-speaking Asian visits. While these differences are at least partially related to pain acuity/chronicity and type, they also point to consideration for cultural preferences. Future studies should compare the data of this study clinic to other clinics and evaluate whether there is a difference in the effect of pain care process and treatment documentation on pain outcomes for LEP racial/ethnic minority patients.

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ORIGINAL RESEARCH

# Respiratory Function and Racial Health Disparities With Residential Proximity to Coal Power Plants in Wisconsin

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## ABSTRACT

**Background:** Burning fossil fuels, including coal, is the primary source of greenhouse gas emissions driving anthropogenic climate change and its associated health harms. Coal-fired power plants supply 23% of electricity nationally and 42% for Wisconsin, contributing to air pollution and associated respiratory diseases, cancers, and cardiovascular and neurologic disorders, especially for vulnerable populations. Authors seek to quantify residential distance from coal-fired power plants, pulmonary function of Wisconsin residents, and demographics.

**Methods:** Data from 2,327 adults aged 21-74 years were obtained from the Survey of the Health of Wisconsin database from 2008 through 2013. Pulmonary function was measured by expiratory volume in 1 second (FEV1) and forced vital capacity (FVC) as a ratio of FEV1/FVC. An average of at least 3 FEV1/FVC readings less than 80% was considered abnormal.

**Results:** Adults living near 1 of 11 coal-fired power plants may have worse pulmonary function. The odds ratio of FEV1/FVC values below 80% for those living within 35 km of a coal-fired power plant was 1.24 (95% CI, 0.90-1.70) when compared to those living greater than 35 km from a plant. While Black individuals made up 4.8% of the total sample population, they accounted for 13.3% of individuals living within 35 km of coal-fired power plants. Similarly, Hispanic populations accounted for 4.8% of those living within 35 km of a plant, while making up 2.8% of the sample population.

**Conclusions:** Significant disparities were found in residential proximity to Wisconsin coal-fired power plants for Black and Hispanic populations, with trends that support worse pulmonary function when living within 35 km of these plants. When linked with socioeconomic and racial/ethnic factors, closing down coal-fired power plants becomes a necessity to reduce disparities and address environmental injustices.

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## BACKGROUND

Rising levels of greenhouse gas emissions are responsible for anthropogenic climate change and adversely affecting human health.[1,2] The primary source of greenhouse gas emissions worldwide is burning fossil fuels—natural gas, petroleum fuels, and coal.[3,4] Worldwide, nearly 1 in 5 people die prematurely secondary to air pollution from fossil fuel combustion.[5] Coal use is a serious concern due to the large proportion of carbon dioxide emissions produced compared to other energy sources available. In 2019 in the United States, coal accounted for 23% of electricity generation and an astounding 60% of carbon dioxide ($CO_2$) emissions by the electric power sector.[6] Certain states choose to use more coal than other states. In 2019, Wisconsin received 42% of its energy from coal, almost double the national percentage.[7]

There are myriad health harms associated with coal mining and the industrial processes necessary to generate electricity from coal.[8-10] For decades, pulmonary diseases in underground workers ("black lung disease") were reported, which drove policy initiatives to offer some protection to miners and workers at coal-fired power plants (CFPP)[11]—the location where coal is burned and electricity generated. Air pollution from CFPP is the dominant health harm; robust scientific evidence documents clear adverse effects from particulate matter and toxic metals associated with respiratory disease, cardiac disease, cancer, neurologic development in children, low birth weight and preterm births, and mortality.[8,10,12] In 2013 in Europe, emissions from

coal caused 22,900 premature deaths—a number similar to road traffic deaths that year.[13]

The treatment of these health conditions result in increased emergency department visits[14] and hospitalizations.[15] Lost work days[16] and costly medication requirements—such as inhalers—associated with these conditions contribute to unnecessary health care costs and economic impact for patients affected.[8] Modeling of closure of CFPP in Texas demonstrated greater economic health costs than the value of electricity generation.[17] Moreover, the health effects were reversible in Pennsylvania when air quality improved following closures of 3 plants.[18] Models for the US suggest early retirement of CFPP could save thousands of lives from reduced particulates alone.[19]

While all people are at risk of health harms from CFPP, specific groups are at increased risk of poor health. Exposure to air pollution from electricity generation was greatest for Black and lower-income individuals, with racial and ethnic disparities dominating.[20] Historically, these facilities were built adjacent to communities of color.[21,22] To our knowledge, no studies have been conducted in Wisconsin to specifically examine the health impacts of CFPP on surrounding communities and the individual demographics of those exposed. As such, the authors seek to quantify the relationship between residential distance from CFPP and pulmonary function of Wisconsin residents, as well as reported race and ethnicity of these residents. We also examine policy changes that could have significant impacts in addressing racial disparities and health equity within Wisconsin.

## METHODS

### Survey of the Health of Wisconsin
Data was obtained from the Survey of the Health of Wisconsin (SHOW) database, which was collected from 2008 through 2013. The SHOW survey is modeled after the National Health and Nutrition Examination Survey (NHANES) and is directed at including information from a representative sample of Wisconsin residents. The SHOW database gathers information from surveys, physical exams, and biospecimens.

### Study Participants
Participants were noninstitutionalized and nonactive duty, adult civilians (21-74 years old) from randomly selected households. Individuals were included in the study if they had valid spirometry data, as well as valid responses to control variable/demographic data. Random selection included a 2-stage probability-based cluster sampling approach, stratified by region and poverty level. Since the start of the program in 2008, sample sizes increased from 400 to more than 1,000 participants per year.

### Control Variables
Individual socioeconomic status was controlled for by including measures of education level (less than high school, high school

degree/GED [general education development], some post-secondary/college/associate's degree, bachelor's degree, above bachelor's or professional degree), sex (female, male), race/ethnicity (non-Hispanic White, non-Hispanic Black/African American, Hispanic, other), age (21–34, 35–44, 45–54, 55–64, 65–74), insurance (uninsured, private, government, other independent insurance, multiple insurance types), occupation (working at a job or business, with a job or business but not at work—vacation or sick leave, not working but looking for work, not working at a job or business and not looking for work), asthma (currently have asthma), and total years smoking tobacco (<5 including never smoked, 5 to <10, 10 to <25, 25+) via multiple linear regression analyses.

### Pulmonary Function
Pulmonary function was measured in all participants using forced expiratory volume in 1 second (FEV1) and forced vital capacity (FVC) as a ratio of FEV1/FVC. Measurements were taken up to 8 times, and an observation was considered valid only if 2 readings were within 10% of the maximum reading. An average of at least 3 FEV1/FVC readings was taken for each participant, and an average value less than 80% was considered abnormal. Despite an FEV1/FVC ratio of less than 70% widely considered to be diagnostic of chronic obstructive pulmonary disease,[23,24] we chose the cutoff of less than 80% to be an abnormal FEV1/FVC ratio, similar to others.[25]

### CFPP Distances
Location of CFPPs in Wisconsin that were operational for the entire duration of the study period were mapped; network distances were calculated using the point location of CFPP and the block group centroid corresponding to an individual's residential address. All participant records were geocoded to address and census block group level to allow for analysis of SHOW data. As in similar studies, we chose a distance that demonstrated the greatest discrimination in unadjusted analyses, which was found at 35 km.[26]

### Statistical Analysis
Statistical analyses were completed using Stata 16.0. Survey regression models were used to assess associations between pulmonary function and distance to CFPPs alongside control variables to further assess protective and risk factors that may be contributing to abnormal pulmonary pathology. The geodetic distances (ie, measurements along the earth's surface) between CFPP locations and participant residence were calculated using ArcGIS software.[26] Project approval was granted through the Medical College of Wisconsin Institutional Review Board.

## RESULTS
Eleven coal-fired power plants were operating in Wisconsin from 2008 through 2013 as shown in the Table and mapped on Figure 1. The majority of CFPPs were in the central and southern parts

**Table.** Operational Power Plants in Wisconsin, 2008-2013

| Coal-Fired Power Plant | Address | Geocoded Address | Closure Data |
|---|---|---|---|
| Columbia Energy Center (Alliant Energy Power Plant) | W8375 Murray Rd, Pardeeville, WI 53954 | 43.486111, -89.420278 | To close by 2025 |
| Edgewater Generating Station (Sheboygan Power Plant) | 3739 Lakeshore Dr Sheboygan, WI | 43.715556, -87.706389 | To close by 2022 |
| Elm Road Generating Station | 11060 S Chicago Rd, Oak Creek, WI 53154 | 42.850058, -87.833035 | None |
| Genoa Generating Station | S4651 WI-35, Genoa, WI 54632 | 43.559167, -91.231944 | Closed in 2021 |
| John P. Madgett Generating Station | 833Q+72 Alma, WI 54610 | 44.303056, -91.9125 | None |
| Pleasant Prairie Power Plant | 8000 95th St, Pleasant Prairie, WI 53158 | 42.538056, -87.904722 | Closed in 2018 |
| J. P. Pulliam Generating Station | 1530 Bylsby Ave, Green Bay, WI 54303 | 44.54, -88.008611 | Closed in 2018 |
| Oak Creek Power Plant | 11060 S Chicago Rd, Oak Creek, WI 53154 | 42.844444, -87.828611 | To close by 2024 |
| Weston Generating Station | 2499 Old Hwy 51, Kronenwetter, WI 54455 | 44.858611, -89.649722 | None |
| E. J. Stoneman Generating Station | 716 Jack Oak Rd, Cassville, WI 53806 | 42.708333, -90.984722 | Closed in 2015 |
| Nelson Dewey Generating Station | 11999 Co Hwy VV, Cassville, WI 53806 | 42.7225, -91.008611 | Closed in 2015 |

**Figure 1.** Location of 11 Coal-Fired Power Plants in Wisconsin



Red dots represent operational plants; green dots represent plants that have closed since 2013; blue dots represent plants with plans to close by 2025.
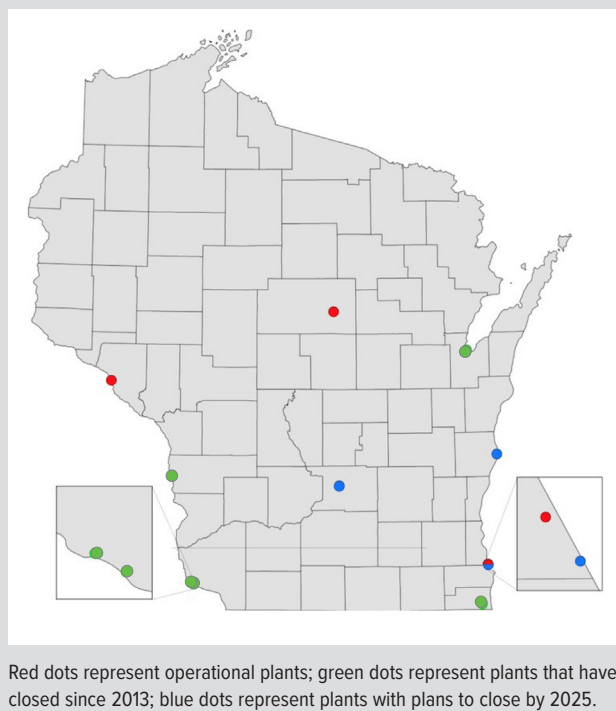
of the state. The highest concentration of plants, including those that have closed since 2013, were in the southeastern corner situated along Lake Michigan and the city of Milwaukee—the largest city in the state by population.

A total of 2,327 adults (21-74 years old) were included in the present study. Of participants, 44.6% were male. Spirometry values as measured by FEV1/FVC were lower for those living within 35 km from one of the 11 CFPPs (OR 1.24; 95% CI, 0.90-1.70) compared to those living further than 35 km from a CFPP. Figure 2 further details this relationship in comparison to the respiratory health of individuals with differing levels of smoking history using an odds ratio in relation to closer distance to a CFPP. Results support that exposure to CFPP trended towards similar effects seen in smoking tobacco for several years.

Figure 3 shows reported race/ethnicity of survey respondents and proximity to a CFPP. While Black individuals made up 4.8% (n = 112) of the total sample population, they accounted for 13.3% (n = 91) of the individuals living within 35 km of a CFPP. Similarly, those who identified as Hispanic accounted for 4.8% (n = 33) of those living within 35 km of a CFPP, while only making up 2.8% (n = 66) of the sample population. Non-Hispanic White individuals composed the greatest proportion of respondents at 88%.

## DISCUSSION

This is the first study in Wisconsin to assess pulmonary function and disparities in relation to residential distance from coal-fired power plants. Results suggest worse pulmonary function as measured by spirometry values in those residing closer to CFPPs, with statistically significant higher percentages of Black and Hispanic survey respondents living near CFPPs.

Our findings suggest a nonsignificant trend towards greater likelihood of worse pulmonary function (FEV1/FVC≤0.8) in adult respondents living within 35 km of a CFPP, compared to those residing farther away. As seen in Figure 2, this association with decreased FEV1/FVC ratio may be similar to trends seen in smokers, a demographic that is strongly associated with increased risk of obstructive pulmonary disease.[27] Although the confidence interval in our study crossed 1, these results were likely influenced by the small sample size of available survey data, as well as this being a statewide rather than national study. A larger sample size may support a significant association. A previous study found a stronger association and demonstrated significantly worse spirometry measurements for villagers living within 5 km of CFPPs compared to those living farther than 30 km away.[28] The close proximity may have strengthened their findings.

Based on the study, we recommend policies to limit exposure to residents living near CFPPs until complete plant closures occur, since closures are frequently announced years in advance. A report demonstrated that more than 1.2 million people live within 20 km of CFPPs in Wisconsin.[29] Ensuring these individuals are protected

from undue health harms represents a significant opportunity to reduce health burdens right now. Specific measures could address vulnerable populations and work to increase adaptive capacity with a focus on health. Cooperation with housing authorities, policymakers, health professionals, local and state public health officials, and urban planners is needed to reduce these effects—especially when combined with frequently compounded climate-related health threats of extreme heat exposure and allergens.

We found that areas nearest CFPPs had a higher percentage of survey respondents who identified as Black or Hispanic compared with White. Tessum and colleagues found Black individuals are exposed 18% more to particulate matter from coal electric generation, while Hispanic individuals were exposed less at -38%.[30] Another study demonstrated racial disparities for people living near polluting industrial facilities, particularly in the Midwest.[31] Our results showed statistically significant discrepancies in race/ethnicity for those living near CFPPs, although lower than some US communities have reported.[22] In the United States, nearly 6 million people live within 5 km of CFPPs and 39% are people of color.[22] This study adds yet another example of pervasive racial and ethnic disparities in the United States—such as that of redlining leading to outcomes of reduced access to greenspace[32] or increased exposure to extreme heat.[33] Since the time of the study, 5 CFPPs have closed and 3 more plan to close in coming years. The most recent projected closure of the Columbia Power Plant by 2025 was announced in February 2021. The initiatives align with Wisconsin's goal to be carbon neutral by 2050.

While closing the 3 remaining Wisconsin CFPPs may seem to be a large transition, Alberta—a Canadian province similar to Wisconsin in both population and gross domestic product—committed to phaseout of coal power and thermal coal mines by 2030.[34] The province, which has the third largest oil reserve in the world behind Saudi Arabia and Venezuela, is also aiming to have 30% of its power sourced from renewables by 2030. This transition was driven primarily by the low global coal prices and logistical difficulties of transporting coal outside of the province, climate change impacts including melting glaciers within the province, and health care impacts from air pollution estimated at $3 billion in negative health outcomes.[34]

Similarly, there are significant economic and health gains for Wisconsin in transitioning to clean energy.[35] In-state production of 100% clean energy would reduce air pollution and thereby save $1 billion every year in avoided health damages; it would create 152,000 net new jobs and grow Wisconsin's gross domestic product by 5%.[35] Such actions support a Wisconsin Medical Society resolution to support policies that limit warming to 1.5 ˚C and reduce emissions.[36] Nationally, 2 of 6 key recommendations from the Lancet US Policy Brief are to remove US fossil fuel subsidies and shift to zero-carbon electricity by 2035.[37] Shutting down CFPPs in a just and equitable manner is a key component to reach these goals. It also challenges industries, such as health care systems, academia, and organizations, to assess their own electricity sources and funding ties with fossil fuel companies. These are practicable actions that actively work to reduce inequities and injustices across our urban and rural communities.

International leaders and policymakers have an opportunity to transform the landscape of global CFPPs and energy for health. Greenhouse gas emissions continue to drive anthropogenic climate change and resulting rising average global temperatures and supercharged extreme weather events that leave lasting impact.[2] While the main producers of these emissions tend to be the larger and richer economies, it is the poorest populations that frequently suffer the most.[38] Shutting down CFPPs and investing in clean energy becomes not only a moral request but a necessity for health as we build back across sectors following



**Figure 2.** Respiratory Function of Residential Proximity of Coal-Fired Power Plant Compared with Impact of Years of Tobacco Use
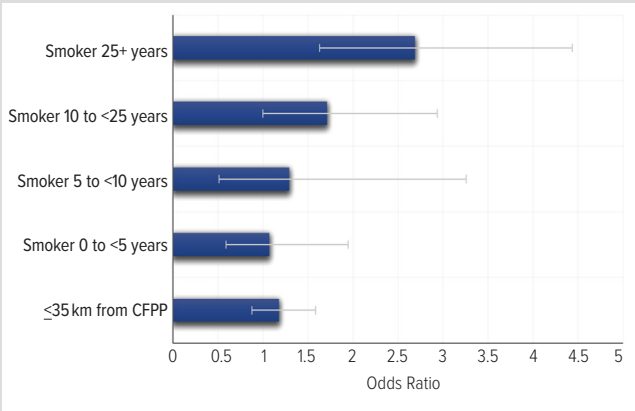
Odds ratio (with 95% CI) of demographic factors and distance from coal-fired power plant (CFPP) and tobacco use as a smoker in years showed in relation to respiratory function as measured by FEV1/FVC ratio.
Abbreviations: CFPP, coal-fired power plant; FEV1, forced expiratory volume in 1 second; FVC, forced vital capacity.



**Figure 3.** Reported Race/Ethnicity and Proximity to Coal-Fired Power Plant
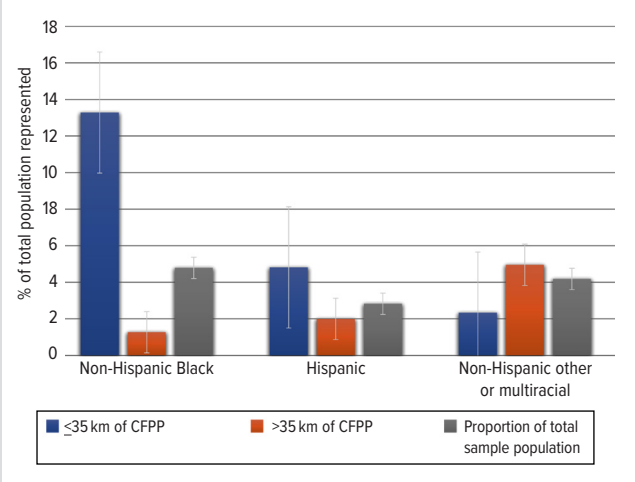
Abbreviation: CFPP, coal-fired power plant.

a global pandemic. As further incentive, there has been a 5-factor reduction in renewable costs since 2010,[38] and the cost of producing new energy via renewables, such as wind or solar, is now cheaper than coal in many countries, including the United States.[39] Further research investments may help guide specific actions and return on investments that reduce fossil fuel pollution and improve health.

### Strengths and Limitations

The study has several strengths. With a small sample size, an effect was found; and even with breaking down the sample more by race and ethnicity, an effect was still evident. Survey respondents were chosen randomly, which reduces bias. We also chose 6 years of data to attempt to minimize variation in sample and population and controlled for multiple variables.

A few limitations remain. While the FEV1/FVC measurement is a valuable tool, it does not provide the complete clinical picture of the respiratory harms of CFPP and does not address the frequently coexisting complexities of duration or intensity of exposure. The sample was also 2,327 individuals randomly sampled in the state and only complete survey data were included, which may be a potential source of bias. The sample did not include children. We believe this may underestimate the true effect due to increased duration of exposure and risk of children. Finally, distance was not stratified. As such, further research could expand upon specific areas of greatest distance linked to maximum health harms and benefits.

### CONCLUSIONS

This paper demonstrates significant racial and ethnic disparities in those living near CFPPs and trends in reduced pulmonary function for those living closer to the plants. As we work to rapidly reduce racial disparities in the United States, our work suggests yet another avenue to address environmental exposures and pollution from fossil fuels. Policies should be created to improve air quality and health of Wisconsin residents, especially those at greatest risk of poor health. The structures that communities and community leaders have created can strengthen people through new policies that prioritize health and justice for all.

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ORIGINAL RESEARCH

# Impact Evaluation of Patient-Centered, Community-Engaged Health Modules for Homeless Pregnant Women

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## ABSTRACT

**Purpose:** Pregnant women who experience homelessness are at a greater risk for poor birth outcomes than the general population. This pilot study describes results of a service-learning program informed by previously identified unmet perinatal health needs. In this patient-centered service-learning program, medical students partnered with homeless women currently residing in a shelter in Milwaukee, Wisconsin.

**Methods:** Medical students in the Health Advocacy in Pregnancy and Infancy (HAPI) project at the Medical College of Wisconsin developed and taught 6 service-learning modules to shelter residents: healthy cooking, mental health, perinatal nutrition, infant care/safety, breastfeeding, and contraception. Implemented between 2018 and 2021, modules were hosted in person and via electronic videoconferences. We gathered qualitative data on participants' perceived impact of the modules and used grounded theory analysis to examine written comments and verbal feedback.

**Results:** A total of 141 participants attended 42 learning sessions. Participants included pregnant and postpartum mothers and women interested in learning about pregnancy-related health. Qualitative analysis revealed 3 universal themes regarding the impact of the sessions on participants: "Knowledge," "Intention to Change," and "Empowerment."

**Conclusions:** Our community-engaged health education partnership program between homeless pregnant women and medical students focused on perinatal health. This well-received, effective strategy cultivated new knowledge, empowering participants to not only change their own behaviors, but to teach and support others. This study demonstrates the ability of using community-based teaching sessions to enhance participants' understanding of pregnancy and postpartum health and empower others to implement changes.

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## INTRODUCTION

The infant mortality rate (IMR) is defined as the number of infant deaths during the first year of life per 1,000 births in 1 year. This metric is often used as a benchmark to assess not only maternal and child health, but the overall health of a society. Although infant mortality may seem like a problem mainly affecting developing countries, the IMR in the United States is among the highest in the world.[1,2] According to the Centers for Disease Control and Prevention, the United States IMR is 5.7,[3] but it is especially high in certain areas of the country, including Milwaukee, Wisconsin. In 2020, Milwaukee's overall IMR was 11.6, while the 3-year rolling average IMR for 2012-2015 in Milwaukee was 9.8.[4,5]

Homeless women and their babies are particularly vulnerable. There are no published data on the IMR of homeless women in Milwaukee. The most recent data on the IMR in homeless women are from a 1990s New York study, which showed that homeless mothers experienced an IMR of 24.9.[6] Furthermore, homeless women were found to have inadequate prenatal care more often, and infants of mothers who had no prenatal care had an IMR nearly 8 times greater than those who had prenatal care.[7] More recent data have shown that infants of homeless mothers face higher rates of complications, including premature delivery and increased odds of neonatal intensive care unit admissions for infants born at term.[8]

The leading causes of infant mortality in Wisconsin are congenital anomalies, premature birth, and maternal complications of

pregnancy.[5] Premature birth is of greater concern in Black women, as this contributes to approximately two-thirds of all infant deaths, compared to about one-third of the infant deaths in the White population.[4] Additionally, the preterm birth rate in Wisconsin is 63% higher for Black women when compared to other women.[9] The substantial morbidity associated with premature birth, including motor delay, intellectual disability, behavioral problems, and respiratory illnesses, additionally contributes to health disparities in the non-Hispanic Black population.[10]

While Milwaukee's IMR of 11.6 is already high compared to state and national levels, the disparity is even more pronounced when separated by race and ethnicity.[5] The IMR is 15.8 for the non-Hispanic Black population, compared to 5.1 for the non-Hispanic White population.[5] This means that in Milwaukee, Black infants are 3 times more likely to die within the first year of life than White infants. In 2016, 53.3% of homeless individuals were White, while 35.9% were Black.[11] Although the IMR has declined for all subgroups over the past several years, the decline has not been as pronounced for the Black population, leading to an ever-widening gap in racial health disparity in Milwaukee.[4] The disparity is evident across all metrics. For example, even when controlled for maternal education, the IMR is still higher in the Black population than the White population.[4] In fact, Black mothers with a college degree have a higher IMR than White mothers with less than a high school education.[4]

### Project Aim

In an earlier study, the Health Advocacy in Pregnancy and Infancy (HAPI) group sought to identify unmet needs and challenges in the pregnancy experience of homeless women in Milwaukee.[12] This prior needs assessment led the HAPI group to develop 6 student-led service-learning modules seeking to address identified needs and deliver these modules at the Milwaukee Women's Center—a local homeless and emergency shelter for women and children—for the past 2 years. By improving access to relevant education regarding pregnancy and childcare, HAPI seeks to decrease infant mortality in this high-risk population. The current study aims to qualitatively identify the impact of these modules on the Milwaukee Women's Center community of women.

### METHODS

This study was approved by the Medical College of Wisconsin Institutional Review Board (PRO00029920).

### Program Description

The Health Advocacy in Pregnancy and Infancy (HAPI) program was conceived as a service-learning outreach program to benefit homeless pregnant women and their babies, while meeting the educational needs of medical students participating in the Urban and Community Health Pathway curriculum.[13] Under faculty supervision and based on a needs assessment published in 2018,[12]

the HAPI team used reputable sources to develop the following modules to meet some of the identified needs: healthy cooking, mental health, healthy nutrition for mom and baby, infant care and safety, breastfeeding, and contraception. First-, second-, and third-year medical students were trained to lead selected sessions at the Milwaukee Women's Center. This site was chosen because of the longstanding relationship with the shelter, which had participated in the needs assessment.[12] Training consisted of an introductory module to the HAPI program, reviewing PowerPoint presentations specific to each teaching module, and shadowing experienced medical students for 2 to 3 sessions before leading a session independently.

Medical students led 60-minute sessions of their respective topics, with time for participants to complete comment cards and debriefing forms. Modules were staggered and held every 4 to 6 weeks, with 1 or 2 medical students leading each module. Sessions held between January 2018 and March 2020 were held in person at the Women's Center. The COVID-19 pandemic necessitated pausing these sessions, which resumed via Zoom from September 2020 to present. During in-person sessions, medical students shared PowerPoint presentations on their personal laptops. The Zoom sessions were set up by the shelter staff, with a tablet and speaker in a communal room for shelter residents to participate. No personal smartphones were used.

### Participant Recruitment

Regardless of pregnancy status or ethnicity, all adult women living at the women's homeless shelter were invited to participate. Participants were informed that any forms completed would remain anonymous and the data were being used to assess the impact of the teaching sessions; participants provided verbal consent. Session dates and times were posted in the common living areas, and overhead announcements were provided at the time of the sessions. When the sessions transitioned to a virtual format, in addition to the fliers posted in the common living areas, the shelter staff personally recruited participants. To encourage attendance, all in-person modules were held after the shelter's curfew, and the medical students provided healthy snacks. Virtual sessions were held in early afternoon. Participants continued to receive health- and maternal-related incentives, which were delivered ahead of time. Participants were not tracked longitudinally, as participation was anonymous and women were usually limited to 4-week stays at the shelter; some did not have access to phones or internet outside of the shelter. However, the consistent times of the sessions allowed women to participate weekly if they chose.

### Modules

Descriptions of modules, including content, format, and incentives, are listed in Table 1.

### Data Collection

Medical students distributed blank comment cards to all partici-

**Table 1.** Description of Modules' Content, Format, and Incentives

| Module | Content | Format | Incentive, Handouts and Materials |
|---|---|---|---|
| Breastfeeding | Participants' experiences with breastfeeding, benefits and challenges of nursing, and ways to overcome them | Discussion-based, complemented by PowerPoint presentation and a video of proper breastfeeding technique | All participants received a nursing cover and 1-page handout |
| Infant Care Safety | Multiple subtopics, including bathing and hot water, feeding (what should your baby eat?), do-it-yourself baby wipes, baby crying, infant development, baby rashes, sick baby, and what to expect at well-child visits. Infant safety included safe sleep, baby-proofing, choking, vaccines, and first aid | Presenters chose 3 subtopics but covered all topics on a rotating basis. Sessions were discussion-based, spending about 15 minutes/topic, and each subtopic was accompanied by PowerPoint visuals | All participants received a first-aid kit and 1-page handout |
| Mental Health | Postpartum depression and stress management | Discussion-based with PowerPoint presentation. First half of session reviewed postpartum depression and finding resources and support. Second half focused on individual signs of stress and stress management techniques | Participants received a 1-page handout and were led through a stress management activity of creating their own "stress sock," incorporating aromatherapy for use as a heating pad |
| Healthy Cooking | Healthy, affordable recipes for children and adults | Two medical students led 2-hour cooking sessions that involved making simple, affordable meals. Participants assembled ingredients, and while meal was cooking, students led discussion on how to incorporate healthy foods into everyday life | All participants received a steam basket and 1-page handout |
| Healthy Eating for Mom and Baby | Healthy, affordable baby food choices and healthy nutrition during pregnancy | Discussion-based with PowerPoint presentation. Medical students and participants discussed prior knowledge and concepts of healthy nutrition, and how to prepare healthy, cheap baby food from scratch. | All participants received a cook-book (Good and Cheap; eat well on $4/day), a vegetable peeler, and a 1-page handout |
| Contraception | Various contraception methods, including ease/frequency of use and effectiveness | Discussion-based with a PowerPoint presentation. Participants encouraged to ask questions and share experiences with different forms of birth control; also given opportunity to explore model IUDs, hormonal arm implant models, and condoms | All participants received condoms as an incentive to practice safe sex, a 1-page handout, and a Planned Parenthood brochure |

pants at the end of each in-person session. Participants were invited to share their impressions about the session; comment cards were left face down without identifiers. Due to varying literacy levels, the medical students also completed a voluntary verbal group debriefing at every session, asking all participants what they liked, disliked, how the sessions could be improved and, most importantly, what participants would do differently after attending a session. The medical students recorded the results of the debriefing conversations on a debriefing form document (Appendix). The debriefing forms and comment cards served as the source documents for this study.

### Qualitative Data Analysis

We used descriptive content analysis and applied open coding strategies to analyze the comment cards and debriefing forms. Content analysis is a qualitative method used to identify the presence of themes within a data set. Our open-coding approach provided a systematic framework for our team to define concepts within our data and to lay the foundation to imply possible relationships to other codes. Four independent coders divided analysis among the 6 topics to generate a preliminary code list, which was determined to be knowledge, intention to change, and empower-

ment.[14,15] To achieve high interrater reliability, 3 additional coders reviewed the list and made suggested edits. The full research team then met to agree on the final code list and address any discrepancies, which was then reapplied to comment cards and debriefing forms. We also reviewed secondary findings by using the comment cards to assess participants' satisfaction with the program, including content and structure.

### RESULTS

While the HAPI program is ongoing, this study encompasses 42 sessions attended by 141 participants. Participants included adult pregnant and postpartum mothers and all adult women interested in learning about pregnancy- and infant-related health. We identified 3 central and cross-cutting themes across all modulus: "Knowledge," "Intention to Change," and "Empowerment." "Knowledge" represents increased knowledge, understanding, or new skills gained by participants during a session. "Intention to Change" reflects behavioral changes the women were interested in implementing directly. "Empowerment" includes any indication by the participants that they were considering larger life changes, planning to advocate for others in the future, and/or transferring newly acquired knowledge to those around them.

**Table 2.** Description of Modules' Attendance and Representative Direct Comments for 3 Themes

| Module | No. of Sessions | No. of Participants | Knowledge | Intention to Change | Empowerment |
|---|---|---|---|---|---|
| Breastfeeding | 7 | 30 | "Taught [me] what is not taught well in the hospital"<br>"Taught [me] information about how to breastfeed"<br>"Now I know about breastfeeding and how to place my breast in my child's mouth" | "Try to breastfeed in the future"<br>"Feeling more confident about breastfeeding, especially in public"<br>"Try to breastfeed for longer over time" | "Empowers women to breastfeed"<br>"Educate other mothers about breastfeeding"<br>"Tell friends about hard palate for latching"<br>"Tell people it's healthier and cheaper" |
| Infant Care and Safety | 8 | 20 | "Tips on scenarios [were] easy to relate to real life."<br>"Understandable and easy to remember" | "Read labels"<br>"Take toys out of [the] crib"<br>"Will babyproof more"<br>"No smoking in house" | "Knew a lot of it already, but will be more confident that [I am] doing it right."<br>"Feel I am able to ask questions [about infant safety]" |
| Mental Health | 11 | 25 | "Helpful tips"<br>"Felt informed about symptoms"<br>"Good to have [a conversation] about mental health signs and symptoms." | "Be aware next pregnancy"<br>"Voice stress"<br>"Change how I parent"<br>"Deep breathing to try and relax"<br>"[Use] stress socks to manage stress" | "Offer to help women that might be having postpartum depression"<br>"Contacting a doctor for help with depression"<br>"Enjoyed talking to one another about what relaxes me and relating to others about struggles/ stress." |
| Cooking | 2 | 8 | "Educational"<br>"Taught me something new"<br>"I really learned a lot" | "Add some more different seasonings"<br>"Will be trying different foods" | "I tried foods I've never heard of"<br>"The session was very uplifting"<br>"Inspiring" |
| Healthy Eating for Mom and Baby | 7 | 36 | "Learned about seasonal veggies and how to prepare them for babies"<br>"Very direct on information containing different food to feed babies"<br>"Learning what the baby can eat" | "Taking prenatal vitamins"<br>"Not eating soft cheeses"<br>"Prep own fruits and vegetables for self and kids<br>"Purchase blender" | "Learning the proteins helped me for things to make to feed my baby"<br>"Learned about proteins you can make yourself vs buying them pre-made" |
| Contraception | 7 | 22 | "Explained a lot of things about hormones"<br>"I learned which ones [contraception] can be used for breastfeeding"<br>"I learned a little more about the different options for birth control"<br>"Handouts were smart, to the point but with details" | "Was going to get my tubes tied, now getting Nexplanon"<br>"Now will use birth control while breastfeeding"<br>"[Going to] try different birth control"<br>"Going to get on birth control after pregnancy" | "It was well taught and plan to use the resources"<br>"Talk to...daughters and grandkids about various birth controls and encourage them to be on one" |

In the following sections, we describe each of these major themes in the context of each module. The quotes listed in Table 2 are representative of each theme.

## Session Modules

### Breastfeeding
The most frequent comments revolved around knowledge about proper breastfeeding technique (Table 3). Among the secondary findings are that participants enjoyed the sessions' conversational format, the video about breastfeeding, and the module leaders' efforts to answer questions.

### Infant Care and Safety
The most frequent theme was intention to change, with participants reporting increased confidence with infant safety and implementing changes (Table 3). Participants also emphasized that the sessions reinforced basic safety principles in infant care and provided reassurance to experienced mothers.

### Mental Health
The most frequent comments revolved around empowerment, with participants expressing motivation to talk to physicians and advocate for themselves and others with mental health challenges (Table 3). Secondary findings emphasized that participants enjoyed the sessions' conversation-based structure and talking to peers with similar experiences. Participants also planned to employ stress reduction practices, such as journaling and deep breathing.

### Healthy Cooking
Comments most frequently centered around knowledge, with participants learning new ways to prepare food (Table 3). Secondary findings include the participants' enjoyment of hands-on food preparation.

### Healthy Eating for Mom and Baby
The most frequent comments were that the session was "educational," and participants planned to change by including more

**Table 3.** Summary of Comment Card and Debriefing Form Content Grouped by Theme

| Module | Knowledge | Intention to Change | Empowerment |
|---|---|---|---|
| Breastfeeding | 11/21 comment cards focused on learning more information about the benefits and techniques of breastfeeding (ie, "very informative," "now I know about breastfeeding") | Participants in 4/7 sessions said that they would place the nipple further in babies' mouths for a better latch<br>Participants in 2/7 sessions discussed breastfeeding with their next baby and breastfeeding longer | Participants in 7/11 sessions discussed encouraging their friends and family to breastfeed |
| Infant Care and Safety | 4/7 comment cards focused on learning from this session (ie, "very helpful," "learned a lot," "session is educational") | Participants in 4/8 sessions discussed specific changes taught during the module they would implement in their lives (ie, "removing toys from crib," babyproofing") | Participants in 2/8 sessions discussed feeling more confident in their abilities to create a safe environment for their babies and asking others about what is safe for babies |
| Mental Health | 5/9 comment cards focused on learning from this session (ie, "got useful information," "very informative," "clear facts, very helpful") | Participants in 4/11 sessions discussed implementing relaxation techniques in their life | Participants in 6/11 sessions discussed how they would speak up about their mental health with physicians, family, and friends<br>Participants in 3/11 sessions discussed offering to help others who are struggling with mental health |
| Cooking | 4/9 comment cards focused on learning from this session (ie, "educational," "very informative teachers taught me something new," "I learned a lot") | Participants in 2/2 sessions discussed implementing teaching points in their lives (ie, "adding some different seasonings" to vary meals, "trying different foods" | Participants in 2/2 sessions discussed how the cooking sessions were inspiring and uplifting |
| Healthy Eating for Mom and Baby | 12/19 comment cards focused on learning from this session (ie, "learned about seasonal veggies and how to prepare them for babies," "learned a lot," "very informative") | Participants in 6/7 sessions discussed implementing teaching points in their lives (ie, "purchase blender [for baby food]," "boil veggies," "prep own fruits and vegetables for self and kids") | Participants in 2/7 sessions discussed that learning helped inspire them to make proteins for their babies themselves |
| Contraception | 8/14 comment cards focused on learning from this session (ie, "very informative and helpful," "learned a little more about all the different options for birth control") | Participants in 4/7 sessions discussed implementing teaching points in their lives (ie, "now will use birth control while breastfeeding," "try different birth control") | Participants in 2/7 sessions discussed teaching others about birth control and using the resources provided (information handouts, Planned Parenthood information) |

proteins, fruits, and vegetables for themselves and their children (Table 3). Secondary findings include participants finding it useful that information was provided about every food discussed.

### Contraception

The most frequent comments related to the clarity of understanding participants gained regarding contraceptive methods (Table 3), and secondary findings include how much participants enjoyed the module and its succinctness.

## DISCUSSION

This study is an evaluation of a series of service-learning modules that were developed based on a community-engaged needs assessment that informed the creation of the Health Advocacy for Pregnancy and Infancy (HAPI) program, a novel shelter-based medical education program. Qualitative analysis of participant feedback revealed themes involving knowledge, intention to change, and empowerment as impact factors that participants experienced through this program. The results showed that these themes applied to all session modules.

Analysis of participant quotes showed not only that these themes were universal across session topics, but that there was a potential interplay between them. For instance, if new knowledge was gained by women, it appeared to influence their intent to change

health behaviors. The intent to change, in turn, may empower the women to advocate for others because of their increased awareness and confidence in handling health issues relating to pregnancy and infancy. This interconnected model between themes represents the possibility of a deeper impact on participants.

Consideration of this interplay between knowledge, intention to change, and empowerment reflects and builds on adult learning theory. Merriam outlines that learning is a multidimensional process beyond simple "cognitive processing;" encouraging dialogue in addition to connecting new skills to an individual's unique context can facilitate learning and further "meaning-making."[16] The largely discussion-based nature of these modules provides a safe space for participants to engage in such dialogue. Furthermore, participant comments signaling an intention to change and subsequent empowerment to advocate for others portray a connection between knowledge gained and unique personal circumstances. While not all our participants were pregnant, some women expressed their intention to share gained knowledge with family members or friends who are pregnant. This transfer of knowledge reflects a function of empowerment to reach a wider audience.

The qualitative analysis shows that not only are these sessions providing the requested health education, but they are also promoting positive changes for individual women and their com-

munity. This level of knowledge transfer demonstrated by participants resonates with Paulo Freire's critical pedagogy work for adult learners. His theory brought attention to notions that adult learners can experience a breakthrough learning moment that leads to a critical consciousness of the topic, which prompts a desire in the learner to share that newfound knowledge with others.[17] Albeit self-report data, our findings consistently demonstrated that participants gained new knowledge with a readiness to identify ways to co-learn and support others in their learning of the same topics.

Beyond their connection to adult learning theory, our findings also can be considered in the context of social determinants of health. There are myriad factors that contribute to a higher IMR in the non-Hispanic Black population. Psychosocial factors, including ethnicity, socioeconomic status, cultural background, access to prenatal care, level of education, work status, and quality of relationships with partners and family, have been identified as determinants of stress during pregnancy.[18] Research has demonstrated that elevated levels of cortisol and adrenaline—the major stress hormones of the body—impact placental blood flow and blood pressure. These both contribute to premature and low-birthweight babies.[4] Another risk factor for infant mortality is limited access to prenatal care. African American mothers were twice as likely to delay prenatal care, mainly due to a lack of early insurance.[19] All of these factors contribute to health disparities in birth outcomes amongst different ethnic groups. By improving access to health education for homeless women who are particularly vulnerable to poor pregnancy outcomes, our team sought to leverage participants' newfound knowledge, behavior changes, and sense of empowerment to help address social determinants of health. This approach holds promise to positively affect infant mortality through implementation of similar health education modules in Milwaukee.

While this research does not investigate the impact of our program on IMR, the approach is in alignment with recommended strategies in the city of Milwaukee's Fetal Infant Mortality Review (FIMR).[4] For example, the FIMR report highlights recommendations for interventions to address the disparities in IMR, one of which is social support programs.[4] The HAPI program seeks to improve social support by providing health education to homeless women in Milwaukee, a group particularly vulnerable to poor pregnancy outcomes. Another important recommendation from the FIMR report is to promote reproductive life planning and contraception.[4] Feedback from our contraception module consistently demonstrated intention to change by more carefully reconsidering birth control options, as well as empowerment to teach family members. Finally, the FIMR report recommends promotion and integration of in-house health education and health promotion across community and service provider settings.[4] HAPI also aligns with other national health promotion programs. For example, HAPI promotes breastfeeding in a community setting, which is a scientifically supported intervention to increase breastfeeding rates and improve health outcomes.[20] As a health education program focused on maternal and infant well-being, HAPI aims to increase education at different perinatal stages, while also being community-engaged through our partnership with the Milwaukee Women's Center.

### Limitations

Limitations of this study include a small sample size from a single site, which may limit the generalizability of this health education model. Although the modules were aimed at educating pregnant women and women with young children, they were open to all women at the shelter. As a result, the sample included women who were not pregnant or beyond childbearing age, making it difficult to discern if our target group of women experienced the same increase in knowledge, intention to change, and empowerment. We did not include a metric for assessing baseline knowledge of session topics prior to participation, which limits our understanding of knowledge gained from the session. Although our informational content was designed to be very easy to understand, low health literacy remains a limitation. Lastly, a part of our study occurred during the COVID-19 pandemic, which necessitated sessions being switched from in person to virtual. While we were able to complete verbal debriefings virtually, we were unable to collect comment cards.

### Future Applications

This study demonstrates the importance of community-based health education as a strategy for empowering women to learn and use their newfound knowledge. Future directions include additional qualitative investigation to further explore the relationship between the identified themes and promotion of healthier choices during pregnancy. It would be interesting to quantify the impact of HAPI's partnership program on birth outcomes and IMR by longer-term follow-up. More community-based health education programs emphasizing similar themes and their interplay may experience comparable results and potentially have a positive impact on IMR.

### CONCLUSIONS

A pregnancy and infant care education program for homeless women in Milwaukee has demonstrated success through participant-reported outcomes. Common themes were a reported knowledge gain, an intention to use that knowledge to change, and a feeling of empowerment. In alignment with adult learning theory, participants articulated a more profound understanding of pregnancy and postpartum health and a plan to share their new knowledge among their social networks, suggesting that similar education strategies may improve health outcomes on a broader scale. Additional investigation of the impact of community-based health education programs on infant mortality and health outcomes is warranted.

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# Factors Associated with Cigarette Smoking in Homeless Adults: Findings From an Outpatient Counseling Clinic

Benjamin Wrucke, BS; Lauren Bauer, MD; Rebecca Bernstein, MD

## ABSTRACT

**Background:** Those who are homeless are 4 times more likely to smoke cigarettes than the general population in the United States. Though research has investigated smoking risk factors among homeless individuals, further investigation is needed to understand factors that can be addressed by smoking cessation programs. This study seeks to understand characteristics associated with cigarette use in clients of the counseling clinic at a Midwest homeless shelter, including whether homeless individuals who smoke demonstrate lower self-efficacy, greater social isolation, poorer perception of therapy, and greater levels of chronic homelessness than nonsmokers.

**Methods:** From 2014 through 2019, clients of the counseling clinic were invited to contribute to a data bank. Logistic regression was performed to determine predictors of smoking status.

**Results:** No association was identified between smoking status and self-efficacy, social isolation, perception of therapy, or chronic homelessness. Compared to those without a high school degree, odds of being a smoker were 95% lower for those with a high school degree or equivalent and 93% lower for those with more than a high school education. Those with 3 or more episodes of prior substance abuse treatment were more likely to be smokers.

**Conclusion:** This study demonstrates that cigarette use among the homeless population is associated with low education level and prior substance abuse treatment. Smoking cessation programs would benefit from tailoring information to the education level of their audience. Further study could determine whether use of other substances may contribute to cigarette use in the homeless population and how this may be addressed by smoking cessation programs.

## INTRODUCTION

Those who are homeless are 4 times more likely to smoke than the general US population.[1] Factors associated with tobacco use in the general population include male gender, low socioeconomic status, unemployment, mental illness, immigrant status, single motherhood, and minority status,[2] as well as lower educational attainment[3-6] and past-year illicit substance abuse.[3] Factors associated with tobacco use in homeless adults include "out-of-home placement in childhood, victimization while homeless, past-year employment, prior illicit drug use, and problem alcohol use."[7]

Smoking cessation programs are valuable for reducing smoking prevalence, and such programs must not ignore how the homeless community is disproportionately affected by cigarette use.[1] Though some research has been done to investigate smoking risk factors among individuals who are homeless, further investigation is needed to understand factors that can be addressed by smoking cessation programs. This study sought to understand personal and health characteristics associated with smoking in clients of the counseling clinic at a Midwest homeless shelter.

### Community Partnership

In 2014, researchers at a medical college joined with a local homeless shelter and service agency to assess client information and outcomes of the agency's counseling clinic. The data were obtained for purposes of quality improvement and clinical reporting, and all clients were offered the opportunity to also include their information in a data bank for research purposes. In addition, medical students conducted smoking cessation education sessions at the agency. Small groups of medical students facilitated conversations with individuals about their experiences with cigarette use and cessation. They provided education about the risks associated with cigarette use and information about smok-

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ing cessation resources. Understanding the factors affecting cigarette use in this homeless population could inform improvements to these classes.

## Objectives

The objective of this study is to investigate the factors associated with cigarette use in homeless adults, including whether homeless individuals who smoke demonstrate lower self-efficacy, greater social isolation, poorer perception of therapy, and greater levels of chronic homelessness when compared with homeless individuals who do not smoke. The hope is to increase outreach for tobacco use prevention and cessation to homeless populations and inform improvements to smoking cessation programs.

## METHODS

### Participants and Data Collection

Data were collected at the agency's counseling clinic from July 17, 2014, through June 25, 2019. Clients completed 3 routine assessments – client characteristics, intake demographics, and monthly outcomes – and each was obtained by counselor interview. A total of 117 out of 198 individuals consented for their assessment data to be included in the data bank for future research. The study population (n = 97) consisted of those who indicated a history of homelessness. The 20 individuals excluded represented community referrals who had not experienced homelessness. Approval to analyze the data was granted by the Medical College of Wisconsin/ Froedtert Hospital Institutional Review Board (Protocol Number PRO00037089).

### Variables and Measurements

The list of the independent variables included in this study with corresponding questions and answer options as they appeared in the forms provided by the counseling clinic is provided in Appendix 1. Variables include information related to demographics, housing, employment, health care, and personal perceptions. Chronic homelessness was defined as being either homeless continuously for at least the last 12 months or homeless 4 or more times in the past 3 months. Perception of therapy refers to seeing the value in therapy. Mental health stage of change and substance use stage of change were assessed by the treating counselor and

**Table 1.** Variables Assessed Via Interviews of Individuals With History of Homelessness in a US Midwestern City

| Variable | n (%) | Variable | n (%) |
|---|---|---|---|
| Median Age (n = 97) | 48.3 | Currently smoke (n = 97) | |
| Sex (n = 97) | | Yes | 71 (73) |
| Male | 91 (94) | No | 26 (27) |
| Female | 6 (6) | Psychiatric hospitalization (n = 97) | |
| Ethnicity (n = 96) | | Yes | 11 (11) |
| Hispanic | 10 (10) | No | 86 (89) |
| Non-Hispanic | 86 (90) | Emergency department visits (n = 97) | |
| Race (n = 97) | | Yes | 25 (26) |
| Black/African American | 45 (46) | No | 72 (74) |
| White/Caucasian | 36 (37) | Previous substance abuse treatment (n = 97) | |
| Other/no response | 16 (16) | No prior treatment | 29 (30) |
| Highest education level (n = 97) | | 1–2 | 28 (29) |
| Some high school or less | 23 (24) | 3+ | 40 (41) |
| High school, GED, HSED | 35 (36) | Previous mental health treatment (n = 97) | |
| Technical training, some college or greater | 39 (40) | No prior treatment | 38 (39) |
| | | 1–2 | 37 (38) |
| Housing (n = 97) | | 3+ | 22 (23) |
| Yes | 28 (29) | Time since last substance use (median in days) (n = 89) | 36 |
| No | 69 (71) | | |
| Chronic homelessness (n = 97) | | Substance use stage of change (n = 90) | |
| Yes | 51 (53) | Precontemplation or contemplation | 25 (28) |
| No | 46 (47) | Preparation | 19 (21) |
| Employment (n = 97) | | Action or maintenance | 34 (38) |
| Yes | 33 (34) | Not currently being addressed | 12 (13) |
| No | 64 (66) | Mental health stage of change (n = 96) | |
| Employment schedule (n = 33) | | Precontemplation or contemplation | 40 (42) |
| Full-time | 14 (42) | Preparation | 23 (24) |
| Part-time | 13 (39) | Action or maintenance | 18 (19) |
| Temporary (not an ongoing thing) | 6 (18) | Not currently being addressed | 15 (16) |
| Employment status behavior (n = 62) | | Perception of therapy (n = 95) | |
| Looking for work | 21 (34) | Strongly agree | 52 (55) |
| Focusing on treatment | 15 (24) | Agree | 29 (31) |
| Applying for disability benefits | 9 (15) | Neutral | 14 (15) |
| Receiving disability benefits | 13 (21) | Disagree | 0 (0) |
| Not looking for another reason or don't want to work | 4 (6) | Strongly disagree | 0 (0) |
| | | Mean social isolation score (n = 97) | 56.97 |
| Health insurance (n = 97) | | Mean self-efficacy score (n = 97) | 4.05 |
| Yes | 85 (88) | | |
| No | 12 (12) | | |

Abbreviations: GED, general education development; HSED, high school equivalency diploma.

refer to behavior changes made as part of mental health or substance use treatment in the counseling clinic. Stages of change are described by the Transtheoretical Model of Behavior Change. For purposes of analysis, some variable categories were regrouped so that at least 10 participants fell into each variable category. Appendix 2 indicates how the categories were regrouped.

Social isolation was measured using the Patient-Reported Outcomes Measurement Information System (PROMIS) Short Form v2.0 – Social Isolation 4a.[8] In this context, social isolation is defined as the "perceptions of being avoided, excluded, detached, disconnected from, or unknown by others."[9] This short form was developed for adults and was presented in English. It consisted of 4 questions each, with 5 responses rang-

**Table 2.** Results of Univariate Logistic Regression Analysis With Odds Ratios for Whether a Given Independent Variable is Associated With Current Cigarette Use

| Variable | Odds Ratio (95% CI) | P value | Variable | Odds Ratio (95% CI) | P value |
|---|---|---|---|---|---|
| Age (n = 97) | 1.02 (0.98 – 1.06) | 0.27 | Health insurance (n = 97) | | |
| Sex (n = 97) | | |   Yes | 0.22 (0.01 – 1.21) | 0.16 |
|   Male | | |   No | | |
|   Female | 1.89 (0.29 – 37.24) | 0.57 | Psychiatric hospitalization (n = 97) | | |
| Ethnicity (n = 96) | | |   Yes | 4.1 (0.73 – 77.19) | 0.19 |
|   Hispanic | | |   No | | |
|   Non-Hispanic | 1.17 (0.24 – 4.62) | 0.83 | Emergency department visits (n = 97) | | |
| Race (n = 97) | | |   Yes | 2.31 (0.77 – 8.62) | 0.16 |
|   Black/African American | | |   No | | |
|   White/Caucasian | 0.95 (0.35 – 2.57) | 0.91 | Previous substance abuse treatment (n = 97) | | |
|   Other/No Response | 1.09 (0.31 – 4.49) | 0.90 |   No prior treatment | | |
| Highest level of education (n = 97) | | |   1 – 2 | 2.59 (0.83 – 8.78) | 0.11 |
|   Some high school or less | | |   3+ | 2.82 (0.98 – 8.52) | 0.06 |
|   High school, GED, HSED | 0.09 (0.004 – 0.5) | 0.02[a] | Previous mental health treatment (n = 97) | | |
|   Technical training, some college or greater | 0.09 (0.005 – 0.51) | 0.03[a] |   No prior treatment | | |
| Housing (n = 97) | | |   1 – 2 | 1.44 (0.52 – 4.06) | 0.49 |
|   Yes | | |   3+ | 1.57 (0.49 – 5.66) | 0.47 |
|   No | 1.13 (0.41 – 2.97) | 0.8 | Time since last substance use (n = 89) | 1 (1.0 – 1.0) | 0.48 |
| Chronic homelessness (n = 97) | | | Substance use stage of change (n = 90) | | |
|   Yes | 1.76 (0.71 – 4.45) | 0.22 |   Precontemplation or contemplation | | |
|   No | | |   Preparation | 0.41 (0.09 – 1.72) | 0.23 |
| Employment (n = 97) | | |   Action or maintenance | 1.1 (0.25 – 4.67) | 0.89 |
|   Yes | 0.96 (0.38 – 2.56) | 0.94 |   Not currently being addressed | 0.19 (0.04 – 0.87) | 0.04[a] |
|   No | | | Mental health stage of change (n = 96) | | |
| Employment schedule (n = 33) | | |   Precontemplation or contemplation | | |
|   Full-time | | |   Preparation | 1.53 (0.5 – 5.02) | 0.47 |
|   Part-time | 0.64 (0.12 – 3.21) | 0.59 |   Action or maintenance | 2.69 (0.73 – 13.05) | 0.17 |
| Employment status behavior (n = 62) | | |   Not currently being addressed | 2.15 (0.57 – 10.61) | 0.29 |
|   Looking for work | | | Perception of therapy (n = 95) | | |
|   Focusing on treatment | 1.1 (0.25 – 5.2) | 0.9 |   Strongly agree | | |
|   Applying for disability benefits | 3.2 (0.43 – 66.03) | 0.32 |   Agree | 1.06 (0.39 – 3.03) | 0.9 |
|   Receiving disability benefits | 1.33 (0.28 – 7.49) | 0.72 |   Neutral | 1.49 (0.4 – 7.25) | 0.58 |
|   Not looking for another reason or don't want to work | 0.4 (0.04 – 3.96) | 0.41 | Social isolation (n = 97) | 0.98 (0.92 – 1.03) | 0.44 |
| | | | Self-efficacy (n = 97) | 1.09 (0.54 – 2.16) | 0.8 |

Abbreviations: GED, general education development; HSED, high school equivalency diploma.
[a] Indicates significance level of P < 0.05.

ing from never to always. A raw score was calculated by summing the values associated with each response. Next, a scaled T-score was generated by using a conversion table provided in the PROMIS Social Isolation Scoring Manual. A T-score of 50 is equal to the mean of the US general population, with 10 being 1 standard deviation from the mean. A high T-score indicated a greater degree of social isolation. Forms were scored only if they included responses to all 4 questions.

Self-efficacy was measured by using the New General Self-Efficacy Scale.[10] This scale has been used previously to compare self-efficacy between homeless and economically disadvantaged smokers.[11] General self-efficacy can be defined as "one's estimate of one's overall ability to perform successfully in a wide variety of achievement situations or how confident one is that she or he can perform effectively across different tasks and situations."[10] The scale consisted of 8 Likert-style questions, with responses ranging from strongly disagree to strongly agree. A score was cal-

culated by taking the average of the values associated with each response. A low score indicated low self-efficacy. Forms were scored only if they included responses to all 8 questions.

### Statistical Methods

Logistic regression was performed in RStudio using a generalized linear model. The independent predictor variables were the study variables provided in Appendix 1. The binary dependent variable was smoking status (meaning current smoker or non-smoker). Univariate logistic regression was first performed with each predictor, and then a multivariate model was created to adjust for confounding. Per convention, a P value cutoff was used to determine variables that should be included in the multivariate model.[12] Variables were included in the multivariate model if they were explicitly associated with the study objective or had a P value of less than or equal to 0.2 and an odds ratio of less than 0.5 or greater than 2. Two variables – emergency department visits in the

past month and psychiatric hospitalizations – were then removed to avoid overfitting the model.[13]

## RESULTS

### Participant Characteristics

Demographic and participant characteristics are reported in Table 1. Participants who indicated that they belong to both Black/African American and Caucasian race categories were categorized as Other/No Response. The population was mostly male, mostly non-Hispanic, and had diverse racial and educational backgrounds. Twenty-nine percent of responders were currently housed. Seventy-three percent of the study population were current smokers.

### Predictors of Smoking

Univariate and multivariate logistic regression results are included in Tables 2 and 3, respectively. Multivariate analysis demonstrated that the odds of being a current smoker decreased as education level increased, with the odds of being a smoker 95% lower for those with a high school degree or equivalent (OR 0.05; 95% CI, 0.002-0.39; $P = 0.01$) and 93% lower for those with more than a high school education (OR 0.07; 95% CI, 0.003-0.49; $P = 0.02$). Other demographic characteristics, including age, sex, race, and ethnicity were not found to have significant association with smoking status in this sample and were not included in multivariate analysis. Those with 3 or more episodes of prior substance abuse treatment were more likely to be current smokers (OR 4.17; 95% CI, 1.19-15.81; $P = 0.03$). No significant association was identified between chronic homelessness, perception of therapy, social isolation, or self-efficacy and smoking status. The multivariate model had an Akaike information criterion of 108.41.

## DISCUSSION

Logistic regression analysis suggests that factors associated with cigarette use in homeless adults include having less than a high school diploma and receiving prior substance abuse treatment. Chronic homelessness, health insurance, perception of therapy, social isolation, and general self-efficacy were not significantly associated with cigarette use in this study. Seventy-three percent of study participants were current smokers, which is consistent with the prevalence of smoking in the homeless population. Previous studies suggest a range of 57% to 80%.[7,14,15]

### Education

This study found that the odds of being a smoker was greatest for those with a low level of education, and these results support findings from previous studies conducted in the general population.[3-6,14] Thus, smoking cessation programming for homeless populations should strongly consider health literacy in order to deliver content in an accessible manner for the audience.

### Substance Abuse Treatment

The results of this study demonstrate that cigarette use is asso-

**Table 3.** Results of Multivariate Logistic Regression Analysis With Odds Ratios for Whether a Given Independent Variable is Associated With Current Cigarette Use

| Variable | Odds Ratio (95% CI) | P value |
|---|---|---|
| Highest level of education (n = 97) | | |
|   Some high school or less | | |
|   High school, GED, HSED | 0.05 (0.002 – 0.39) | 0.01[a] |
|   Technical training, some college or greater | 0.07 (0.003 – 0.49) | 0.02[a] |
| Chronic homelessness (n = 97) | | |
|   Yes | 2.46 (0.79 – 8.02) | 0.12 |
|   No | | |
| Health insurance (n = 97) | | |
|   Yes | 0.11 (0.005 – 0.91) | 0.07 |
|   No | | |
| Previous substance abuse treatment (n = 97) | | |
|   No prior treatment | | |
|   1 – 2 | 3.54 (0.90 – 15.27) | 0.08 |
|   3+ | 4.17 (1.19 – 15.81) | 0.03[a] |
| Perception of therapy (n = 95) | | |
|   Strongly agree | | |
|   Agree | 1.38 (0.43-4.76) | 0.59 |
|   Neutral | 2.18 (0.41 – 16.28) | 0.40 |
| Social isolation (n = 97) | 1.02 (0.95 – 1.10) | 0.56 |
| Self-efficacy (n = 97) | 1.41 (0.53 – 3.87) | 0.49 |

Abbreviations: GED, general education development; HSED, high school equivalency diploma.
[a] Indicates significance level of $P < 0.05$.

ciated with prior substance abuse treatment. Tobacco use in the homeless population is associated with prior substance use,[7] and cigarette smoking has been associated with substance use disorder relapse.[16] Future studies should investigate how cigarette smoking may be a barrier to successful substance use treatment. Further study also is needed to determine whether use of other substances may contribute to cigarette use in the homeless population and how this information may be addressed by smoking cessation programs. If a causative relationship is found, smoking cessation programs for homeless adults could benefit from highlighting how smoking cessation may improve one's ability to quit using other substances. Similarly, treatment for nicotine dependence could be offered alongside treatment for other substance use disorders.

### Perception of Therapy

This study population may have had a strong/positive perception of therapy because they were clients at a counseling clinic. However, it is encouraging that smoking status did not affect attitudes towards counseling in this population. Smoking cessation sessions could promote counseling as an important aspect of treatment, but these attitudes may not be a barrier to cessation.

### Self-Efficacy and Social Isolation

The study population had a high mean general self-efficacy score of 4.05 out of 5. Although the mean social isolation score was 56.97, which is above the mean of the general US population score of 50, it is still within 1 standard deviation. The fact that self-efficacy

and social isolation were comparable for smokers and nonsmokers suggests that these characteristics are not major barriers to smoking cessation in this population. In fact, these results could suggest that these individuals may have strong readiness to quit[17] and may, therefore, be responsive to smoking cessation intervention. It is important to note that this study measured general self-efficacy, which—though positively influences specific self-efficacy[10]—is not specific to smoking cessation. Overall, these results can encourage implementation of smoking cessation initiatives targeting homeless smokers engaged in outpatient counseling programs.

A 2013 study conducted on both homeless and non-homeless smokers in Dallas, Texas found homeless smokers to have similar levels of general self-efficacy when compared with non-homeless smokers but lower motivation to quit and lower self-efficacy for quitting than non-homeless smokers.[11] Based on this current study and previous research, general self-efficacy may not differ based on homelessness or smoking status. Though homeless smokers may not lack general self-efficacy, more research is needed to understand how to support motivation to quit smoking in the homeless population.

### Limitations and Generalizability

Social desirability bias may have affected respondents, particularly because their interviewers were also their behavioral health counselors. The results of this research can only be generalized to populations similar to that of this study. This research specifically studies homeless individuals engaged in outpatient counseling. A significant portion of the homeless population is not connected with these services, and this study cannot be generalized to those individuals. As such, this study includes a convenience sample of the homeless population. Participants were mostly male, English-speaking clients of a counseling clinic at a homeless shelter, and not all were currently homeless. Additionally, the sample size was modest, which contributed to less precise confidence intervals. Lastly, though this study was cross-sectional in its design, it combines data collected over a 6-year period. Changes that may have occurred over this time period are not captured.

### Future Directions

To develop a deeper understanding of the factors that influence cigarette use and cessation in this population, next steps could include interviews of clients of the homeless shelter to investigate personal experiences with cigarette use and cessation and link quantitative and qualitative information. The results of a qualitative study may support results from this study and provide greater insight about how smoking cessation programs may be improved.

### CONCLUSION

This study demonstrates that cigarette use among the homeless population is associated with low education level and prior substance abuse treatment. Smoking cessation programs would benefit from tailoring information to the education level of their audience. Further study could determine whether use of other substances may contribute to cigarette use in the homeless population and how this may be addressed by smoking cessation programs.

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ORIGINAL RESEARCH

# Factors Influencing Show Rates of Emergency Department Referrals to Primary Care Safety Net Clinics

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## ABSTRACT

**Background:** Utilization of emergency departments for non-urgent conditions has been a long-standing problem leading to excessive health care spending, unnecessary testing, and missed opportunities for patients to form longitudinal relationships with primary care clinicians. The Milwaukee Health Care Partnership established the Emergency Department Care Coordination program to decrease avoidable emergency department visits and connect high-risk individuals with primary care medical homes. Emergency department providers from 8 hospitals schedule patients to safety net clinics to establish follow-up care. During 2018 and 2019, there were 5,035 appointments scheduled, with a 43% show rate. This project aimed to identify factors influencing the show rate to follow-up appointments and to develop program interventions.

**Methods:** This project utilized a database of deidentified patient and referral information and performed logistic regressions to determine factors that influence show rates.

**Results:** There was a significant difference in show rates when looking at days between the emergency department visit and follow-up appointment, age, receiving clinic, and insurance status (all $P > 0.001$). Patients seen within 5 days of emergency department visit, patients 65 and older, and uninsured patients had increased likelihood of attending follow-up appointments.

**Conclusions:** These results demonstrate that older adults are more likely to attend appointments, and more efforts are needed to engage younger people. The analysis shows the need to schedule patients with follow-up primary care quickly, as a short number of days from emergency department visit to primary care appointment was strongly correlated with a higher show rate. In addition, uninsured patients are good candidates for Emergency Department Care Coordination program referrals.

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## INTRODUCTION

On average, 37% of all emergency department (ED) visits are non-urgent,[1,2] defined as "conditions for which a delay of several hours would not increase the likelihood of an adverse outcome."[1] Using the ED instead of ambulatory care facilities causes excessive health care spending, unnecessary testing and treatment, and a missed opportunity to form a longitudinal relationship with a primary care clinician. The population utilizing the ED is diverse, and there are many factors that contribute to a patient's decision to seek care at an ED for non-urgent conditions.[3]

In the United States, EDs are required by law to provide treatment to anyone seeking care, regardless of their ability to pay.[4] This creates an environment where those who could not otherwise afford care at alternative locations can receive treatment at the ED. Many patients who are uninsured will use the ED in place of a primary care clinic. Patients with insurance, such as Medicaid, may have similar copays at their primary care physician's office and the ED. However, if their primary care physician recommends additional testing or specialty appointments, it may end up costing the patient more than an ED visit,[3,5] which can provide the additional services that ambulatory care settings cannot.[6,7]

EDs are open 24 hours a day, and no appointment is required.[4] This allows patients the flexibility to seek care when it is convenient for them, which often may be outside of normal business hours. In addition, patients may not understand the full benefits

of establishing care with a primary care medical home, such as forming a longitudinal relationship with a clinician who has more extensive knowledge of their medical conditions and past treatment courses.[8]

The Milwaukee Health Care Partnership is a public/private consortium with a mission of improving health outcomes, reducing disparities, and lowering the total cost of care for low-income, vulnerable populations in Milwaukee County, Wisconsin. One program the partnership has implemented is the Emergency Department Care Coordination (EDCC) initiative, which aims to decrease avoidable ED visits, reduce duplicative ED tests and procedures, and connect high-risk individuals with primary care medical homes. Specifically, the EDCC program focuses on ED patients who are not established with a primary care clinician, those who have a chronic condition, and the Medicaid and uninsured populations. The EDCC program was established in 2007, and it now includes 8 adult hospital EDs and 20 safety net clinics throughout Milwaukee County. When a patient enters an ED and the clinician thinks the patient would benefit from a referral to the EDCC program, a care coordinator approaches the patient and schedules an initial appointment at the clinic through an intersystem scheduling platform before the patient leaves the ED. In 2018-2019, there were 5,035 appointments scheduled in the ED, with a 43% show rate to these appointments. Figure 1 shows the appointments scheduled and show rate by month. In an evaluation looking at appointments scheduled from 1 ED to 1 Federally Qualified Health Center (FQHC), there was a 44% reduction in ED usage in the next 6 months among patients connected to primary care.[9]

For interventions such as the EDCC program, it is important to identify the subgroups this intervention would benefit, how to best target this population, and then evaluate ways to reduce possible barriers. The aim of this study was to identify factors that contribute to patients of the EDCC program attending their scheduled follow-up appointments.

## METHODS

Expedited institutional review board approval was applied for on July 19, 2019 and approved on October 25, 2019. Appointment referrals to the EDCC program in the years 2018 and 2019

were used. The study utilized the MyHealthDirect (cloud-based scheduling tool used to make EDCC appointments) database of deidentified patient information and referral information to assess factors contributing to patient show rates. All referring EDs were included, and only FQHCs were included amongst the receiving clinics. This created data standardization between varying receiving clinics and their available resources, as it excluded smaller non-FQHC receiving clinics. The Box includes the MyHealthDirect database information available for each EDCC referral.

The reason for referral information in MyHealthDirect was a free response text box. These data were categorized based on organ system and then further subcategorized into common diagnoses. Data entries with no diagnosis, insufficient information to infer a diagnosis, and dental complaints were excluded from the analysis. The data set was analyzed with binary logistic regressions using SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp). When performing the binary logistic regressions, a comparison group was chosen for each category based on which group was hypothesized to have the highest show rate from our literature review and personal knowledge of the EDCC program patterns. The age category was grouped into age brackets to reflect cohorts for young adults, middle-aged adults, and older adults.

## RESULTS

There were 5,035 EDCC referrals during 2018 and 2019, with 1,780 attended follow-up appointments, 2,389 no-shows, and 866 with unknown follow-up status, for an overall show rate of 43% after excluding referrals with unknown follow-up status. Table 1 outlines the show rates separated by individual factors. When looking at show rates based on the number of days elapsed between ED visit and follow-up clinic appointment date, there was a significant difference with patients being seen within 5 days of their ED visit having an increased likelihood of attending ($P \geq 0.0001$).

There was a significant difference in show rates among various FQHCs, with patients seen at Clinic A more likely to attend than patients seen at Clinics D and E ($P \geq 0.0001$). There was not a statistical difference in show rates between Clinics A, B, and C. There also was a significant difference in show rates between uninsured and Medicare patients and among different age groups. Uninsured patients were more likely to attend follow-up appointments than Medicare insurance holders ($P = 0.014$), and patients aged 65 and older had an increased likelihood of attending vs the comparison group of patients aged 16-39 ($P \geq 0.0001$).

While clinician type (physician vs advanced practice provider) was significant in the univariate analysis, when looking at the predictive model, it was no longer important when adjusting for lead time, FQHC, age, and insurance. There was no significant difference in show rates between males and females.

Table 2 lists show rates based on the reason for referral separated by chief concern.

## DISCUSSION

Looking at programs similar to the EDCC program, show rates to follow-up appointments have ranged from 37% to 50%.[10-12] The EDCC program's show rate of 43% was similar to other programs providing referrals from ED visits to primary care medical homes. However, based on our literature search, these programs all followed program models of 1 ED providing referrals to 1 primary care clinic. The EDCC program has a unique model in that this is a community-wide initiative involving 8 EDs over 3 different health care systems referring to over 20 community safety net clinics. This allows patients to choose which clinic will best serve their needs and greater flexibility in scheduling appointments.

### Days to Appointment

Patients seen within 5 days of their ED visit had higher show rates, which is consistent with other studies.[13,14] More timely appointments may have been at the forefront of patients' minds more so than appointments farther out, and the acute health condition they sought treatment for in the ED was more likely to still be present. With appointments that were scheduled farther out, health issues may have resolved, so the perceived need for an appointment seemed less urgent.

Since shorter lead time to appointments leads to increased show rates, it is imperative that receiving safety net clinics have an appointment system that provides ample appointment slots within a few days' notice. A model that books appointments into a safety net clinic's walk-in/urgent care center may allow for more appointment flexibility, as some participating FQHCs currently do. Another option FQHCs use is to double-book visits into the same appointment slot, which allows for more available appointments and mitigates the effects of no-shows, although it can create workflow issues if both patients arrive.

It also may be important for ED clinicians to emphasize to patients the importance of follow-up appointments for their conditions. Spending a few extra minutes at discharge with the patient could help them understand that establishing primary care with regular and timely outpatient follow-up may prevent future avoidable ED visits.

### Insurance Type

The higher show rates for uninsured patients compared to patients with Medicaid insurance may have been due to a higher motivation by uninsured patients to establish care because they had fewer options for access to health care.[15,16] By providing a referral appointment in the ED, this reduced the amount of research that uninsured patients had to complete to appropriately navigate the health care system. If the barrier of not knowing where to seek care was alleviated through appointment referrals, it may have led to

**Table 1.** Show Rates Categorized by Individual Factors

| | Attended | Did Not Attend | Grand Total | Show Rate (%) | Odds Ratio (95% CI) | P value |
|---|---|---|---|---|---|---|
| FQHC | | | | | | |
| Overall clinic comparison | | | | | | 0.0001 |
| Clinic A | 464 | 460 | 924 | 50 | | |
| Clinic B vs A | 524 | 545 | 1069 | 49 | 0.90 (0.74 – 1.10) | 0.311 |
| Clinic C vs A | 419 | 639 | 1058 | 40 | 1.09 (0.88 – 1.13) | 0.435 |
| Clinic D vs A | 291 | 549 | 840 | 35 | 1.49 (1.21 – 1.84) | 0.0001 |
| Clinic E vs A | 82 | 196 | 278 | 29 | 2.18 (1.60 – 2.96) | 0.0001 |
| Total | 1780 | 2389 | 4169 | 43 | | |
| Lead time (days) | | | | | | |
| Overall lead time comparison | | | | | | 0.0001 |
| 0 – 5 | 802 | 836 | 1638 | 49 | | |
| 6 – 10 vs 0 – 5 | 583 | 780 | 1363 | 43 | 1.31 (1.12 – 1.52) | 0.001 |
| 11 – 15 vs 0 – 5 | 162 | 270 | 432 | 38 | 1.59 (1.26 – 2.01) | 0.0001 |
| 16+ vs 0 – 5 | 233 | 503 | 736 | 32 | 1.91 (1.54 – 2.37) | 0.0001 |
| Total | 1780 | 2389 | 4169 | 43 | | |
| Insurance | | | | | | |
| Overall insurance Comparison | | | | | | 0.011 |
| Uninsured | 775 | 924 | 1699 | 46 | | |
| Commercial vs uninsured | 98 | 104 | 202 | 49 | 0.79 (0.59 – 1.08) | 0.13 |
| Medicaid vs uninsured | 857 | 1288 | 2145 | 40 | 1.10 (0.96 – 1.27) | 0.157 |
| Medicare vs uninsured | 50 | 73 | 123 | 41 | 1.69 (1.11 – 2.58) | 0.014 |
| Total | | 1780 | 2389 | 4169 | 43% | |
| Age | | | | | | |
| Overall age comparison | | | | | | 0.0001 |
| 16 – 39 | 957 | 1567 | 2524 | 38 | | |
| 40 – 64 vs 16 – 39 | 751 | 752 | 1503 | 50 | 0.61 (0.53 – 0.70) | 0.0001 |
| 65+ vs 16 – 39 | 52 | 39 | 91 | 57 | 0.37 (0.23 – 0.59) | 0.0001 |
| Under 16 vs 16 – 39 | 20 | 31 | 51 | 39 | 0.92 (0.52 – 1.64) | 0.781 |
| Total | 1780 | 2389 | 4169 | 43 | | |
| Provider specialty | | | | | | |
| Overall provider Specialty comparison | | | | | | 0.313 |
| Internal/family medicine | 1549 | 2090 | 3639 | 43 | | |
| APP | 231 | 299 | 530 | 44 | 1.24 (0.90 – 1.41) | 0.313 |
| Total | | 1780 | 2389 | 4169 | 43% | |
| Gender | | | | | | |
| Overall gender comparison | | | | | | 0.224 |
| Female | 777 | 1061 | 1838 | 42 | | |
| Male vs female | 1003 | 1328 | 2331 | 43 | 1.08 (0.95 – 1.23) | 0.224 |
| Total | 1780 | 2389 | 4169 | 43 | | |

Abbreviations: FQHC, Federally Qualified Health Centers; APP, advanced practice provider.

**Table 2.** Show Rate Categorized by Chief Concern

| Chief Concern | Attended | Did Not Attend | Total | Show Rate (%) |
|---|---|---|---|---|
| Behavioral Health | 38 | 53 | 91 | 42 |
| Cardiovascular | 242 | 283 | 525 | 46 |
| Dental | 2 | 6 | 8 | 25 |
| Dermatology | 61 | 119 | 180 | 34 |
| Endocrine | 62 | 63 | 125 | 50 |
| Ear, Nose, Throat | 28 | 49 | 77 | 36 |
| Gastrointestinal | 144 | 232 | 376 | 38 |
| Genitourinary | 16 | 28 | 44 | 36 |
| Hematology | 3 | 1 | 4 | 75 |
| Musculoskeletal | 186 | 202 | 388 | 48 |
| Neurology | 106 | 136 | 242 | 44 |
| Obstetrics | 48 | 44 | 92 | 52 |
| Ophthalmology | 7 | 17 | 24 | 29 |
| Pain | 27 | 39 | 66 | 41 |
| Pulmonary | 128 | 143 | 271 | 47 |
| Renal | 11 | 12 | 23 | 48 |
| Trauma | 61 | 64 | 125 | 49 |
| Unknown | 610 | 898 | 1508 | 40 |

higher show rates versus other patients on Medicaid who did not have as significant of a barrier.

### Advanced Practice Provider vs Physician

There was no significant difference in show rates based on whether the referring receiving clinician was a physician or an advanced practice provider (APP). There may not be a perceived difference in emphasis on the value of a follow-up appointment based on whether it is with a primary care physician vs an APP. This may be due to a culture shift, as APPs are becoming more widely utilized in health care and the public is more accepting of them,[17] which may allow flexibility in the primary care setting to delegate appointment referrals to other health care clinicians.

### Age Groups and Gender

This study found that older individuals were more likely to attend follow-up appointments, which is consistent with the literature.[8,18] This may be because older individuals typically have more comorbid health conditions to manage. There also may be more of an emphasis on managing these chronic health care conditions. Conversely, younger individuals could perceive their health as stable, causing them to feel less motivated to attend follow-up appointments. Our study also showed that there was no difference in show rates between males and females, which is also consistent with the literature. However, new data exist indicating that men may be less likely to keep their appointments.[19]

### FQHC Differences

There were statistically significant differences in show rates among the individual FQHCs, which could be due to multiple factors, including differences in resources, cultural competency, appointment times and availability, and clinic location. Individual FQHC

resources could alleviate certain barriers to seeking care, such as providing transportation services. In addition, differences in relationships with the community and cultural competence could foster increased trust in the clinic, translating to increased show rates. Ultimately, more work is needed to analyze individual clinic workflows and implementation of the EDCC program referrals to understand these differences in show rates. In analyzing differences, it will be important to examine outreach prior to appointment, how many appointment slots are available to patients, other services offered to patients such as transportation and in-person interpreters/bilingual physicians, and overall clinic workflow.

### Chief Concern

The top reasons patients sought treatment at the ED were for cardiovascular, musculoskeletal, gastrointestinal, and pulmonary concerns. Of these complaints, patients presenting with gastrointestinal concerns were less likely to attend their follow-up appointments than those with other chief concerns. This could be due to gastrointestinal complaints being more likely to be resolved than other concerns by the time of follow-up appointments.

### Limitations

This study had limited demographic information for each appointment referral; race, ethnicity, income, and education information for each patient would have provided a more complete analysis. In addition, staffing variability per ED and per FQHC was not analyzed. For example, some EDs have medical assistants make EDCC referrals, while some EDs will have staff with a master's degree in social work make these referrals, which could influence outcomes.

Additionally, there was a shift in 2020 to telehealth due to SARS-CoV-2, which has led to a significant decrease in appointments but an increase in show rates that was not explored given the study's timeframe.

### CONCLUSIONS

Non-rgent utilization of emergency departments is a well-known problem with many factors contributing to the issue. To reduce non-urgent ED utilization, multiple approaches are needed to target the underlying reasons patients decide to seek care at EDs. Programs such as the Emergency Department Care Coordination initiative are important in targeting a certain subset of this patient population by linking them to primary care medical homes. Through this study, it was found that the patients who attended scheduled follow-up appointments at primary care medical homes were older individuals, uninsured individuals, and those individuals who had follow-up appointments scheduled within 5 days of their presentation to the ED. More research is needed to discern factors that influence the differences in show rates to follow-up appointments among individual

receiving clinics. The next steps will be to meet with individual FQHC leadership to discuss the barriers individual clinics face and what strategies they have utilized to successfully integrate EDCC appointments into their workflows. Additionally, meetings will be conducted with ED staff regarding which patients are good candidates for EDCC referrals and what populations may need additional interventions. These lessons learned will be disseminated to other receiving clinics and EDs in order to improve show rates to these follow-up appointments and, ultimately, reduce non-urgent utilization of community EDs.

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# Analysis and Observations of Telehealth in Primary Care Follow-Up Appointments for Vulnerable Populations

Ben Kannenberg, BS; Greg Stadter, MPH

## ABSTRACT

**Background:** The Milwaukee Health Care Partnership's Emergency Department Care Coordination (EDCC) initiative allows vulnerable patients in 8 local emergency departments to schedule a follow-up primary care appointment upon discharge at primary care safety net clinics. In March 2020, EDCC receiving clinics transitioned all appointments to telehealth due to the COVID-19 pandemic. The objectives of this study were to examine the effect of telehealth on the show rate at EDCC initial follow-up appointments and obtain perspectives on the strengths and weaknesses of primary care via telehealth through statistical analysis of appointments and patient and provider feedback.

**Methods:** EDCC data were analyzed for appointments scheduled from 2018 through 2021. Using univariate logistic regression, the show rate was examined before and after the adoption of telehealth. In addition, surveys of EDCC patients were conducted after telehealth visits, and feedback was solicited from receiving clinic providers.

**Results:** Nearly 3900 (n=3897) primary care visits were scheduled through EDCC within the date range; 284 were conducted via telehealth. After controlling for age, sex, insurance, clinic location, and lead time, telehealth appointments were associated with a lower no-show rate than in-person appointments (P=0.002). Qualitative studies revealed that telehealth can help patients overcome barriers, specifically transportation and childcare concerns, but is difficult for older and non-English speaking patients.

**Conclusions:** Patients were significantly more likely to attend follow-up visits conducted via telehealth. Patients and clinicians identified telehealth as a means of overcoming socioeconomic barriers but also cited drawbacks to its use. Further research is needed to identify the ongoing role of telehealth and specific populations that would benefit most from its potential.

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## INTRODUCTION

Patients in medically underserved areas often experience socioeconomic barriers to care, such as transportation or childcare concerns.[1,2] Telehealth has long been promoted as a means of overcoming these barriers, but growth of the modality was previously hampered by logistical challenges, including restrictive reimbursement patterns.[3,4] However, as the COVID-19 pandemic shuttered brick-and-mortar clinics across the nation and emergency legislation markedly expanded access and coverage, telehealth use soared.[5,6] Nationwide, telehealth claims increased 78-fold from February through April 2020, and roughly 1 in 3 visits in April was conducted virtually. Even with widespread vaccination and relaxation of restrictions, claim volume remained 38 times higher in July 2021 compared to prepandemic levels, with approximately 1 in 7 medical visits still occurring via telehealth.[7] Wisconsin's patterns were consistent with national trends; over 160,000 virtual visits were conducted in 2020, compared to less than 3000 the year prior.[8]

Federally Qualified Health Centers (FQHC) demonstrated similar patterns to private and nonprofit health care networks in regard to treatment modality, with 30.2% of visits conducted via telehealth between July and November 2020.[9] The massive expansion of telehealth among FQHCs – clinics that primarily provide primary care to un- and underinsured patients under a sliding-scale fee system based on ability

to pay – creates a unique opportunity to assess the role of telehealth in providing primary care to vulnerable patients. One 2021 cross-sectional study noted a reduction in no-shows when comparing non-procedural telehealth to in-person visits at a large urban medical center.[10] However, little research exists regarding telehealth as a means of increasing show rate for primary care visits among socially vulnerable patients, particularly those with Medicaid and the uninsured.

Prior to the pandemic, patient and clinician satisfaction with telehealth was generally mixed, despite evidence of improved outcomes.[11] However, since March 2020, patient satisfaction with telehealth has generally improved.[12,13] Clinician satisfaction has followed similar trends, with multiple studies finding greater than 80% satisfaction.[14,15] Nonetheless, qualitative research regarding patient and clinician perceptions of telehealth remain lacking, especially in low-income clinical settings such as FQHCs.

The Emergency Department Care Coordination (EDCC) initiative, a program facilitated by the Milwaukee Healthcare Partnership, has worked since 2007 to connect uninsured and underinsured patients without an established primary care provider to primary care at local FQHCs and safety net clinics. The program targets patients with complex or chronic medical needs, including frequent emergency department (ED) users, and leverages ED social workers, nurses, and other staff to schedule a primary care appointment before the patient discharges. The program does not target patients who are otherwise eligible for internal primary care follow-ups within the health care system. Through the EDCC, thousands of appointments are scheduled every year; however, prior to the pandemic, show rates had consistently hovered around 45%. As receiving clinics transitioned to telehealth at the beginning of the pandemic, the EDCC served as a direct window into the quantitative and qualitative impacts of care modality on providing accessible and quality care for vulnerable patients.

## METHODS

A cross-sectional study was conducted of ambulatory appointments following EDCC referrals at 5 FQHC receiving clinics in Milwaukee, Wisconsin, between April 5, 2018, and March 31, 2021. Patient visits prior to March 23, 2020, took place in person; visits after this date were conducted via telehealth, either by video or telephone. Deidentified patient data were obtained from EDCC's cloud-based intersystem technology software, MyHealthDirect, which sources data directly from the referring EDs and the receiving FQHCs. This study was deemed a quality



**Figure.** Emergency Department Care Coordination Appointment Volume and Show Rate, April 2018 – March 2021
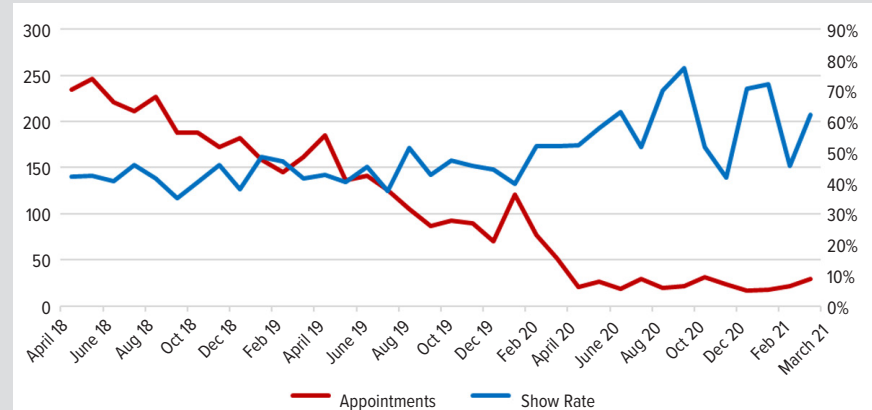
**Box.** Standardized Survey for Patients

**General Perceptions:** "How did the visit go? Did you feel prepared for the visit?"

**Accessibility:** "Was it easier to attend the visit via telehealth?"

**Desirability:** "Which type of visit did you prefer, or were they about the same?"

**Sustainability:** "Would you consider making another telehealth visit?"

improvement initiative and therefore IRB-exempt by the institutional review board of the University of Wisconsin.

EDCC referrals were included regardless of the referring ED, but only adult medicine referrals to FQHCs were included; pediatric, OB/GYN, and dental appointments were excluded. The EDCC data set included limited patient information, including age, sex, patient insurance status, and appointment lead time. Binary logistical regression was conducted using the Statistical Program for Social Sciences SPSS 27.0 software (SPSS Inc, Chicago, Illinois). While many factors were considered in the logistic regression model, the main outcome of interest was differences in show rate for telehealth primary care appointments compared to traditional appointments, and these additional factors were considered to control for confounding factors that were available in the data set.

In parallel, we conducted standardized, qualitative, opt-in interviews of patients referred through EDCC who attended their virtual visit. Interviews were designed to elicit perspectives on telehealth on 4 axes, as illustrated in the Box. These interviews were facilitated by clinic staff at the 2 FQHCs performing the most telehealth appointments and were incorporated as part of the standard visit follow-up procedure. We additionally performed qualitative interviews with physicians and advanced practice providers at EDCC receiving clinics through existing communication channels, such as the EDCC work group's monthly Zoom meeting. We conducted these unstructured interviews ourselves; the questions were not standardized, but conversation focused on the advantages

**Table 1.** Demographic Data

| | In Person | % Total | Telehealth | % Total |
|---|---|---|---|---|
| **Attendance** | | | | |
| Attended | 1547 | 43 | 169 | 59 |
| Did not attend | 2065 | 57 | 116 | 41 |
| **Federally Qualified Health Center** | | | | |
| Clinic A | 835 | 23 | 130 | 46 |
| Clinic B | 942 | 26 | 125 | 44 |
| Clinic C | 788 | 22 | 0 | 0 |
| Clinic D | 853 | 24 | 30 | 11 |
| Clinic E | 194 | 5 | 0 | 0 |
| **Lead time (days)** | | | | |
| 0 – 5 | 1497 | 41 | 195 | 68 |
| 6 – 9 | 1238 | 34 | 71 | 25 |
| 10 – 14 | 446 | 12 | 10 | 4 |
| 15+ | 431 | 12 | 9 | 3 |
| **Insurance status** | | | | |
| Commercial | 170 | 5 | 8 | 3 |
| Medicaid | 1813 | 50 | 119 | 42 |
| Medicare | 119 | 3 | 11 | 4 |
| Uninsured | 1510 | 42 | 147 | 52 |
| **Age** | | | | |
| 16 – 39 | 2214 | 61 | 156 | 55 |
| 40 – 64 | 1317 | 36 | 119 | 42 |
| 65+ | 81 | 2 | 10 | 4 |
| **Sex** | | | | |
| Female | 1595 | 44 | 117 | 41 |
| Male | 2017 | 56 | 168 | 59 |

and disadvantages of telehealth, with a special focus on barriers overcome or created by distanced visits. All interviews took place between September 1, 2020, and July 31, 2021.

## RESULTS
### Effect of Telehealth on Show Rates
Via the EDCC, 3613 in-person visits were scheduled between April 5, 2018, and March 23, 2020; 284 telehealth visits were scheduled between March 24, 2020, and March 31, 2021. As seen in the Figure, alongside the change in modality and decrease in referral volume, overall show rate increased, totaling 43% for in-person visits and 59% for telehealth visits.

As this shift in modality occurred, the patient panel demographics shifted slightly alongside it, as demonstrated in Table 1. Two of the larger FQHCs handled 90% of telehealth visits, with a third handling the rest. The EDCC referral pool during COVID was slightly older and more male, with uninsured patients eclipsing Medicaid as the most common insurance status. On univariate analysis, the decrease in no-show rate retained statistical significance when controlling for concurrent changes in patient demographics, insurance status, clinic location, and appointment lead time as shown in Table 2.

When looking at show rates comparing telehealth to in-person visits, there was a significant difference, with telehealth visits having an increased likelihood of attendance ($P=0.002$). There was also a significant difference in show rates when examining other factors, including across the different FQHCs ($P\leq 0.0001$). When examining show rates based on the number of days from ED visits to appointment, there was a significant difference, with patients seen within 5 days of their ED visit having an increased likelihood of attending ($P\leq 0.0001$). Insurance type also was examined, and uninsured patients were seen as more likely to attend than other insurance types ($P=0.012$). Patient age also showed a significant difference, with older and middle-aged patients being more likely to attend than younger patients ($P\leq 0.0001$). However, there was not a significant difference when comparing show rates by sex ($P=0.96$).

### Patient/Provider Interviews
Surveys were posed to 50 patients following a telehealth visit at 2 FQHCs; 28% (14 patients) opted in. Sixty-four percent (n = 9) reported feeling prepared for their visit, with the remaining 5 patients remarking that instructions were not available in Spanish or that the distinction between phone versus video visits was not made clear by EDCC staff in the ED. Though 86% of patients surveyed felt that telehealth appointments were more accessible, citing barriers in transportation and childcare as the main factors, just 36% stated that they preferred a virtual visit to an in-person visit. However, of those who preferred an in-person visit, 78% said that they would consider making another telehealth appointment.

Twenty-one FQHC and free clinic providers also were interviewed via an unstructured format through existing communication channels. All clinicians we approached participated in the interview. Many reported that a higher-than-expected share of their patient panel was able to access video or telephonic technology, which improved clinic workflow. By screening patients for COVID symptoms and exposure before in-person visits, physicians at high personal risk could continue to safely resume their practice, even without a full vaccination course. Physicians who had previously incorporated telehealth into their practice said that higher Medicaid/Medicare reimbursement (due to emergency legislation) was a key piece in allowing clinics to expand virtual visits to the degree necessary over the early months of the pandemic.

## DISCUSSION
Prior to March 2020, the EDCC program had never recorded a show rate greater than 47%. This was attributed to numerous factors, some of which were procedural. For example, longer lead times before appointments previously had been associated with lower show rates. However, other proposed factors included social determinants of health that prevent patients from reaching the receiving clinic, such as childcare responsibilities or lack of transportation. Telehealth has demonstrated promise as a solution for patients affected by barriers like these, and the significant increase in show rate to nearly 60% as the EDCC transitioned to virtual

appointments supports the notion that telehealth may be more accessible for some segments of these vulnerable patients.

One factor playing a role in the increased show rate is the notably decreased lead time before appointments. The EDCC previously determined that scheduling an appointment within 5 days is a best practice, and the flexibility of telehealth allows for this practice to be implemented more smoothly. Another potential explanation lies with the FQHC distribution – two of the larger FQHCs took the majority of telehealth patients, and it is possible that the community connections formed before the pandemic helped these clinics function more efficiently during the pandemic. However, the regression suggests that neither lead time nor receiving clinic identity accounted for the full magnitude of change seen during the study period.

Additionally, patients cited neither of these criteria when asked about the increase in show rate, instead discussing almost exclusively the overall convenience of telehealth. The majority of patients—even those who later stated they preferred in-person visits—identified telehealth as more accessible. When asked why, most identified the ability to stay home with children during the appointment and/or not having to make use of public transit and associated affordability issues. In Milwaukee's low-income communities, these barriers often go hand-in-hand; Medicaid's nonemergency medical transport facilitates transport to appointments, but it cannot accommodate children—even if the patient is the sole caretaker. Telehealth visits allowed patients with young dependents to sidestep both hurdles at once.

Providers largely identified pandemic-specific factors, such as clinic flow improvement and staff safety, as benefits of telehealth. For elderly or immunosuppressed clinic providers, telehealth represented the sole mechanism of providing care without undertaking prohibitive personal risk; this benefit was a particular lifeline for free clinics, many of which rely on retired volunteer physicians. Even outside of free clinics, telehealth visits served as an effective triage mechanism, allowing receiving clinics to manage patient load efficiently. However, as the threat of dangerous infectious disease wanes, the benefit of both of these factors will likely decline alongside it.

Both patients and clinicians also identified drawbacks to the widespread use of telehealth. While simplifying clinic flow on the provider end, patients with somatic complaints often ended up scheduling an additional in-person visit afterwards, erasing any convenience benefit gained from the initial virtual visit. While the majority of patients were able to successfully adjust to video technology, some older patients found the software too difficult to use – although telephonic visits were generally accessible for all age groups. Additionally, information for logging into many of these platforms was only available in English, and the incorporation of interpreters during virtual visits remained a challenge, both of which limited telehealth efficacy for Milwaukee's substantial non-English-speaking population. Clinicians also reported that some patients rejected an EDCC referral after learning that it would take place via telehealth because they only wanted to be seen in person. Overall, the majority of patients surveyed stated that they preferred an in-person visit if given a choice.

**Table 2.** Show Rates Categorized by Individual Factors

| | Attended | Did Not Attend | Grand Total | Show Rate % | Odds Ratio (95% CI) | P value |
|---|---|---|---|---|---|---|
| **Telehealth visit** | | | | | | |
| Overall telehealth comparison | | | | | | 0.002 |
| No | 1547 | 2065 | 3612 | 43 | | |
| Yes vs No | 169 | 116 | 285 | 59 | (0.515 – 0.857) | 0.002 |
| Total | 1716 | 2181 | 3897 | 44 | | |
| **Federally Qualified Health Centers (FQHC)** | | | | | | |
| Overall FQHC comparison | | | | | | 0.0001 |
| Clinic A | 490 | 475 | 965 | 51 | | |
| Clinic B vs A | 537 | 530 | 1067 | 50 | (0.352 – 0.686) | 0.311 |
| Clinic C vs A | 301 | 487 | 788 | 38 | (0.332 – 0.645) | 0.435 |
| Clinic D vs A | 327 | 556 | 883 | 37 | (0.383 – 0.780) | 0.0001 |
| Clinic E vs A | 61 | 133 | 194 | 31 | (0.471 – 0.983) | 0.0001 |
| Total | 1716 | 2181 | 3897 | 44 | | |
| **Lead Time (Days)** | | | | | | |
| Overall Lead Time Comparison | | | | | | 0.0001 |
| 0 – 5 vs 0 – 5 | 855 | 837 | 1692 | 51 | | |
| 6 – 10 vs 0 – 5 | 560 | 749 | 1309 | 43 | (1.121 – 1.521) | 0.001 |
| 11 – 15 vs 0 – 5 | 167 | 289 | 456 | 37 | (1.256 – 2.009) | 0.0001 |
| 16+ vs 0 – 5 | 134 | 306 | 440 | 30 | (1.540 – 2.369) | 0.0001 |
| Total | 1716 | 2181 | 3897 | 44 | | |
| **Insurance** | | | | | | |
| Overall insurance comparison | | | | | | 0.012 |
| Uninsured | 789 | 1143 | 1932 | 41 | | |
| Commercial vs uninsured | 80 | 98 | 178 | 45 | (0.361 – 0.829) | 0.004 |
| Medicaid vs uninsured | 793 | 864 | 1657 | 48 | (0.333 – 0.913) | 0.021 |
| Medicare vs uninsured | 54 | 76 | 130 | 42 | (0.420 – 0.961) | 0.032 |
| Total | 1716 | 2181 | 3897 | 44 | | |
| **Age** | | | | | | |
| Overall age comparison | | | | | | 0.0001 |
| 16 – 39 | 925 | 1445 | 2370 | 39 | | |
| 40 – 64 vs 16 – 39 | 738 | 698 | 1436 | 51 | (1.733 – 4.563) | 0.0001 |
| 65+ vs 16 – 39 | 53 | 38 | 91 | 58 | (1.054 – 2.772) | 0.03 |
| Total | 1716 | 2181 | 3897 | 44 | | |
| **Sex** | | | | | | |
| Overall sex comparison | | | | | | 0.960 |
| Female | 732 | 980 | 1712 | 43 | | |
| Male vs female | 984 | 1201 | 2185 | 45 | (0.873 – 1.138) | 0.960 |
| Total | 1716 | 2181 | 3897 | 44 | | |

It must be noted that the onset of telehealth adoption in this study coincided with COVID-19, which itself produced far-reaching effects in the public's relationship to health care and may serve as a confounder. It is possible that with public consciousness focused on health, show rate at in-person visits may have increased at a proportional rate if offered. Additionally, the precipitous decline in EDCC referrals after telehealth adoption, in addition to the uneven distribution of referrals to FQHCs during the pandemic, may have directly affected the show rate. Though partly due to lower ED volumes and fewer available ED staff that made these referrals, it also may represent patients self-selecting for those willing and able to attend a virtual visit. The combination of these circumstances, in addition to the limited number of patient and provider interviews, limit the generalizability of these findings, and further research is needed to determine the sustained impact of telehealth as the pandemic wanes.

## CONCLUSIONS

Show rate at primary care follow-up appointments after ED discharge increased upon adoption of telehealth. Patients and clinicians generally had positive perception of telehealth appointments and identified specific barriers to care overcome by telehealth appointments; however, challenges remain in developing efficient and equitable practice guidelines. Further research is needed to understand which populations benefit most from telehealth use, whether these benefits will persist after the pandemic, and what additional strategies might help patients attend their telehealth appointments.

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# Surveillance of SARS-CoV-2 in Asymptomatic Faculty and Staff at the University of Wisconsin-Madison

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## ABSTRACT

**Introduction:** Surveillance of SARS-CoV-2 among university employees is an important part of mitigation strategies to prevent asymptomatic transmission and ensure a safe learning and work environment. Here, we assess the feasibility and performance of a program that relies on monitored self-collected nasal swabs to detect SARS-CoV-2 among asymptomatic faculty and staff.

**Methods:** We recruited 1,030 faculty and staff via rolling enrollment who completed the required University of Wisconsin-Madison employee COVID-19 training and reported working on campus. Asymptomatic participants visited a designated location during a specified timeframe each week where they self-collected nasal swabs supervised by study staff. Specimens were stored in a cooler between 2 °C and 8 °C, then transported to the Wisconsin Veterinary Diagnostic Laboratory for polymerase chain reaction testing. Symptomatic participants or participants with a known exposure were advised to test elsewhere and follow quarantine guidelines from the Centers for Disease Control and Prevention.

**Results:** Over the course of 31 weeks, 1,030 participants self-collected 17,323 monitored nasal swabs resulting in high participation (90%). SARS-CoV-2 was detected in 16 specimens. Eight specimens were inconclusive but were treated as positive results because of the implied detection of 1 or more SARS-CoV-2 genes. There were no invalid tests. Weekly SARS-CoV-2 incidence among participants ranged from 0 to 1.54% ($\bar{x}$ = 0.20%). The SARS-CoV-2 incidence among participants was similar to estimated incidence in the greater university employee population.

**Conclusion:** Weekly SARS-CoV-2 surveillance of asymptomatic faculty and staff on campus allowed for estimation of weekly SARS-CoV-2 incidence among on-campus employees. This surveillance protocol presents a low-cost, effective, and scalable option to identify asymptomatic cases of SARS-CoV-2 among university employees.

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## INTRODUCTION

In response to the coronavirus disease 2019 (COVID-19) pandemic, the University of Wisconsin – Madison (UW – Madison) joined other institutions of higher education across the United States and quickly transitioned to online instruction starting March 23, 2020, when students were scheduled to return from spring break. Access to campus facilities and in-person activities were limited throughout the summer as leadership discussed how to safely reopen for the fall semester. One of the primary concerns was how to identify and disrupt asymptomatic transmission.

A limited number of essential faculty and staff were allowed to return to the UW–Madison campus during the spring and summer months of 2020. Individuals were required to apply for approval and undergo COVID-19 safety training. By August 2020, approximately 7,000 of 19,225 (36.4%) faculty and staff had returned for work on campus.

Approaches to ensuring safe in-person learning and work environments varied greatly across institutions due to cost, logistics, testing supply shortages, and laboratory capacity.[1] There is a growing body of research dedicated to campus testing strategies,[2-5] primarily aimed at students, but none of the studies focus on faculty and staff. At the UW–Madison, it was necessary to (1) assess whether it was safe for employees to return to campus, and (2) provide early warning should an acceleration in incidence of SARS-CoV-2 be etected, particularly in asymptomatic or presymptomatic individuals.[6] Our goal, therefore, was to implement cost-

effective SARS-CoV-2 surveillance to detect asymptomatic cases, estimate weekly incidence of SARS-CoV-2, provide reassurance to returning faculty and staff, and support continued university operations. This report reviews the UW–Madison SARS-CoV-2 Incidence Surveillance Program (UWSISP) and evaluates its function over a 31-week period.

## METHODS

All surveillance program study participants were UW–Madison employees who reported working on campus in some capacity and had completed the required UW employee COVID-19 training for on-campus workers. The surveillance program was considered a research study. The protocol was reviewed and approved by the UW Health Sciences Minimal Risk Institutional Review Board and was conducted in compliance with human subjects' protection policies.

The target surveillance population was 1,000 individuals based on estimated likelihood of ≥95% to detect a weekly incidence of ≥0.3% using calculators from the Influenza Virologic Surveillance Right Size Roadmap.[7] This also allowed for confidence intervals around point estimates of ≤0.25%.

Recruitment began with an email notice and invitation to join the study with an embedded link for an online Qualtrics survey (Qualtrics, Provo, Utah) that included questions to ensure eligibility. Contact information of interested, eligible UW–Madison employees was imported into a secure REDCap database, and potential participants were sent a consent form and screening survey.[8]

Upon completion and confirmation, participants were enrolled and assigned to their preferred weekly time slot and campus location. Enrolled subjects received a weekly reminder text message via their mobile phone that included a link to a survey addressing general health, COVID-19 symptoms, expected work attendance, and recent travel. Sending a link either via email or text to a smart phone allowed for encrypted communication. This process was automated through REDCap survey distribution tools. If subjects reported fever, shortness of breath, and/or cough, they were directed to a dedicated COVID-19 test site.

University-owned minivans parked at 3 designated locations served as specimen collection sites. Surveillance staff provided each participant with a collection kit that included a nasal swab, a container filled with phosphate-buffered saline, and an absorbent pad in a biohazard bag. Participants reviewed a video (https://www.youtube.com/watch?v=EnD1SVZc9j4) on how to obtain an anterior nasal swab specimen prior to their first collection; written instructions were available, and staff coached participants as needed. Surveillance staff monitored the collection process. Participants provided weekly monitored nasal swab specimens for SARS-CoV-2 testing.[9] Specimen containers were tightly sealed by participants, placed into a biohazard bag with an absorbent pad, and placed into a cooler between 2 °C and 8 °C. Samples were transported by surveillance staff to the Wisconsin Veterinary Diagnostic Laboratory (WVDL) for testing.

From week 1 through week 9, specimens were tested for SARS-CoV-2 at WVDL using the polymerase chain reaction (PCR) assay developed by the Centers for Disease Control and Prevention (CDC) and the TaqPath COVID-19 ThermoFisher assay.[10] Starting on week 10, WVDL began using a laboratory-developed test (LDT) modeled after the original real-time PCR assay developed by the CDC and used the TaqPath assay for confirmatory testing on inconclusive specimens. On week 18, WVDL switched exclusively to the LDT assay. The TaqPath assay has emergency use authorization from the US Food and Drug Administration. Emergency use authorization for the LDT was submitted on September 4, 2020, and currently is still under review.

Results of each specimen, coded with a unique identifier, were provided to the surveillance team through a secure server, usually within 24 hours from collection time. The data were entered into a password-protected, dual-authenticated REDCap database daily. Negative results were not routinely shared with participants. A positive result prompted an immediate phone call to the participant.

As mandated, identifiable information and data were shared with Public Health Madison and Dane County, the Wisconsin Department of Health Services Division of Public Health, and University Health Services (UHS) for the purposes of contact tracing. UW–Madison campus officials (UHS and Office of Human Resources) also were notified to address public health prevention measures on campus and to ensure appropriate cleaning of work areas. Test results were not recorded in employee personnel files.

Weekly incidence rates and 95% confidence intervals were calculated using standard methods. During the same time period as our surveillance program, UHS operated several locations on campus for drop-in testing of students and employees. Testing for SARS-CoV-2 in symptomatic and asymptomatic faculty and staff provided a background comparator to assess the validity of incidence estimates generated in the surveillance program. We used a denominator of 7,000 faculty and staff for the drop-in testing population based on the approximate number of employees who had received online training for return to campus.

## RESULTS

Participants were recruited on a rolling basis to allow for a gradual increase in supply production, time to formulate a system for weekly organization and distribution of kits, and to assess feasibility of the protocol on a small scale before expansion (Figure 1). Recruitment via Qualtrics invitations began on August 10, 2020, and the first group of 48 participants was enrolled to begin surveillance the week of August 24, 2020. Weekly enrollment increased steadily by an average of 18% per week until week 23, at which time the university implemented mandatory, campus-wide COVID-19 saliva testing for employees and students during the Spring 2021 semester, and new enrollment in our study

**Figure 1.** Comparison of Weekly Enrollment Numbers With Weekly Participants Who Collected a Nasal Swab Specimen
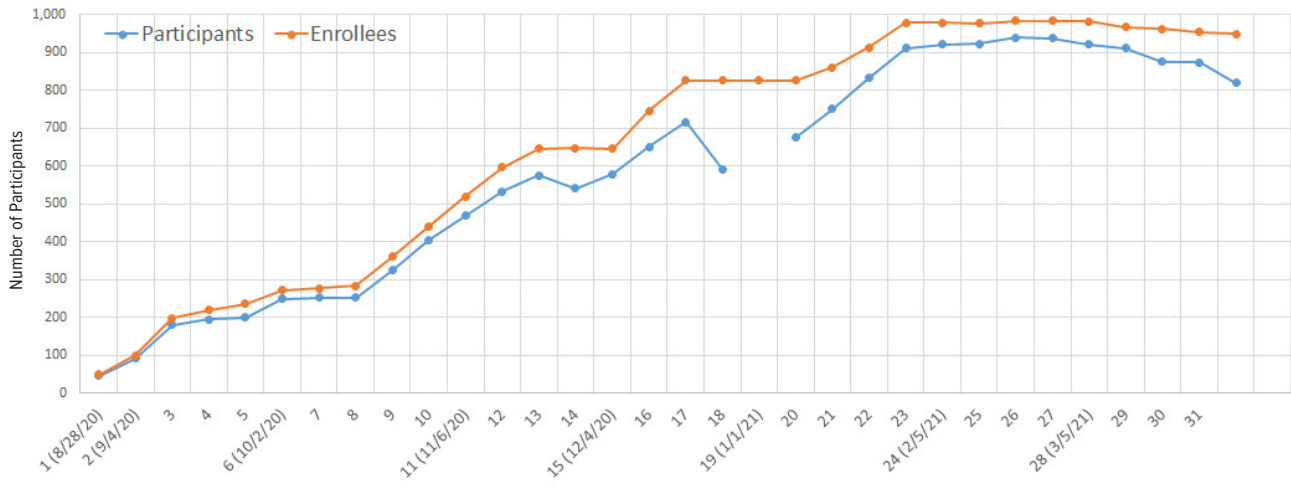
Week 19 represents winter break when few faculty and staff were on campus and the surveillance program was suspended.

was paused (Table 1). Overall compliance of the surveillance participants was 90.0% (95% CI, 89.5-90.4).

Over the course of 31 weeks, 1,030 participants self-collected 17,323 monitored nasal swabs; SARS-CoV-2 was detected in 16 specimens. Eight of these specimens were inconclusive. Inconclusive results, however, were treated as positive results because of the implied detection of 1 or more SARS-CoV-2 genes and to give a conservative estimate of incidence. Positive specimens were indicated by the amplification of 2 or 3 of the 3 gene targets when using the CDC-developed assay during week 1 through week 9 or both SARS-CoV-2 gene targets when using the LDT PCR assay developed by WVDL from week 10 through week 31. Weekly SARS-CoV-2 incidence among participants ranged from 0 to 1.54% ($\bar{x}$ = 0.20%), as shown in Figure 2.

Participants were invited to return for weekly testing 14 days after their initial positive result. Two of the 16 positive specimens were from participants who had previously tested positive for SARS-CoV-2 in our study within 90 days and were likely residual positive results from initial infection. Follow-up surveys were available for 9 of the 14 participants with a SARS-CoV-2 detection. Three partici-

**Table 1.** University of Wisconsin SARS-CoV-2 Incidence Surveillance Program (UWSISP) Weekly Enrollment and Testing Statistics

| Study Week (Start Date) | No. Enrolled | Specimens Tested | Attendance Rate | Inconclusive Specimens | SARS-CoV-2 Positive Specimens | UWSISP SARS-CoV-2 Prevalence | New SARS-CoV-2 Cases in Dane County |
|---|---|---|---|---|---|---|---|
| 1 (8/28/20) | 48 | 46 | 96% | 0 | 0 | 0.00% | 520.000 |
| 2 (9/4/20) | 99 | 91 | 92% | 0 | 0 | 0.00% | 1493.000 |
| 3 (9/11/20) | 198 | 180 | 91% | 2 | 0 | 1.11% | 1143.000 |
| 4 (9/18/20) | 219 | 195 | 89% | 2 | 1 | 1.54% | 895.000 |
| 5 (9/25/20) | 236 | 200 | 85% | 0 | 0 | 0.00% | 867.000 |
| 6 (10/2/20) | 271 | 249 | 92% | 0 | 0 | 0.00% | 843.000 |
| 7 (10/9/20) | 277 | 252 | 91% | 0 | 0 | 0.00% | 1278.000 |
| 8 10/16/20) | 283 | 252 | 89% | 0 | 0 | 0.00% | 1292.000 |
| 9 (10/23/20) | 361 | 325 | 90% | 0 | 0 | 0.00% | 2020.000 |
| 10 (10/30/20) | 441 | 404 | 92% | 0 | 1 | 0.25% | 2451.000 |
| 11 (11/6/20) | 517 | 469 | 91% | 2 | 1 | 0.64% | 3203.000 |
| 12 (11/13/20) | 596 | 533 | 89% | 0 | 1 | 0.19% | 3246.000 |
| 13 (11/20/20) | 646 | 576 | 89% | 0 | 3 | 0.52% | 2162.000 |
| 14 (11/27/20) | 646 | 541 | 84% | 0 | 1 | 0.18% | 1812.000 |
| 15 (12/4/20) | 646 | 578 | 89% | 0 | 2 | 0.35% | 1372.000 |
| 16 (12/11/20) | 746 | 650 | 87% | 0 | 0 | 0.00% | 1221.000 |
| 17 (12/18/20) | 826 | 717 | 87% | 0 | 2 | 0.28% | 1032.000 |
| 18 (12/25/20) | 826 | 592 | 72% | 0 | 1 | 0.17% | 1199.000 |
| 19 (1/1/21) | | | | | | | 1419.000 |
| 20 (1/8/21) | 826 | 675 | 82% | 1 | 1 | 0.30% | 1170.000 |
| 21 (1/15/21) | 860 | 750 | 87% | 0 | 0 | 0.00% | 856.000 |
| 22 (1/22/21) | 913 | 833 | 91% | 0 | 2 | 0.24% | 837.000 |
| 23 (1/29/21) | 979 | 911 | 93% | 0 | 0 | 0.00% | 819.000 |
| 24 (2/5/21) | 978 | 922 | 94% | 1 | 0 | 0.11% | 624.000 |
| 25 (2/12/21) | 977 | 923 | 94% | 0 | 0 | 0.00% | 654.000 |
| 26 (2/19/21) | 984 | 939 | 95% | 0 | 0 | 0.00% | 496.000 |
| 27 (2/26/21) | 984 | 938 | 95% | 0 | 0 | 0.00% | 465.000 |
| 28 (3/5/21) | 982 | 922 | 94% | 0 | 0 | 0.00% | 383.000 |
| 29 (3/12/21) | 968 | 912 | 94% | 0 | 0 | 0.00% | 325.000 |
| 30 (3/19/21) | 962 | 875 | 91% | 0 | 0 | 0.00% | 332.000 |
| 31 (3/26/21) | 954 | 873 | 92% | 0 | 0 | 0.00% | 381.000 |

New weekly case counts of SARS-CoV-2 in the surrounding community of Dane County, Wisconsin, included for comparison. Inconclusive and positive specimens were combined to calculate weekly incidence.

**Figure 2.** Estimated Incidence of SARS-CoV-2 Among University of Wisconsin-Madison Faculty, Staff, and Graduate Assistants (green line), With 95% CIs (red lines)
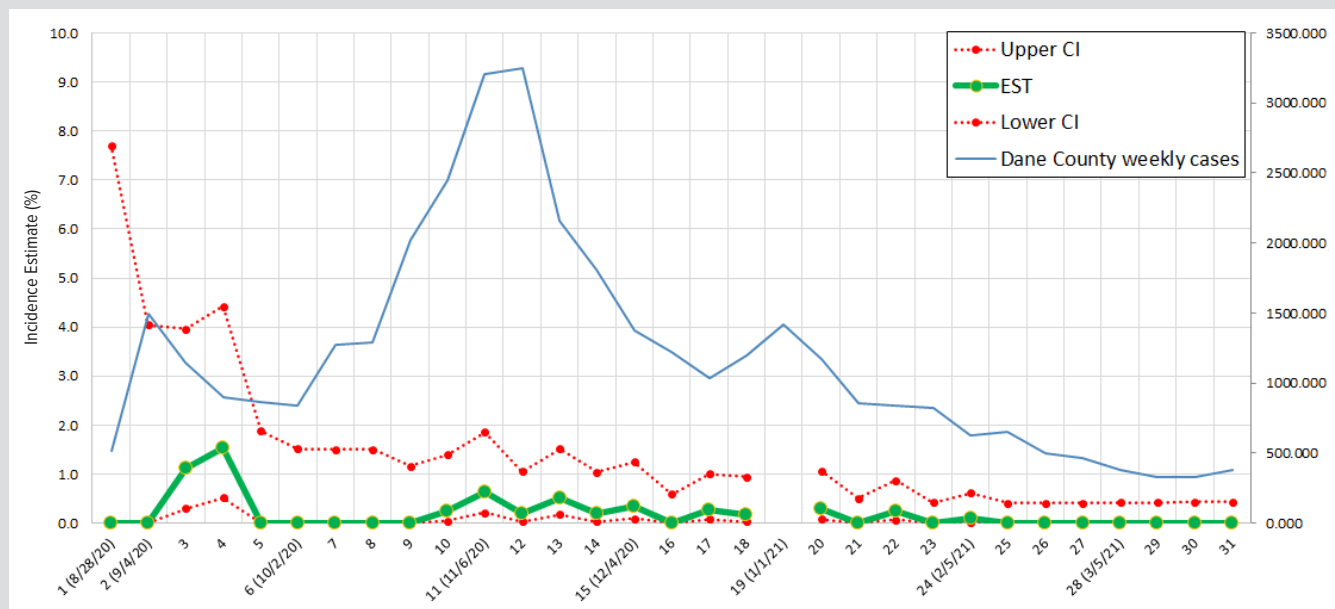


New weekly cases in Dane County (blue line) juxtaposed for comparison. Specimens were not collected the week of January 1, 2021 (week 19) due to anticipated diminished number of employees on campus during the holidays.

**Table 2.** University of Wisconsin SARS-CoV-2 Incidence Surveillance Program Participant Demographics and Characteristics

| Characteristic | Total, n (%) |
|---|---|
| Total participants | 1,030 |
| Sex | |
| Female | 602 (58.4) |
| Male | 423 (41.1) |
| Declined response | 5 (0.5) |
| Age (mean, [range]) | 40.4 [18.9-77.2] |
| Race | |
| Asian | 76 (7.4) |
| Black/African American | 15 (1.5) |
| White | 883 (85.7) |
| American Indian/Alaska Native | 2 (0.2) |
| Unknown/not reported | 25 (2.4) |
| 2+ races | 29 (2.8) |
| Ethnicity | |
| Hispanic/Latino | 43 (4.2) |
| Non-Hispanic or Latino | 968 (94.0) |
| Declined response | 19 (1.8) |
| University position | |
| Academic staff | 338 (32.8) |
| Administrative staff | 24 (2.3) |
| Faculty | 152 (14.8) |
| Graduate students | 266 (25.8) |
| Postdoctoral students | 31 (3.0) |
| University staff | 187 (18.2) |
| Other | 32 (3.1) |

pants developed symptoms by the following week and would be considered presymptomatic at the time of specimen collection, while 6 remained asymptomatic. The overall prevalence of SARS-CoV-2 in this asymptomatic cohort was estimated to be 1.4% (95% CI, 0.8-2.3%). The 14 participants who tested positive

for SARS-CoV-2 were distributed across 13 departments and 12 work buildings and were unlikely to represent on-campus transmission. Two participants reported working at UW Hospital on different floors and in different departments, and 3 participants cited Wisconsin Institutes for Medical Research as their worksite but reported working on different floors of the facility.

Demographics were evaluated for all participants enrolled at any point in the study and are largely representative of the general employee population at UW–Madison (Table 2). A majority of participants were female (58.4%), White (85.7%), and non-Hispanic (94.0%). Participants ranged in age from 18.9 years to 77.2 years, with a mean age of 40.4 years (SD 13.5). Home addresses from 58 cities and townships were provided, the most common being Madison (69%).

Of UW–Madison's 37 divisions and 521 departments with individuals who completed the UW employee COVID-19 training for on-campus workers, study participation encompassed individuals from 30 (81%) divisions and 221 (42%) departments. Positions held by participants varied widely and included academic staff, graduate students employed as teaching assistants, research assistants and fellows, university staff, faculty, postdoctoral students, and administrative staff.

Eighty-one participants withdrew from the study at various points, some because of retirement or ending employment with UW–Madison (n=13), a move out of state or change to working off-campus (n=9), or another reason that made it difficult to get to the collection site on a weekly basis (n=11). A majority of withdrawals (n=33) occurred after university officials lifted the mandated weekly testing requirement for vaccinated individuals on week 29.

**Figure 3.** Confidence Intervals Derived From University of Wisconsin SARS-CoV-2 Incidence Surveillance Program Weekly Incidence Data Compared With Actual Incidence Demonstrated by Weekly Cases Detected at University Health Services Among UW–Madison Faculty and Staff
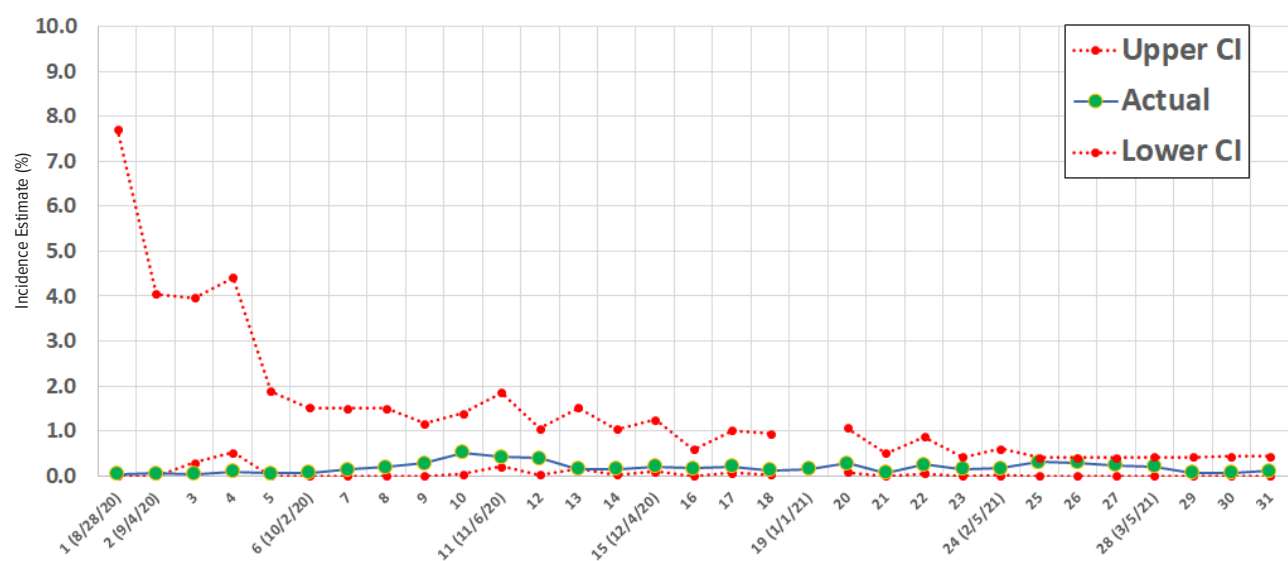
Weekly incidence of SARS-CoV-2 among UW employees, calculated from available UHS testing data, ranged from 0.043 to 0.529% and remained within the 95% confidence intervals determined using our asymptomatic cohort, except in weeks 3 and 4 (Figure 3). During those weeks, very few faculty and staff presented for specimen collection at the campus drop-in testing centers and WVDL reported 4 inconclusive results in the surveillance population. When counted as positives, these specimens accounted for 80% of positive results for those 2 weeks. Incidence estimates based on drop-in testing cases of staff and faculty peaked on week 10 (0.529%, Figure 3), corresponding well with a peak in incidence estimates within the UWSISP population on week 11 (0.640%, Figure 2).

## DISCUSSION

This is one of the first studies to our knowledge that evaluates regular weekly SARS-CoV-2 testing of asymptomatic faculty and staff in an academic setting. Very low weekly incidence rates of SARS-CoV-2 were found in this cohort between August 2020 and March 2021. This is in contrast to high incidence within on-campus and off-campus students and widespread cases of SARS-CoV-2 in the surrounding community of Dane County (Figure 2, Table 1).[11] Our results concur with evidence from several surveillance studies of college students, suggesting transmission among asymptomatic individuals in campus settings is limited.[12,13] The surveillance protocol reported in this paper allowed researchers at UW to efficiently evaluate the weekly incidence of SARS-CoV-2 in asymptomatic employees, thus providing ongoing situational awareness of the potential for on-campus transmission and enabling employees to return to work to perform essential activities during the COVID-19 pandemic. Results were communicated regularly to campus officials, who used the data to update the UW–Madison COVID-19 dashboard and keep employees informed on detection rates and transmission activity. This information provided reassurance for on-campus employees and evidence that mitigation strategies were working to ensure the UW–Madison campus was a safe work environment during the SARS-CoV-2 pandemic.

This surveillance program also demonstrates and fulfills key principles of the CDC Framework for Evaluating Public Health Surveillance Systems, namely those associated with outbreak detection (timeliness and validity) and systems experience (system acceptability, portability, and system costs).[14]

### Timeliness

Participant results were available via an online data portal within 24 hours of specimen collection, at which time positive results were reported to the participant and to UW campus officials to enable appropriate infection control practices, and to the Wisconsin Department of Health Services Division of Public Health to facilitate contact tracing and disease monitoring. This expedited timeframe allowed participants with positive test results to rapidly isolate and gave UW officials the chance to quickly enact public health interventions per UW campus protocol. As participants were tested on a weekly basis, the interval between an exposure to SARS-CoV-2 and a positive test result was consistently minimized.

### Validity

Our program is unique in that complementary testing data from the entire on-campus faculty and staff population were available for comparison from UHS. The SARS-CoV-2 incidence among participants was closely associated with estimated incidence in the greater university employee population reported by UHS, as illus-

trated in Figure 3. The incidence calculated using UHS testing data remained within the confidence intervals estimated from our asymptomatic cohort, except for 2 weeks early in the program and only when 4 inconclusive results were treated as positive results. Accordingly, UWSISP provided an accurate assessment of SARS-CoV-2 activity on campus among UW faculty and staff through systematic, weekly testing of a representative cohort.

### System Acceptability

Five months before the UW mandated weekly testing for all on-campus employees beginning in January 2021, we were able to recruit willing participants at a steady rate, increasing our cohort from 48 in week 1 to 979 in week 23. Although participation was not incentivized and all participants consented to sharing of personal information and results with public health and UW campus officials, 90% of possible specimens were collected. Overall participant retention was 92%, dropping slightly from 96% after the UW dropped the mandated weekly testing requirement for fully vaccinated individuals in week 29. These data, along with strong weekly participation rates and positive anecdotal evidence from participants, support widespread acceptability of our surveillance program.

### Portability

This surveillance system was operated with minimal person-dependent steps and relied on the ability of participants to self-collect a simple, front-of-the-nose nasal swab with staff monitoring. We have previously demonstrated the high acceptability of self-collection of anterior nasal swab specimens.[9] The absence of invalid results and any testing-related errors indicates this procedure is easily taught and performed and could be replicated in similar settings. Test results and data imports were managed through a REDCap online database, and survey invitations sent via Qualtrics survey software, platforms which are accessible and configurable for any organization.

### System Costs

Because this surveillance program involved a subset of asymptomatic faculty and staff, testing costs were limited to less than 1,000 specimens per week, while still providing an accurate estimate of SARS-CoV-2 incidence among on-campus employees. Staffing and operational costs were limited by offering an inclusive variety of specimen collection timeframes at 3 separate on-campus locations and using university fleet vehicles for specimen and supply transportation.

### CONCLUSION

With low average weekly incidence rates (0.20%), high participant retention and participation (92% and 90%, respectively), and no identified clusters of on-campus transmission or outbreaks throughout the study period, this surveillance protocol provided needed situational awareness and high precision estimates of SARS-CoV-2 incidence at a relatively low cost. This approach was an easily scalable, effective alternative to methods involving

mandatory testing of all on-campus employees. Furthermore, self-collected nasal swabs monitored by a trained researcher are a reliable collection medium for SARS-CoV-2 testing, with minimal inconclusive results and no invalid results.

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ORIGINAL RESEARCH

# Acceptability and Preferences of Simulation-Based Continuing Education Among Emergency Medical Service Providers

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## ABSTRACT

**Introduction:** Simulation-based education (SBE) has been shown to be an effective and accepted teaching modality across multiple fields of medical education. Prehospital systems currently utilize simulation for initial training; however, few studies have determined the acceptability of simulation-based training for continuing education among emergency medical service (EMS) providers.

**Methods:** We performed a retrospective mixed method review of data from prehospital provider evaluations of high-fidelity SBE training sessions. Survey responses included questions on a Likert scale pertaining to acceptability of the training, as well as free-text comments. Providers included a mix of crews with varying levels of training.

**Results:** We received a 96% response rate for providers who completed the training. Participants rated simulation as an educational tool and the overall value of the session highly for EMS providers across all levels of training with no difference among training level. All providers also indicated they would like similar training on a frequent basis in the future.

**Conclusion:** Simulation-based education was found to be an acceptable tool for EMS training and should be considered for use during continuing education for all levels of practicing EMS providers. In addition, EMS providers indicated a preference for participating in SBE on a frequent basis. EMS training programs should consider incorporating more frequent SBE.

## INTRODUCTION

Medical education encompasses much more than teaching core material to learners. It is equally important for medical professionals to learn procedural skills, patient communication skills, and interprofessional communication. This multifaceted approach to medical education has led to the expansion of education techniques beyond traditional methods. One such method is simulation-

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based education (SBE), which is defined as any educational activity that utilizes simulation aids to replicate clinical scenarios.[1] Due to its ability to integrate multiple educational objectives into a single training method, SBE has become widely accepted within health care training.[2] This teaching method is integrated into the curriculum of numerous health care professional education programs, including medical schools, pharmacy schools, nursing schools, and residency physician training programs.[3-7] It is now used extensively in emergency medicine residency training programs to teach clinical knowledge and procedural skills, to reinforce the importance of communication, and for performance assessment.[6,8-12] Simulation has been shown to have multiple advantages over traditional teaching methods for emergency medicine physician training, including creating an active learning environment in a controlled setting while providing realistic patient encounters.[13-14] SBE has also traditionally been a part of the initial training of prehospital providers.[15-16]

Current practices in the United States for emergency medical technician training use SBE during primary paramedic training programs, which is supported in the National Registry for Emergency Medical Technician training requirements. Many accredited emergency medical services (EMS) training centers have access to SBE resources of varying degrees of complexity.[14] These high-fidelity simulations use visual and auditory cues in combination with dynamic patient conditions to replicate a realistic clinical patient encounter. As EMS providers also encounter critically ill patients, potential benefits for EMS provider education exist.[17]

SBE also may offer the ability to increase the amount of learning opportunities for EMS providers in need of skill retention for low-frequency, high-acuity prehospital procedures and patient encounters as a tool for continuing education.[18] Recent studies also have suggested using simulation techniques for paramedic performance assessments.[19] In addition to its utility as an educational tool, SBE has been shown to lead to improved clinical outcomes when compared to lecture-focused curricula.[20] Continuing education is required of prehospital providers, with varying state and national requirements for each provider level. For example, Wisconsin paramedics must complete 48 hours of training over each 2-year period to renew their state certification.

A recent systematic review evaluating the use of SBE in nurse practitioner training suggested that in addition to enhancing clinical knowledge, SBE increases student satisfaction with their training when compared to traditional teaching methods.[21] Although SBE is used by many training centers in the initial training for providers at education centers, it has not been widely integrated into continuing education for providers across the United States. A recent study in the field of nursing education explored the utility of using simulation-based learning as a method of continuing training over consecutive years. These researchers found that annual simulation training resulted in increased participant satisfaction, as well as increased self-confidence in targeted training areas.[22] Few existing studies have evaluated the acceptability of continuing simulation education training and evaluation among EMS providers. Additionally, the acceptability of SBE among prehospital providers has not yet been established, and the optimal use of realistic patient simulation outside of the primary paramedic training program remains unknown.

In this study, we aimed to evaluate the acceptability of high-fidelity in situ simulation training among practicing EMS providers. Secondarily, we sought to compare the opinions and perceptions of SBE among various levels of EMS providers.

## METHODS

We performed a retrospective mixed method review of both qualitative and quantitative data from prehospital provider evaluations of high-fidelity SBE training sessions collected over a 2-year period from August 1, 2015, through July 31, 2017. Learners for the SBE training sessions included adult practicing providers at various levels of medical training, including emergency medical technician-basic (EMT-B), advanced emergency medical technician (AEMT), and emergency medical technician-paramedic (EMT-P) providers. The SBE sessions were held as part of the scheduled continuing education training program for licensed EMS providers within the Dane County, Wisconsin EMS system, consisting of 23 transporting 911 EMS agencies. There was a mix of urban, suburban, and rural agencies, as well as a mix of basic life support, AEMT, and advanced life support EMS crews. Training sessions were conducted by a consistent group of emergency medi-

cine and EMS physicians using a portable high-fidelity programmable patient simulator (Simulaids SMART STAT Basic, Nasco). This high-fidelity simulation was purchased by the county EMS office to be shared across all EMS agencies. All educators were experienced instructors and familiar with SBE best practices. Each training session lasted 1 hour for each crew of 2 to 3 EMS providers and included a prebriefed introduction, case-based scenario, and debriefing component. The patient scenarios for each training group were chosen from a pool of 5 cases developed specifically for EMS training sessions by a physician with extensive training and expertise in simulation instruction and case development. Scenarios included a patient with atrial fibrillation with rapid ventricular response (RVR) in the setting of sepsis, a patient with a severe asthma exacerbation, a patient fall with head injury, a motor vehicle collision involving a traumatic amputation, and a patient with angioedema. Each case had predetermined learning objectives and critical interventions appropriate to the training level of the EMS providers.

Simulation parameters were set to realistically represent each clinical case. For instance, in the case of a patient with symptomatic atrial fibrillation with RVR in the setting of sepsis, the portable patient simulator was programmed with parameters to replicate vitals and clinical findings consistent with a patient with these conditions. The simulator was transported by the instructor to the location chosen by the EMS agency for which the training was taking place—usually their EMS station. The simulator was placed on an EMS cot in the agency's own ambulance to enable an in situ simulation. EMS crews worked in small groups of 2 to 3 during simulated patient care, reflecting their usual ambulance staffing model. Learners used the agency's ambulance and training supplies, such as equipment and medications, for the training session to maintain as high-fidelity training as possible. Training sessions were designed to incorporate previously established simulation education best practices as described by Issenberg et al.[13]

Training sessions included a 30-minute simulated case followed by a 30-minute debrief. The debrief session was used to provide a summary of the case, a discussion of approach to the patient, pathophysiology of disease, mechanisms of interventions, and a review of the critical actions expected for appropriate patient care. This approach allowed learners to engage in discussion regarding clinical care and medical training topics, while also allowing time for providers to have their questions answered. Immediately after every training session, each participating provider was asked to voluntarily fill out a paper evaluation survey. The survey asked the learners their opinions and perceptions of SBE as a training tool, as well as the overall quality of the training session. A question assessing how often providers would like to receive similar SBE training in the future was added to the survey later in the study. In addition, the survey included a free-text section for comments on "what you liked" and "areas for improvement." A Likert scale ranging from 1

(very poor) through 5 (very good) was used, and suggested frequency of future SBE training responses included never, quarterly, bimonthly, monthly, biweekly, weekly, and biannually.

Data were deidentified and aggregated for analysis. Demographic characteristics were captured, including provider training level. The primary outcomes of interest were the ratings for "simulation as an educational tool" and "overall value of this session." Comparisons between the 3 groups (EMT-B, AEMT, EMT-P) were then measured using analysis of variance.

## RESULTS

During the 2-year period, we received a total of 268 completed evaluations from the 279 providers who completed the training—a 96% response rate. Of the survey responses, 58 (21.6%) were EMT-B, 33 (12.3%) AEMT, and 177 (66.1%) EMT-P.

Participants rated simulation as an educational tool 4.76 (SD 0.47), 4.76 (SD 0.49), and 4.69 (SD 0.57) for EMT-B, AEMT, and EMT-P providers, respectively ($P = 0.605$) Similarly, participants rated the overall value of the session 4.82 (SD 0.39), 4.79 (SD 0.41), and 4.88 (SD 0.37) for EMT-B, AEMT, and EMT-P providers, respectively ($P = 0.330$). See Figure 1.

A total of 73 providers also were asked to determine how often they would like these training sessions in the future. Responses consisted of "never" (n = 0, 0.0%), "quarterly" (n = 24, 32.8%), "bimonthly" (n = 11, 15.0%), "monthly" (n = 33, 45.2%), "biweekly" (n = 5, 6.8%), "weekly" (n = 1, 1.4%), and "biannually" (n = 1, 1.4%) (Figure 2).

In addition to the questions stated above, free-text comments for SBE training strengths and weaknesses were analyzed for general themes. Representative comments are included in the Table.

Several themes were identified for what providers specifically liked about the SBE training, including the realistic nature of the simulation training, the location of the training within the ambulance setting, and the utility of the debriefing session immediately following the case scenarios for further discussion. Providers also consistently commented favorably regarding the ability to perform hands-on skills. In fact, this was also noted to be a theme for the area of improvement given the many comments suggesting adding more hands-on and procedural skills to the case scenarios.

## DISCUSSION

In this US-based study, EMS providers of all levels reported positive experiences with SBE. Across all levels of training, SBE was rated very highly by trainees in response to "simulation as an educational tool" and "overall value of this session." When assessed on a Likert scale, the average response rates for the use of simulation as an education tool and overall response to the SBE training session were strongly positive, with no statistically significant difference between the level of providers surveyed. This suggests that the utility of SBE training may be accepted among a wide variety of EMS professionals, regardless of their current training



**Figure 1.** Provider Responses to Acceptability of Simulation-Based Continuing Education

Provider impression of simulation as an educational tool
Provider impression of the overall training session
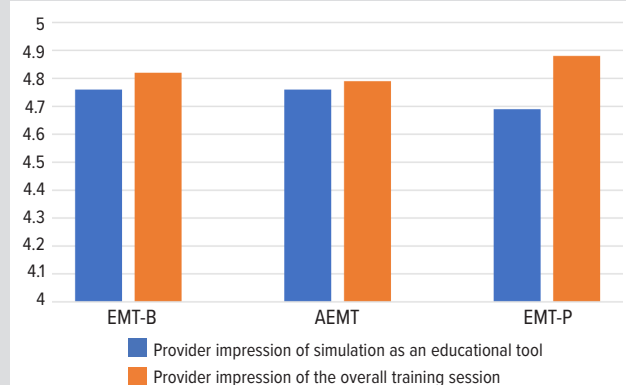
Responses based on 5-point Likert scale.
Abbreviations: EMT-B, emergency medical technician-basic; AEMT, advanced emergency medical technician; EMT-P, emergency medical technician-paramedic.



**Figure 2.** Survey Response to Emergency Medical Services Providers' Preferences for Future Simulation-Based Education Training Sessions
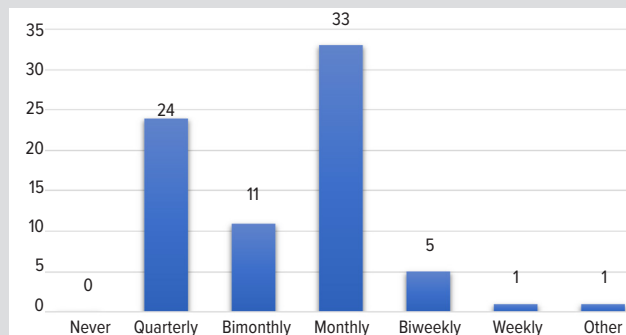
level. Providers at all levels also responded that they would like to have similar simulation training sessions on a regular basis; 98.6% said they would like these sessions at least quarterly. The most popular response (45%) was to have simulation training monthly. This suggests that not only did EMS providers of all levels rate SBE highly, but they would also prefer to participate in SBE on a more frequent basis.

Several specific themes were identified from the survey's free-text comment section for both what providers felt were positive attributes of SBE and suggestions for improvement. Within the positive comments, identifiable themes included the hands-on nature of the simulation, the location of the field training within the prehospital setting, and a positive reaction to the debriefing session following the scenarios. These themes are based on responses such as, "nice to be in our environment (ambulance)," "liked it in the medic unit," "real-life situation…. finally," and "good Q&A; good discussion." There was also an identifiable theme for areas of improvement. Providers consistently stated that they would like future SBE training sessions to incorporate even more proce-

**Table.** Representative Free-Text Survey Responses of Strengths and Weaknesses of Simulation-Based Education Training Sessions Used to Generate Identifiable Themes

| Comments on Strengths | Comments on Areas for Improvement |
|---|---|
| • "Liked it in the medic unit" | • "More hands-on with skills" |
| • "Good Q&A, good discussion, nice to be in our environment (ambulance)" | • "Would be nice to use equipment on patient, ie, blood pressure cuffs, IVs, etc" |
| • "Great discussion afterwards" | • "Incorporate crew actions and note-taking" |
| • "Dynamic changes to sim man based on treatments" | • "Hands-on" |
| • "Hands-on sim man. Talking after the call. Reasoning" | • "More skills" |
| • "Real-life situation.... finally" | • "Actual drawing up meds and pushing" |
| • "Back of rig, real training" | • "Actual radio reports" |
| • "Nice to be in our environment (ambulance)" | • "More hands-on with complicated procedures" |
| • "Continuous challenges and real-life results" | |

Abbreviation: sim man, simulation mannequin.

dural skills. Specific comments included, "more hands-on skills," "would be nice to use more equipment (IVs, blood pressure cuff, etc)," and "actually drawing up meds and pushing, even if into IV arm." In general, the free-text feedback was positive and reflected the high provider ratings given to the SBE sessions. The feedback regarding areas of improvement is useful to further understand how these trainings can improve to generate even greater provider satisfaction in the future.

Our findings are consistent with previous findings suggesting benefit for other health care professional fields, mainly in hospital or professional school settings. Continuing medical education places an increased emphasis on interprofessional communication and teamwork within practicing provider and existing care teams. It has been suggested that to build high quality care teams, teams should learn and train together.[13] For this reason, SBE could be a very efficacious tool in the continuing education of prehospital care teams, allowing them to work on communication skills, medical knowledge, and procedural skills in an educational setting that forces teamwork within a care team unit while simultaneously producing high levels of student satisfaction with their training.

Based on our results, as well as the results of previous studies, we believe there is potential to enhance the level of SBE used for EMS provider continuing education. Specifically, there exists an opportunity to augment the current practices for continuing education of EMS providers, which currently are heavily focused on lecture-based education models for many EMS systems and medical directors. It is our belief that SBE should be included and encouraged as a training modality for continuing education of EMS providers. The optimal simulation training interval may vary based on the location of EMS services and their annual call volume. It is likely that more frequent training would further benefit providers who are exposed to less call volume and severity throughout the year. Based on the survey responses, we would recommend a continued simulation interval between monthly and quarterly. A consistent interval of SBE may offer significant benefits for providers if inte-

grated in a structured fashion into EMS continuing education.

We believe our experience establishing a county-based simulation training program following a continuing education model of EMS providers was feasible and reproducible. To achieve the same level of success, we would recommend the development of reproducible simulation cases, a patient simulator, training supplies, and educational materials. Immediately following the hands-on simulation component, simulation sessions should include a debriefing session by the instructor. In our experience, having a physician instructor for the debrief discussion was beneficial for the small groups. However, we recognize that EMS instructors at various other levels could potentially be utilized as lead simulation instructors, as this may be more practical for some EMS systems.

### Limitations

Our study has several limitations. First, there is no control group against which to compare the Likert survey responses from the SBE participants. Also, our survey was a customized questionnaire that has not been validated previously to assess the acceptability and preferences of simulation. This study was conducted in a medium-sized Midwest city, which may not reflect the practice and training environment of other EMS systems. While high-fidelity simulations are preferred, not all EMS systems have access to them due to cost. However, this may be attenuated by larger collectives jointly purchasing simulation equipment or renting equipment from a local simulation center. If these options are still unobtainable, low-fidelity simulation is reasonably obtainable by most EMS systems and would suffice. However, this study did not evaluate the preferences of EMS providers using low-fidelity simulation, and their acceptability is being inferred.

We did not include emergency first responder learners in this study and did not differentiate between career providers and volunteers or differentiate providers by their years of experience. Frequency of training was added to the survey midway through the study and only captured a subset of the providers who evaluated SBE as an educational tool. Notably, we did not assess patient-level outcomes following the simulation training. Further studies may be required to better account for the above limitations.

### CONCLUSION

Simulation-based education was received positively by EMS providers, without significant differences in acceptability among the various levels of providers, including EMT-B, AEMT, and EMT-P. Simulation education was found to be an acceptable tool for EMS training and should be considered for use during continuing

education for all levels of practicing EMS providers. In addition, EMS providers indicated a preference for participating in SBE on a frequent basis. EMS training programs should consider incorporating more frequent SBE. Further studies are needed to rigorously evaluate the effectiveness of this teaching method for EMS providers.

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# The Effect of Racism and Discrimination on the Health of Milwaukee's African American Population

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## ABSTRACT

**Background:** This scoping review focuses on the intersections of racism, health, and health care, as well as interventions for the African American population in Milwaukee, Wisconsin—one of the most hypersegregated regions in the country. We investigate what existing research provides about the impact of segregation and racism on health and consider how community setting informs health interventions, practice, and policy.

**Methods:** We analyzed studies that address racism and health in Milwaukee to assess the state of the science in this area. We searched databases using the terms "African American," "racism," "segregation," and "health." A total of 296 studies resulted, and 54 met the inclusion criteria.

**Results:** Racism is a known determinant of health. However, a lack of research investigating the impact of racism on health in Milwaukee County leaves a knowledge gap necessary for improving health among African American residents. The adverse effects of racism on health are compounded by the social, economic, and policy context of geographic and social segregation that limit access to care and resilience. Themes identified in the review include measures of physical and mental health, community factors related to health (eg, housing, environmental contamination, economic and social exclusion), intervention strategies, and theoretical gaps.

**Discussion:** Professionals must work across disciplines and social sectors to address the effects of racism on the physical and mental health of African American individuals in urban metropolitan environments. Health research and medical interventions in hypersegregated communities must center structural racism in their analysis.

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## BACKGROUND

Structural racism is a root cause of health inequity in the United States and manifests in unique ways in highly segregated urban metropolitan communities like Milwaukee, Wisconsin. The inequitable allocation of resources (ie, goods, services, societal attention) and the organization of power affect health outcomes.[1]

For example, health disparities in hypertension, heart disease, stroke, cancer, and diabetes remain a persistent and significant problem, with only minor progress in reducing the gap in health outcomes between the African American and majority White populations.[2] Similarly, a meta-analysis of US research[3] reports that racism is associated with poorer mental health—including depression, anxiety, and psychological stress—and poorer physical health. Age, sex, birthplace, and education level do not moderate the effects of racism on health.[3]

The first official report on African American and White health disparities was written by then Health and Human Services Secretary Margaret Heckler in 1985.[4] This report was followed in 2003 by the Institute of Medicine's report "Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care," which highlighted the body of research documenting the existence of disparities in the delivery of health care services.[5] According to the report, racial and ethnic minorities received fewer interventions for common diseases than White patients.[5] Research consistently shows that racial identity predetermines health care providers' quality of care.[6]

There have been few efforts to assemble reviews of the impact

of racism on health care practices and policy. We argue that this gap limits the understanding of clinicians, educators, scientists, and policymakers of the experience, context, and manner of racism, discrimination, and inequities as they occur in health, thus limiting the responsiveness of interventions to address health disparities. This review aims to guide next steps by addressing the research question, "What is known from the existing literature about the context and recent trends examining racism and discrimination on the health of African Americans in Milwaukee, Wisconsin?"

## CONCEPTUAL FRAMEWORK

Race is a constructed, organized system that categorizes people into artificially created racial groups and then devalues, disempowers, and provides fewer opportunities to racial groups regarded as inferior.[1] Racism normalizes negative attitudes (prejudice) and beliefs (stereotypes) toward racial groups and differential treatment (discrimination) of selected groups by both individuals and within social structures.[2] Divisions among the manufactured social groups define power over resources, leadership, and control. Whiteness, a concept developed through legal and social practices of the 19th and 20th centuries, regulates many human relations and structures, as noted by critical race theory.[7] Constructed racial groups are bereft of any biological basis for their existence. However, in practice, racial divisions carry a great deal of meaning. This is amplified in racially hypersegregated communities where "Whiteness" defines nearly every aspect of daily existence—from housing to education, job opportunity, wealth accumulation, and health. Nationally, there is a growing body of epidemiological evidence documenting racism's adverse health outcomes and effects on mental health.[3]

Critical race theory calls for awareness of how the normalization of race and racism operate at a system level, shaping individual experiences. Developing medical and community health interventions in racially hypersegregated contexts requires the inclusion of measures of racism and its effects on health and methods for disrupting White dominant cultural assumptions across health infrastructures. Health is tied to systems of daily life, racialized distribution of resources, social capital, and the structures inequality perpetuates when policy and practice are infused with racist norms.[7]

Racism often presents as implicit (unconscious) bias (responding to stereotypes based on memory images). Since 1965, support for the principle of equity has increased among White people but not support for policies and laws that increase equity. Structural racism is a multilevel system of ideologies, institutions, and processes that have established racial inequities.[1] Segregation refers to the physical separation of the races in racially distinctive neighborhoods and communities developed to "safeguard" White populations from residential closeness to African American populations. Milwaukee is persistently at or near the top of the most hypersegregated US cities.[8] Only 9% of African Americans in the metropolitan Milwaukee area live outside of the city of Milwaukee.[9]

Racial discrimination is a psychosocial stressor that can lead to adverse health outcomes and altered behavioral patterns that increase health risks. Concentrated poverty (Black populations) and concentrated wealth (White populations) lead to critical health differentials. Health disparities are associated with the institutional and structural racism that for generations has affected housing, neighborhood, and educational quality; employment opportunities; and other essential resources in predominantly African American communities. During the height of home foreclosures in 2008-2010, Massey and Tannen found a direct connection between hypersegregation and foreclosure.[10] Lack of financial resilience and social capital results in great measure from residential segregation, leaving African Americans vulnerable to conditions that increase stress and undermine preventive health practices.[10]

At both the societal and individual levels, racism negatively affects economic status and health by creating a policy environment that is not equal, triggering negative stereotypes and discrimination that foster health-damaging psychological responses, stereotype threats, and internalized racism.[11] For example, segregation in urban environments like Milwaukee leads to divestment in predominantly African American spaces. The resultant poverty in predominantly African American communities serves to further White ideologies that African American people are inherently limited in their ability to advance and contribute to society. Simultaneously, they tout White people as having earned superiority, discounting the advantages provided to them by the very same policies. Limited interactions among African American and White populations result in missed opportunities for understanding equity and diversity, including among White medical professionals.

## METHODS

As an interdisciplinary, multiracial team, we conducted a comprehensive scoping review[12] of research that explores the impact of racism on health inequities experienced by African American residents in Milwaukee. A scoping review synthesizes evidence and maps a body of literature specific to location and identifies primary concepts and gaps in the science. The group includes staff from the City of Milwaukee and the Milwaukee County Office on African American Affairs and university faculty from nursing, sociology, public health, and political science departments. Team members have extensive experience and expertise in health disparities research, epidemiology, and health policy. We aimed to identify and summarize science that defines, describes, and explores the impact of racism on the health status, health care utilization, and health care delivery of Milwaukee's African American population. We conducted this review in 5 phases (see Appendix).

## RESULTS

The researchers used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) as a framework in this review. The Figure is a flowchart of the literature retrieved and

selected. Of the 275 unique articles identified in the initial search, 54 met the inclusion criteria (Table). We identified 4 major content categories with subthemes under each:

1. Measures of health/ill-health included (a) incidence and prevalence of health disparities, (b) physical conditions, (c) mental effects, and (d) institutional barriers.

2. Community factors that promoted racism and affected health or ill-health included (a) environmental contamination; (b) economic, employment, educational, and residential exclusion; (c) historical foundations of exclusion; and (d) violence in the community – structural and direct.

3. Interventions included (a) individual factors, (b) community factors, (c) structural, and (d) research that considered racism as a variable.

4. Theoretical gaps identified a lack of theoretical frameworks in the articles and little direct analysis of racism.

**Measures of Health/Ill-Health**

The studies showed extensive support for claims of Black/White health disparities, including that African American children



**Figure.** PRISMA Flow Diagram of Literature Retrieved and Selected

with private dental insurance had half as many preventive dental procedures as White children.[13] Mohiuddin et al reported that 64% of deaths from asthma occurring in Milwaukee outside a hospital were African American, independent of education and income.[14] Another study reported mental health disparities for African American,[15] while another showed that liver cancer linked to hepatitis C infection rates and alcoholism is more prevalent in poor African American neighborhoods.[16]

Few studies directly measured the health effects of racism. However, an extensive data set that included Milwaukee found that emotional and physical stress symptoms from perceived racial treatment predicted the number of poor mental and physical health days, leading to poorer health.[17p55] The researchers asked, "Within the past 30 days, have you experienced any physical symptoms, for example, headache, upset stomach, tensing of your muscles, or a pounding heart, as a result of how you were treated based on your race?" and "During the past 30 days, have you felt emotionally upset, for example, angry, sad, or frustrated as a result of how you were treated based on your race?"[17] African American people have the highest stress rates, with 18.2% experiencing emotional stress symptoms and 9.8% experiencing physical stress symptoms,

compared to 3.5% and 1.6%, respectively, for White people. They also have a notably high number of poor health days than White people.[17] Another study found that overall segregation leads to worse breast survival outcomes and diagnosis at a later stage.[18]

*Physical Conditions*

Cancer screening allows for early detection of cancer and better outcomes. Beyer et al[19] found that neighborhood conditions affected cancer screening rates. Perceptions of social and physical disorder, fear of crime, and visible garbage in the streets in poor Black neighborhoods correlated with lower cancer screening—especially colorectal screening.[19]

Racism also plays a role in poor outcomes for maternal and fetal health. Preterm births and low birthweight births were 3 times higher for African American women than White women.[20]

HIV/AIDS is a serious health problem among young African American men who have sex with men (MSM).[21] African American MSM are diagnosed with HIV at higher rates than any other group. African Americans comprise 13% of the US population but account for nearly half of all new HIV diagnoses—8 times the diagnosis rate of White individuals.[21] Additionally, African
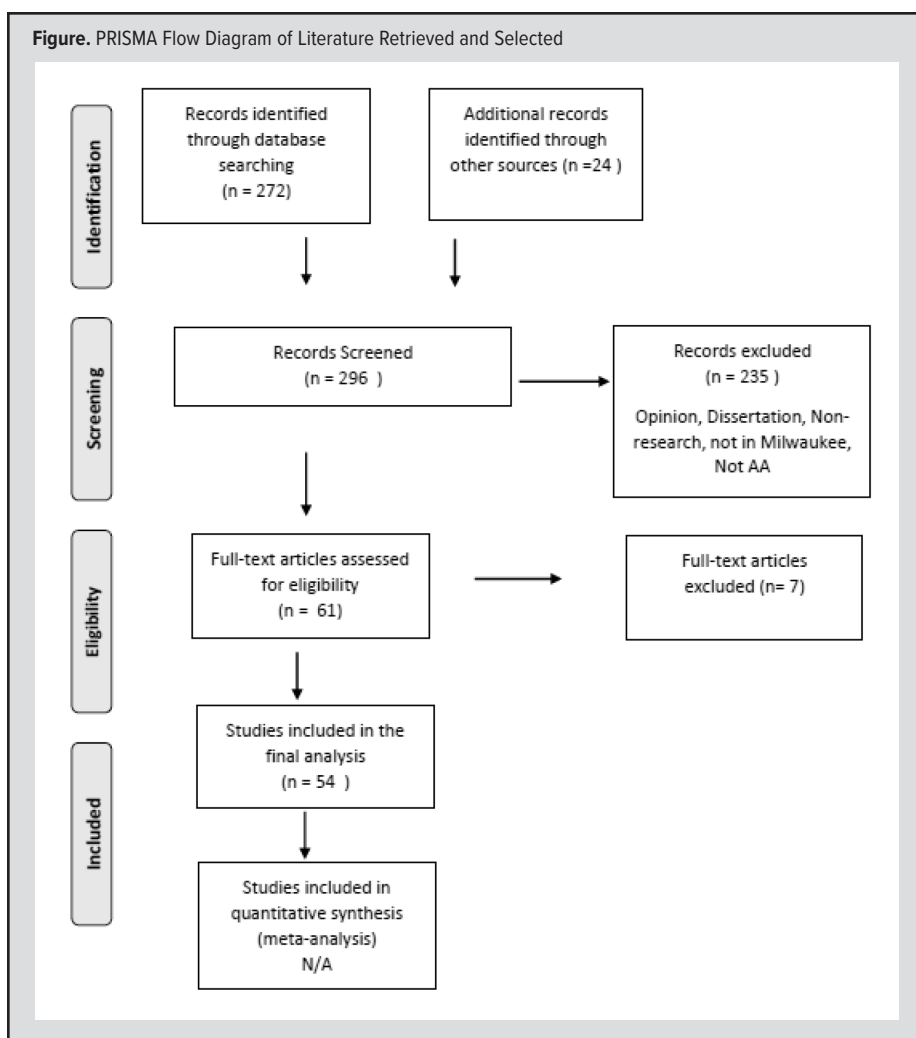
American MSM are less likely to use protection/prevention and have higher HIV/AIDS morbidity, with the highest rates in the highest poverty areas.[21]

Socioeconomic inequities in health influence prevention and intervention efforts. The use of PreP (HIV pre-exposure prophylaxis) is lower in young African American MSM related to the effect of racism and homophobia.[22] They report that previous and anticipated negative interactions with physicians and distrust of the health care system are barriers to their use of PreP.[22] However, interventions with African American men, such as geosocial networking and the use of smartphones mobile applications, have been used to disseminate HIV prevention information to thousands of men.[23]

Milwaukee's infant mortality rate, which is among the highest in the nation, is 2.3 times higher among African American versus White infants.[24] Salm Ward et al studied racial discrimination experiences during prenatal care. They found that institutionalized racism (women report being treated differently by staff and clinicians based on public vs private insurance) and personally mediated racism decreased prenatal care quality.[25] Lifetime racism also leads to poor and inadequate prenatal care. African American mothers were 8 times as likely as White mothers to have insufficient prenatal care and 3 times more likely than poor White mothers to have insufficient prenatal care, contributing to disparities in infant mortality.[26] Ake reports that low employment opportunities, lack of insurance, neighborhood violence, and housing eviction risk are linked to low birth weight.[27] Racism causes chronic stress in pregnant women—especially those living in homeless shelters—affecting birth outcomes.[27] Ngui reports the disparities and factors associated with preterm birth, including race,[20] and finds that parental involvement, paternity status, and welfare reform affect infant mortality.[28] Meanwhile, Johnson et al report that racism, poverty, and perception of stress are contributors to poor maternal and fetal outcomes in African American women in their 20s;[29] and Mazul et al report that barriers to prenatal care for African American women included transportation, insurance, negative attitudes toward prenatal care, perceived poor quality of care, and overall life stress and chaos.[30]

### Mental Health Effects

Physical and emotional stress are pathways by which racism harms health. Cichy reports that African Americans experience more physical reactions to daily family stressors, and these reactions are longer-lasting. Prolonged biological reactivity triggers stress hormones.[31] Chronic upregulation of stress hormones leads to inflammation and chronic diseases, such as hypertension and cardiovascular disease. While people of all races and ethnicities are generally emotionally reactive to daily family stressors, African Americans tend to be more physically reactive.[31] Police brutality is another form of societal stress that fosters poor mental health outcomes among African Americans.[32]

## Community Factors in Health/ Ill-Health Related to Race and Racism

### Connecting Health and Exclusionary Housing Policy

Milwaukee's population has changed over time, from primarily American Indian to White European immigrants, with few African American residents. In 1840, Milwaukee had a population of 20,000, with only a few hundred African American residents. By 1915, Milwaukee had approximately 1500 African American residents, all whom found themselves—even the upper class—consigned to the "colored district" known as "Milwaukee's Little Africa."[33] Redlining began in the 1930s, allowing African American residents to buy homes only in identified areas, and in 2020, the city map looked much the same in terms of racial segregation.[34]

The African American "Great Migration" came later to Milwaukee than many Midwestern cities. Thus, migrants arrived in larger numbers into communities that were already residentially segregated, forcing them into low-quality housing. Housing restrictions intensified due to the increased flow of African Americans into the Milwaukee area in the 1940s and 1950s. Segregation policies led to structural racism and exacerbated poverty while enhancing stereotypes of African Americans as incapable. The economic status of White communities grew, as did White fear of African Americas, and the push to enforce divisions prompted the racialization of policing practices.[35] Threats to health grew as access to care was segregated, and financial stability depended on race.

However, class and race divisions were complex, and clashes ensued.[35] African American workers were excluded from labor unions due to racism, but factory jobs created a middle-class African American Milwaukee with home ownership. Then, in the 1970s, Milwaukee's manufacturing base collapsed, leaving it as one of the many midwestern "rustbelt" cities, with a blighted, low-income inner core of African American residents and White flight to the growing suburbs—a situation that persists. In the 1970s alone, 76% of manufacturing firms left Milwaukee.[36,37]

Some of the largest housing protests in the 1960s were in Milwaukee, with much pushback against displacement and eviction.[38] Jones referred to Milwaukee as "the Selma of the north."[39] After the assassination of Dr Martin Luther King, Jr in 1968, Milwaukee had the largest march in the nation, challenging its black "ghetto" image, evidence of the strength of activism in the city.[39] In 1970, urban flight to the suburbs intensified.[40] Segregation is especially prevalent in the suburbs—most of which range from 85% to 98% White. Racialization of space and the limited interaction between African American and White people led to dramatic disinvestment in the city and a crumbling health care system.[39]

### Environmental Contamination

Discriminatory policies in Milwaukee have created racial patterns of residential housing, and geographic location can be associated with poor health outcomes. For example, research on lead exposure in hypersegregated neighborhoods in north and central

Milwaukee, where most African Americans reside, finds disproportionate exposure.[41,42] Early childhood lead exposure has been linked to hyperactivity and sensory defensiveness, which increase classroom misbehavior. The most common reaction of schools is student suspension, which has important implications for future employment, life trajectories, and overall life chances. Lead-exposed children were twice as likely to be suspended as non-exposed children.[41] Early lead exposure also may influence later decision-making ability and criminal behavior, including firearm violence.[42]

Collins discusses the concept of environmental justice and explains that air pollution is higher in segregated African American areas, and only a few facilities account for all the pollution. Of 299 facilities in Milwaukee, 10% are heavy polluters and cause 90% of the health risk. The facilities are constructed in these areas purposively and exemplify structural racism.[43]

### Economic and Social Exclusion

The 53206 ZIP code in the heart of the city of Milwaukee has been studied extensively and is described as "an ecosystem of disadvantage built on segregation, racial inequality, and historical patterns of discrimination, disinvestment, and official neglect."[44p61] Structural have resulted in fewer available resources in this area, where 95% of the residents are Black, and one-fourth of the housing units are vacant. Examples include high local unemployment due to jobs moving to White-dominated suburbs and loss of health care institutions in poor urban communities Researchers describe the 53206 ZIP code area as a racial segregation prototype, leading to multigenerational poverty, poor infrastructure, and concentrated and cumulative disadvantage.[44] Half of the working-age men are employed compared to 89.4% in the White suburbs. Twenty percent of the employed residents report income below the poverty level.[32] A high school dropout in an adjacent county composed of predominantly White residents earns about the same as a college graduate who lives in 53206. Education is mediated by the stratification system that affects different population segments and maintains inequality.[44,45]

Institutional racism through mortgage discrimination and resultant racial segregation leads to poorer health outcomes. In the 53206 ZIP code area, 75% of mortgages are high risk (subprime or high interest).[46] Most lending action is home refinancing. Mortgage discrimination and redlining still exist, although both are illegal since the 1968 Fair Housing Act.[47] Following White flight, higher paying jobs are purposely located in the suburbs, where transportation is a barrier for African Americans workers.[48] The lack of livable wages reduces economic/residential mobility.[49]

Difficulty in establishing paternity is a barrier to child support and, as Ngui demonstrated, this is higher among African Americans in low-income areas.[28] The 1996 Temporary Assistance for Needy Families (TANF) welfare policy revision was a barrier to employment and contributed to health challenges, limited education, and socioeconomic marginalization.[50] These realities serve to keep Black families in poverty. Bhatt and Schellhase surveyed clients of a Milwaukee free clinic and found that 51% said they remained uninsured because insurance was too expensive, 56% misunderstood their Medicaid eligibility, and 69% misunderstood the Affordable Care Act marketplace eligibility.[51]

Beyer et al reported that African Americans have significant disparities in breast and colorectal cancer related to hypersegregation and racist policies, which lead to poorer health outcomes.[52] This finding contrasts with Beyer's previous findings of a protective effect in all-Black neighborhoods for African American women's breast cancer survival. In this 2016 study, African American women had the poorest survival rate from breast cancer in Milwaukee and 7 counties surrounding Milwaukee, and White women had the best survival.[52] The neighborhood is thus called a "double agent" that can worsen or mitigate cancer outcomes. Another study by Zhou, Bemanian, and Beyer that examined the relationship between housing discrimination, segregation, and colorectal cancer survival found racial bias in mortgage lending, which negatively influenced colorectal cancer survival in African American women.[53]

## Intervention Strategies Toward Expanding Health

### Social/Ecological Factors

Research links socioecological factors to structural racism and health disparities. These factors include the impact of joblessness on physical and mental health, the lack of urban job opportunities and barriers to suburban jobs, racist housing policies, and the relation of poverty to HIV (higher rates of infection for African Americans, even with fewer partners). Education does not enhance the lives of African Americans as much as it does for White people, and there are higher rates of recidivism for African American versus White people.

Studies of older African Americans, many of whom reported daily discrimination, found that a social support intervention helped reduce disparities.[54] They also noted that many African Americans do not trust health care providers, so they underreport depression. Academic and community partners who implemented a birthing project for African American women in Milwaukee showed how young pregnant African American women found value in being mentored by older African American women throughout their pregnancy, during delivery, and postpartum.[55]

### Mitigating the Impact of Racism on Health

There is limited research on factors that ameliorate racism and its health effects, but the research does suggest possible avenues for mitigating the effects of racism on health. One study examines the connections between African Americans to spirituality and faith.[56] Nurse case management for African American patients with hypertension was found to improve stress and lower blood pressure, showing that this population needs special care.[57] Goal congruence and self-efficacy also has been found to improve medication adher-

**Table 2.** Evidence Table (N=54 articles)

| Citation | Study Population | Objectives R/t Racism | Health Factors | Main Findings |
|---|---|---|---|---|
| Ake et al[27] | Homeless, pregnant | AA unmet needs | Birth outcomes | Chronic stressors in AA lives impact birth outcomes |
| Anderson KF[17] | Blacks, Whites, others | Racism effects on stress | Mental and physical | Racism causes mental and physical stress, highest in AA |
| Amato et al[41] | < 3 years old | Lead exposure, old housing stock | School suspension | Early lead exposure predicts 4th grade school suspension |
| Bartfeld J[49] | Children on welfare | Race is a variable | Gaps in child support | Greater gaps in child support for children on welfare |
| Bemanian et al[16] | Liver cancer | Racial disparities | Liver cancer rates | Incidence r/t neighborhood higher in poor and AA |
| Bemanian et al[18] | Women w/ breast cancer | Segregation | Breast cancer survival | Higher survival AA neighborhoods |
| Beyer et al[19] | Screening behaviors | Neighborhood quality | Cancer screening | Cancer screening behaviors vary by neighborhood factors |
| Beyer et al[47] | Women w/ breast cancer | Redlining and racial bias in mortgage lending | Breast cancer survival | AA neighborhood racial bias in lending, leads to poorer breast cancer survival |
| Beyer et al[52] | White and Blacks | Health disparities | Breast, colorectal cancer | Poorer survival in AA |
| Bhagavatula et al[13] | Children | Racial disparities | Dental procedures | AA have less preventive dental procedures |
| Bhatt et al[51] | Urban free clinic | Barriers to enrollment | Uninsured | More uninsured AA |
| Boardman et al[48] | Men | Spatial mismatch, race differentials | Male joblessness | AA males from central city travel farther to low paying jobs, negative health effects from joblessness |
| CDC[21] | Young, AA MSM | Health disparities | HIV infections | Higher rates young AA men; community action intervention |
| Chaskin RJ[60] | Community organizations | Segregation | Community capacity | Organizations compete for resources; tension between short-term and long-term goals |
| Cichy et al[31] | AA and White | Racial differences | Reactivity to stressors | AA more reactive to physical stressors; response lasts longer, triggers stress hormones and health disadvantage |
| Collins MB[43] | Geographical areas | Risk-based targeting: disproportionalities | Industrial pollution | More pollution in segregated AA communities |
| Connell T[37] | 1950s Milwaukee | Race, class and a city divided | 1950s Milwaukee | Bias against southern AA migrant farmers; class, race discrimination |
| Czarny et al[23] | MSM | Geosocial mobile apps | HIV | Smartphones used to share HIV info for young high-risk males |
| DeVries et al[62] | Persons w/ disabilities | Health care experiences, perceptions | Disabilities | Operations, finances, and time are barriers |
| Desmond et al[38] | Pre Fair Housing Act | Neighborhood consequences | Forced displacement | History racist housing policies against AA |
| Ellis et al[58] | Women 50+ | Health disparities | Medication self-management | Self-efficacy and goal congruence influence medication management |
| Emer et al[42] | Children | AA areas higher lead levels | Lead levels and firearm violence | Poor AA neighborhoods, higher lead levels correlate with increased violence |
| Geib P[36] | 1940-1960 | Housing discrimination | Southern AA migration | Southern migration later to Milwaukee; 176 manufactuers closed in 1970s, leaving urban poverty |
| Gibson et al[68] | 2009-2014 | Census tract poverty, racial disparities | HIV | HIV affects mostly AA |
| Gordon D[11] | AA neighborhoods | Segregation | Daily mobility | Policies cause racialization of space, but AA blamed for being inferior |
| Hildebrandt et al[50] | Women on welfare | Race as a variable | Welfare program unmet needs | More AA on welfare program, TANF, inadequate |
| Hornik et al[40] | River remediation project | Racism, suburbanization, urban blight | Environmental justice | Efficacy of using organizations vs individuals |
| Jang et al[15] | Mental health issues | Service use | Self-rated mental health | Disparities in mental health care |
| Johnson et al[29] | Infants | Racism | Fetal and infant mortality | Racism, poverty, stress, lack of transportation, substance use lead to poor outcomes |
| Jones WP[35] | 1930s | Segregation, proletarianization | AA working class history | Southern AA farmers started civil rights movement in 1930s |
| Jones PD[39] | 1958-1970 | Race relations, civil rights, insurgency | Violence | Fr. Groppi, AA leaders march to south Milwaukee; led to 1968 Fair Housing Act |
| Lechuga et al[63] | Several races | Cultural predictors | HPV vaccinations | Need culturally tailored interventions |
| Lennon et al[64] | Younger siblings of teens | Racism | HPV immunization | Need culturally specific interventions to improve immunization rates |
| Levine M[44] | 2000-2012 53206 | Racism and police killings | Inner city distress | Police killings of unarmed AA men cause mental health problems |
| Levine M[32] | 53206 | Racism and police killings | Inner city distress | Police killings of unarmed AA men cause mental health problems |
| LoConte et al[65] | FQHC | Racial disparities | Colorectal cancer | Systemic multigenerational poverty |
| Mazul et al[30] | Low-income women | Barriers and facilitators | Prenatal care | Perceived racial discrimination is barrier for AA |
| Mkandawire-Valhmu et al[55] | Pregnant women | Intervention of safe spaces | Birth outcomes | AA women need safe spaces; live in stress due to racism |

**Table.** Evidence Table (N=54 articles) *continued from page 137*

| Citation | Study Population | Objectives R/T Racism | Health Factors | Main Findings |
|---|---|---|---|---|
| Mohiuddin et al[14] | 2004-2008 | Urban hospital | Asthma deaths | Race increases asthma deaths separate from income, education |
| Ngui et al[20] | Paternity status | Racial disparities | Birth outcomes | Paternity related to preterm birth in AA |
| Ngui et al[28] | Paternity status | Racial disparities | Infant mortality (IM) | Paternity, race and welfare reform increase IM |
| Pawasarat et al[46] | 53206 | Mortgage lending | Housing crisis | Lending is low, home ownership low |
| Quinn et al[22] | Young AA MSM | Racism and homonegativity | MSM AA men PreP use for HIV prevention | Racial disparity in PreP use due to discrimination from providers |
| Quinn L[45] | 53206 | Neighborhood indicators | Neighborhood need | AA ZIP code high unemployment, high incarceration |
| Salm Ward TC[25] | Low income women | Structural racism | Prenatal care | Structural racism barrier to prenatal care |
| Schmidt D[34] | Neighborhoods | Housing discrimination | Neighborhood quality | 1970s redlining led to disinvestment in communities |
| Sims et al[26] | Infant mortality | Health disparities | Infant mortality | AA IM 2x that of Whites; lack of access prenatal care |
| Singh et al[61] | Black and White women | Racial disparities | Invasive breast cancer | AA women less access to health care |
| Warren-Findlow et al[54] | Middle-aged and older women | Social relationships | Emotional well-being | Psychosocial support critical in AA families helps health disparities |
| Warren-Findlow et al[59] | Secondary data | Social ties | Self-rated physical health | Family support improves physical health |
| Williams et al[56] | Older AA | Segregation and conflict | Spiritual well-being | AA church most important place of support; faith and health are connected |
| Wiese A[69] | 1960s | Racism and housing | Racism and housing | Housing protests; policy borders of AA neighborhoods then stereotyped the "ghetto" |
| Zabler et a[57] | Low-income | Case management | Hypertension | Improves stress and hypertension |
| Zhou et al[53] | Colorectal cancer survivors | Housing discrimination | Colorectal cancer | Living by other AA has protective effect |

Abbreviations: AA, African American; R/t, related to; CDC, Centers for Disease Control and Prevention; MSM, men who have sex with men; HPV, human papillomaviurs; TANF, Termporary Assistance for Needy Families; FQHC, Federally Qualified Health Center; PreP, pre-exposure prophylaxis.

ence in African American patients;[58] and the role of social-emotional ties in guiding interventions shows family ties as an important part of health care for aging African American adults.[59]

Another set of research examines capacity building at the neighborhood level, including individuals, formal organizations, and relationships. For example, case studies of the Harambee neighborhood in Milwaukee describe a collaborative organized around the goal of providing livable wages. A collaboration of 5 organizations planned to revitalize an industrial park and formed an economic development corporation to encourage investment in businesses and housing in Harambee. However, there were tensions and competition between existing and newer organizations. Competition between organizations for resources and leadership can be a barrier to collaboration.[60] The work of Beyer suggests that stronger neighborhood and family support contributes to better health outcomes.[52]

### Theoretical Gaps/ Barriers to Help/Research

Race is often included as a variable in studies but is not necessarily theorized or connected to discrimination or health care barriers. For example, there is a connection between racism and maternal/birth outcomes, but participants are hesitant to identify this issue. Similarly, African American women have poorer breast cancer outcomes and disparities regarding access to health care, including obtaining mammograms and quality treatment.[61] Barriers to care reported for disabled persons include race,[62] and Bhatt reported

race as a barrier to health insurance under the Affordable Care Act.[51] Additionally, health beliefs and lack of trust in health care providers affect access to immunization.[63] For example, culturally tailored interventions are needed to increase human papillomaviurs (HPV) immunization,[64] and Federally Qualified Health Centers (FQHC) are associated with increased colorectal screening.[65]

### DISCUSSION

The research focused on the effects of racism on health has grown considerably based on patterns made apparent by looking at health/ill-health measures, community factors in health, intervention strategies, and theoretical gaps. While not typically studied in direct relation to health, racism is an explanatory factor in studies of physical and mental disease among African Americans.

Racism creates stress and limits access to mitigating resources, such as wealth and employment. Studies found measurable differences in health between African American and White populations in a wide variety of diseases. Research suggests that being African American is related to the risk for ill-health. Socioecological factors related to race affect health, including segregation, poverty, inadequate housing, transportation, unemployment, and limited health care access. Community factors contribute to situations of risk for ill-health, while at times also mediating circumstances through strong family/neighbor care. Interestingly, in the studies reviewed, race is included primarily as a categorical factor, and studying racism itself is uncommon. Structural racism is difficult to measure, so

research often considers situational factors like neighborhood segregation or poverty. Finding better measures of racism and the impact of mutual supports systems are gaps that needs to be addressed.

Using science to theorize the centrality of White dominant culture and its impact on health disparities is essential to deconstructing racism. Nonetheless, successful interventions are more challenging to sustain despite Milwaukee's strong community organizing tradition. Racism has so systematically attacked the spirit of cooperation, interdependence, and connectedness endemic to African culture that it is very difficult for individuals in the community to experience the wholeness and wellness needed to thrive.

Addressing decades of systematic disinvestment requires shifting resources while dismantling the privileges of being White, and this cannot be done by African Americans alone. It takes commitments of medical systems and health care providers and a new definition of health. Those with power must eradicate structural racism. Race becomes not a factor in health; rather, we recognize that racism is a disease—a public health crisis to which we must attend. The Milwaukee County Board of Supervisors created the Milwaukee County's Office on African American Affairs (OAAA) in 2016 to address disparities affecting African American residents. The OAAA was successful throughout 2018 in normalizing conversations among top leaders about race, racism, and the role government entities play in resolving racial inequities and created a roadmap for developing a countywide racial equity initiative with full leadership support. In May 2019, Milwaukee County declared racism a public health crisis and launched a racial equity instructor-led training and the Racial Equity Ambassador Program to guide this work.

Making this declaration ensured Milwaukee County would not focus solely on the symptoms of the problems in the community (disparities in housing, transportation, food access, education, youth engagement, and criminal justice) but rather on the root cause: racism. This public commitment has created a transformational shift in the organization, most recently in spring 2020, with the passage of a local racial equity ordinance. It resolved that by achieving racial equity, the county will eliminate health and opportunity gaps along racial lines and increase the success of all groups by distributing resources justly across all communities. Milwaukee has seen a rise of Black political leaders committed to improving health outcomes. Milwaukee County took a leading role in tracking data on COVID-19 disease and death factored by race and the resulting policy initiatives to ensure that vaccinations are provided equitably.[66]

## CONCLUSIONS

This scoping review demonstrates the need for further research on racism and health that explicitly measures racism as contributing to systemic health disparities. Our analysis contributes to the literature by reviewing research specific to Milwaukee, Wisconsin, institutional and structural racism, and racialized policies. These stud-

ies reviewed reveal worse health outcomes for African American patients in many areas of health and wellness, demonstrating the impact of place on health in a hypersegregated city and state.

The racial divide exists, and African Americans are less likely to participate if viewed simply as study subjects, making it urgent that African American researchers lead the work. Structural racism extends into the field of education, as evidenced by the disparate doctoral degree achievement.[67] Another concern is the amount of research on individual attitudes rather than the system of racism. Finally, there is a lack of accountability and responsibility to dismantle the system of racism and acknowledge its role in health disparities. While Milwaukee's efforts exemplify steps toward change, they must be coupled with research and practice, including the adverse effects of systemic racism and its connections to health.

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# Understanding Barriers to Care for Refugee Patients: Lessons From Focus Groups

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## ABSTRACT

**Background:** Refugee populations resettled in the United States face health disparities and barriers to accessing care. Better understanding of the barriers this population faces may help clinicians address them.

**Methods:** Focus groups with refugees were held in Wisconsin. Discussion prompts such as "What could be done to improve health in your community?" were used. Notes from the focus groups were organized and coded using MAXQDA.

**Results:** Six themes were identified from the focus groups regarding health care barriers and experiences: language, interpretation, pharmacy, insurance, transportation, and respect.

**Discussion:** Clinicians working with refugee populations can strive to minimize barriers to care for refugee patients by being aware of the barriers, implementing changes in their practice, and/or community advocacy.

## BACKGROUND

In the United States, refugees face health disparities in numerous areas, including chronic conditions,[1] perinatal morbidity,[2] oral health,[3] and mental health.[4] Compounding these issues, refugees experience challenges in accessing services to address these conditions.[5] Health care providers are in a unique position to address these barriers. To better understand and address the specific health challenges refugees face, a series of focus groups with resettled refugees was designed by community health workers (CHW) and the State of Wisconsin Refugee Coordinator's office.

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## METHODS

Focus group guides with prompts were developed collaboratively with CHWs from target communities, the Wisconsin State Refugee Health Program, and the State Refugee Coordinator's Office, with funding from the Refugee Health Promotion grant. The groups were designed to collect data on the community's health needs for the purpose of guiding the development of appropriate health-related programming. Focus groups were held in southern Wisconsin during 2015-2017 by the Department of Health Services, Division of Public Health, Refugee Health Program. The 7 groups ranged from 5 to 15 participants (mean = 9) and were organized by language (Arabic, Burmese, Chin, Karen, Rohingya, and Somali).

Discussions were facilitated by CHWs in the language of the participants. Consistent with recommended methodology for research in refugee populations,[6] confidentiality was an important consideration; as such, names of participants and other identifying data were not collected. For participants' comfort, groups were not recorded; instead, notes were taken by moderators and observers during and after the discussion. These notes comprise the data for this project. After completion of the focus groups, the results were discussed and addressed by CHWs through workshops—a method recommended and requested by CHWs themselves.

The Institutional Review Board (IRB) at the Medical College of Wisconsin granted approval for the use of this previously collected data for the purposes of research; the focus groups notes were analyzed under an IRB-approved waiver of consent because there was no identifiable patient data. An initial review of the notes was used to develop a codebook of keywords, issues, and topics that arose during the discussion. The codebook was applied

using MAXQDA software, and key themes related to health and barriers to health were identified and are described herein.

## RESULTS

Participants discussed a range of topics, and 6 main themes were identified: language, interpretation, pharmacy, insurance, transportation, and respect.

### Theme 1: Language

Participants described language as a barrier in different ways: making appointments, understanding voicemails and voicemail menus, provider communication, and filling forms. One participant described how language barriers interrupt care: "One woman, a single mother, had a situation where one of her children wouldn't eat. A physician suggested a procedure that was supposed to help. The woman had difficulty understanding the procedure and why it was necessary due to language barriers… she was asked to sign something saying she understood [the proposed] procedure. [Because] they didn't explain it well enough [she didn't sign]. They thought she was refusing [but] she really just didn't understand and wanted to before consenting to the procedure."

### Theme 2: Interpretation

Related to but distinct from language barriers, participants described challenges regarding interpretation: insufficient time, discordance in dialect, perceiving that the interpreter was not communicating everything, and fear of breach of confidentiality if from the same community as the interpreter. Participants said that if they have concerns, they have no way to report it and described situations in which interpreters were asked to practice beyond their defined roles. One participant relayed how an interpreter advised them to change their HMO plan; now with their new plan, some of their prescribed medications are no longer covered.

### Theme 3: Pharmacy

Participants described barriers related to pharmacies: not understanding refills, prescriptions not being covered, and no interpretation. One participant said: "…we ordered two medicines and they gave us only one. We want to ask why they didn't give us the other one, but we don't speak English and they don't have [an] interpreter." Another said, "Sometimes the pharmacist talks a lot when we pick up our medicines, but we don't understand what they say."

### Theme 4: Health Insurance

Participants acknowledged the essential need for insurance but also described challenges: misunderstanding its use and limitations, difficulty navigating plans, difficulty resolving billing errors, insufficient insurance when changing to an employer plan, and difficulty accessing noncovered prescribed medications.

### Theme 5: Transportation

Participants described ways in which transportation was a barrier: lack of a car, not knowing the clinic location, difficulty navigating roads. One participant said: "For example, you know how to drive but the problem is you don't know how to get to your appointment because of the language, also the technology stuff like GPS." When transportation assistance was provided through the non-emergency medical transport (NEMT) service, participants reported difficulty communicating with the service. Further, because children often cannot ride along in NEMT, childcare becomes an additional barrier.

### Theme 6: Respect

Some participants reported receiving respectful care, others reported disrespectful treatment. Disrespect manifested as long waits (hours past appointment time), not being provided same-sex clinicians when requested, delays in referrals, and general discrimination. Participants described situations when, although the clinician showed respect, their experience was negatively affected by interactions with staff, such as nurses or receptionists. One participant said staff "…treated us like we are not people who deserve care. Every time we go for appointments, we have to wait at least 2 or 3 hours to see the doctor, even when we have the appointment."

## DISCUSSION

The focus groups provide insight about challenges faced by refugees when interacting with the health care system. Practice implications based on each theme are summarized below.

### Theme 1: Language

Language is a well-known barrier to care,[7] yet solutions remain elusive. Clinicians must look to reduce language barriers in ways that are appropriate for their practice setting. Possibilities include enhanced awareness of their body language, increased availability of interpreters, coordinating patient appointments with appropriate interpreter availability, training staff on the advantages/disadvantages of telephonic interpretation, using interpreters to make reminder calls, simplifying voicemail menus, and providing help with forms.

### Theme 2: Interpretation

Even with an interpreter present, barriers to effective communication remain. To ensure understanding, clinics should utilize interpreters who speak the correct dialect, are well-trained, and have enough time. Interpreters should not be put in situations where they need to act in a capacity beyond their scope. When a clinic has a "regular" interpreter, consider avenues for patients to express when they are uncomfortable with that individual (such as calling them with a telephonic interpretation and asking if they prefer the

"regular" interpreter or a telephone interpreter). While in-person interpretation can seem superior, when a patient desires a more anonymous experience, telephonic interpretation may be preferred.

### Theme 3: Pharmacy

Commercial pharmacies often do not provide interpretation. In these cases, medication counseling is more effective at the clinic where there is interpretation. Clinicians should advocate for the regular use of at least telephonic interpretation in pharmacy settings and must understand that problems with insurance at the point of medication pickup will be extremely difficult to resolve due to unavailability of interpreters.

### Theme 4: Health Insurance

Clinicians should be aware that it may be difficult for some patients to obtain medications if they are not covered by their plan, and care should be taken to prescribe accordingly. While efforts have been made to assist patients in understanding insurance,[8] providing insurance navigators with appropriate interpretation services may be useful.

### Theme 5: Transportation

Clinicians should be aware that transportation and childcare can be a barrier for patients who rely on NEMT. Offering evening or weekend appointments could potentially ease difficulty in finding childcare. Family practices could consider scheduling children's appointments before/after parents' appointments so that they could be transported together by NEMT. Providers can advocate for an improved transport system, encouraging services to better meets the needs of patients by giving them a place at the table when deciding policies.

### Theme 6: Respect

Clinicians should be aware that dignified care starts with the receptionists and other staff. Staff should be provided training in cultural competence/humility. Wait times should be reduced. When possible, choices should be provided to patients regarding their clinicians, their interpreters, and their treatment plans.

While the perspectives presented do not represent the experiences of all refugees, nonetheless they provide an opportunity to hear some refugee voices and consider how to address barriers to care. This report complements previous literature[9] on this topic by reinforcing some already known barriers to care at a local level, by providing some unique examples of how these barriers manifest on an individual level (including examples of serious health implications, such as a mistaken refusal for a procedure), and by considering actionable solutions to mitigate these barriers.

Because clinics have varying levels of resources, this report provides a range of potential solutions—from specific actions to simply being aware of these issues. We acknowledge that many of the proposed solutions require investments of time or money at a time when clinicians are being asked to do more with less resources. However, with the current administration indicating an intention

**Table.** Summary of Barriers Identified in Focus Groups and Potential Actions to Address Them

| Identified Barrier | Potential Provider Actions |
| --- | --- |
| Language | Budget for sufficient in-person interpreters. |
| | Provide staff training on use of in-person and telephonic interpretation. |
| | Use interpreters when leaving appointment reminders/confirmations. |
| | Make forms available in multiple languages and provide in-person interpretation for forms. |
| Interpretation | Allot extra time for appointments that require interpreters. |
| | Use well-trained, linguistically appropriate professional interpreters. |
| | Do not put interpreters in situations where they may be asked to function outside their scope. |
| | Confirm if patients are comfortable with the "regular" in-person interpreter. |
| | Consider using phone interpretation if patient not comfortable with available in-person interpreter. |
| Pharmacy | Provide thorough counseling on prescribed medications (importance, use, side effects, timing) in office. |
| | Advocate for commercial pharmacies to utilize telephone interpretation services. |
| Insurance | Be aware of patient's insurance coverage when prescribing medications. |
| | Use or promote the use of insurance navigators. |
| Transportation | Be cognizant that transportation may be a barrier for patients. |
| | If requested and possible, schedule families together. |
| | Consider weekend or evening appointments to accommodate transportation and childcare barriers. |
| | Advocate for enhanced funded transportation system (non-emergency medical transport). |
| Respect | Train all staff in cultural competence/cultural humility. |
| | Respect appointment times. Respectfully communicate delays. |
| | Respect the patient's preference of sex of clinician or interpreter. |

to increase refugee admissions in the coming years,[10] attention to these issues is timely and important. Clinicians striving to provide equitable, quality care will be aided by maintaining awareness of these issues and, when possible, implementing systems to improve care to refugee communities.

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## The Effect of Racism and Discrimination on the Health of Milwaukee's African American Population

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# Caring for Refugee Patients: An Interprofessional Course in Resettlement, Medical Intake, and Culture

Alana Petrassi, MD; Melissa Chiu, MD; Kelsey Porada, MA; Bryan Johnston, MD; Michael Toppe, PA-C; Michael Oldani, PhD; Caitlin Kaeppler, MD

## ABSTRACT

**Introduction:** Refugees access health care at rates similar to US citizens. Many clinicians, however, do not feel prepared to care for them. This study evaluated whether an interprofessional presentation could improve knowledge of refugee health and cross-cultural comfort.

**Methods:** The session consisted of a lecture and 3 small-group sessions. Students from various health care programs attended via Zoom. Participants completed pre- and postsurveys to assess cross-cultural comfort and knowledge of refugee health.

**Results:** Of 161 attendees, 63 completed the presurvey (39%) and 49 completed the postsurvey (30%). All 9 knowledge questions demonstrated statistically significant improvements, while only 1 cross-cultural question showed significant improvement.

**Discussion:** The session improved knowledge of refugee health but not cross-cultural comfort, indicating the need for further interventions.

## INTRODUCTION

Over 3 million refugees have resettled in the United States since 1975,[1] and the annual resettlement cap is expected to rise significantly in the next few years.[2] Through the Office of Refugee Resettlement, these new arrivals receive complete medical coverage for their first 8 months. Afterward, they are eligible for the same insurance options as US citizens[3] and have been shown to use primary care services at comparable rates.[4] So for health care providers, the question is not "Is refugee health relevant to me?" but "Am I prepared to care for refugees?"

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In a survey of 42 trainees (74% medical students, 17% medical residents, 7% pharmacy students, and 2% nursing students) conducted in 2019, 51% of respondents reported they had no class time dedicated to medical issues unique to immigrants and refugees.[5] Only 21% reported that they were adequately comfortable caring for patients who speak a language other than English. In order to address this gap, we hosted a refugee health education night in January 2019. Survey data demonstrated that attendees had improved knowledge about the refugee resettlement process and refugee health. In addition, attendees said they were more confident in providing care for non-English speaking patients ($P = 0.023$).

Other medical educators have devised various curricula to address this education gap. A comprehensive review of the various curricula was published in June 2020.[6] Twenty-four curricula were evaluated. The authors found that workshops and simulations were the most beneficial and that students participating in these curricula reported increased comfort in providing care to refugees.

Considering the results of our previous survey and this review, we modified the curriculum from our 2019 session and expanded our audience to a large interprofessional venue at the Our City of Nations conference in November 2020. Our objective was to familiarize students with the refugee resettlement process, discuss clinical concepts unique to refugees, introduce the concept of cultural humility, and improve trainees' understanding of the refugee experience.

## METHODS
### Curriculum Development

We had intended to format our curriculum as 5 distinct inter-

active sessions, but due to the COVID-19 pandemic, we chose to condense and host it virtually. We developed a 2-hour session that included a didactic presentation on the resettlement process, the refugee demographics of our state, and an introduction to cultural humility. This large-group session was followed by 3 small-group sessions: Clinical Considerations and Medical Intake, Systems Approach, and The Refugee Experience. Content for this curriculum was based on literature review, material from our January 2019 education night, and the Immigrant Partnership and Advocacy Curricular Kit (I-PACK), a module-based refugee and immigrant health curriculum.[7]

### Implementation

Our session was hosted via the video conferencing app Zoom. All attendees remained in 1 large group for the introductory didactic session and were then assigned to 1 of 3 small groups. Each small group rotated through 3 breakout rooms that were moderated by a physician or medical student. Every breakout room included firsthand accounts from refugees and local experts, including case managers and health workers.

### Evaluation

Electronic Qualtrics surveys were administered before and after the sessions. The presurvey was split into 3 parts: demographic information, assessment of comfort in cross-cultural interaction, and assessment of knowledge. We used The Cross-Cultural Competency Survey (CCCS) as a guideline for our questions assessing cross-cultural comfort.[8] No question was taken directly from the CCCS. Questions were reworded or combined to better address the themes most pertinent to refugee health. The postsurvey contained 2 parts: assessment of comfort in cross-cultural interaction and assessment of knowledge. Survey responses were multiple choice on a 5-point Likert scale. Pre- and postsurvey responses were correlated using a unique 5-character identifier. Wilcoxon signed rank testing was used to assess changes for paired surveys, while Mann Whitney U testing was used to assess changes for unpaired surveys.

## RESULTS

One hundred sixty-one participants were present for this session. We received 63 presurvey responses (39%) and 49 postsurvey responses (30%). The majority of the respondents were enrolled in graduate health programs throughout Wisconsin (see Table 1).

Those who completed the presurvey also were asked to rate the amount of dedicated class time they had addressing refugee health. On a 5-point Likert scale (1 = none at all, 2 = a little, 3 = a moderate amount, 4 = a lot, 5 = a great deal), the median response was 2. The survey, however, did not inquire into prior experience participants may have had with the refugee community, as a primary motive of this study was to evaluate the current state of formal refugee health education.

From the pre- and postsurvey responses, 26 pairs were identified. The Wilcoxon signed rank test was used to interpret paired changes. Unpaired presurvey responses were numbered at 37, while there were 23 unpaired postsurvey responses. The Mann Whitney U test was used to interpret changes between unpaired surveys.

Three survey questions evaluated participant comfort and confidence with cross-cultural interaction (see Table 2). Changes in response for the 26 paired surveys demonstrated a statistically significant change only for the question addressing comfort/confidence when interacting with an individual who speaks a language other than English ($P = 0.015$). Changes in response from pre- to postsurvey were not statistically significant for any of the 3 questions for the unpaired surveys.

Nine questions evaluated participant knowledge of refugee health (see Table 3). Evaluation of the 26 paired surveys demonstrated a statistically significant increase for all questions. The unpaired surveys demonstrated statistically significant increases for 5 questions. The 4 questions that did not demonstrate statistically significant increases centered on being able to define refugee status and an understanding of cultural humility. These results could indicate that more time should be devoted to highlighting these foundational topics.

In comparing these results to those of the 2019 survey, they are similar but differ in 2 notable ways. First, the 2019 survey demonstrated that 51% of respondents received no class time dedicated to refugee health, while the 2020 survey demonstrated the median response on a 5-point Likert scale was 2, indicating that students, on average, had at least a little dedicated class time. Second, the 2019 survey found a statically significant increase in participants' confidence in providing culturally sensitive care to refugees ($P < 0.01$), while the 2020 survey did not.

## DISCUSSION

The value of our curriculum lies in its obvious need. With so little student-reported instruction time, it is not surprising that many trainees are at least somewhat uncomfortable providing care for refugees. Our study demonstrates that short educational seminars may be an effective means to improve knowledge on refugee health.

The power of our study, however, was limited by the relatively low number of paired pre-post data sets (n=26) and by the fact that our surveys were not themselves validated. The individuals who did not complete the surveys were likely very similar to those who did, in that they were primarily graduate students in health care programs. The large discrepancy between the number of participants and completed surveys could have resulted from virtual lesson fatigue or from the difficulties in survey distribution. Only participants who had preregistered received the survey links via email, and though the survey links were shared multiple times via Zoom chat, participants could only see them if they were logged in at the moment it was sent. Additionally, although some of the survey questions were modeled after the CCCS, our surveys were not themselves validated.

Another limitation of this session was the lack of physical interaction between participants and presenters. Though we saw statistically significant changes in knowledge, we saw only minor changes in cross-cultural comfort. Not being able to physically interact with presenters and refugees may have left participants less engaged and unable to form interpersonal connections. The only significant change observed was in comfort/confidence when interacting with an individual who speaks a language other than English. Though the curriculum did not directly address language, all 3 small-group sessions allowed students to ask refugee participants for advice in overcoming a language barrier. This change could represent the effect of the insights offered. Cross-cultural comfort is a lifelong process that requires developing cultural self-awareness, gaining cultural knowledge, recognizing power imbalances, and holding power structures accountable.[9] The results of the review of refugee health curricula made clear that cross-cultural comfort is best achieved through interactive, longitudinal experiences that allow for both reflection and applied use of knowledge.[5]

Lastly, it would be prudent to consider

**Table 2.** Comfort/Confidence Survey Responses Analysis

| Survey Item | Paired Responses (N=26) | | | Unpaired Responses (N=37; N=23) | | |
|---|---|---|---|---|---|---|
| | Presurvey Mean (IQR) | Postsurvey Mean (IQR) | $P^a$ | Presurvey Mean (IQR) | Postsurvey Mean (IQR) | $P^b$ |
| I feel comfortable/confident interacting with individuals who speak a language other than English | 4 (2-5) | 4 (3.75-5) | 0.015 | 4 (2-5) | 4 (4-5) | 0.258 |
| I feel comfortable/confident interacting with individuals with different cultural values, practices, and beliefs. | 4 (3.75-5) | 4 (4-5) | 0.095 | 5 (4-5) | 5 (4-5) | 0.920 |
| I feel comfortable/confident providing care to refugees in my field of practice | 4 (3-4) | 4 (3.25-4) | 0.084 | 4 (3-5) | 4 (4-5) | 0.897 |

Abbreviation: IQR, interquartile range.
[a]Wilcoxon Signed Rank test.
[b]Mann Whitney U test.

**Table 3.** Knowledge Survey Responses Analysis

| Survey Item | Paired Responses (N=26) | | | Unpaired Responses (N=37; N=23) | | |
|---|---|---|---|---|---|---|
| | Presurvey Mean (IQR) | Postsurvey Mean (IQR) | $P^a$ | Presurvey Mean (IQR) | Postsurvey Mean (IQR) | $P^b$ |
| I can accurately describe the factors, as defined by the UN, that makes an individual a refugee. | 4 (2-4) | 4 (4-5) | 0.001 | 3 (2-4) | 4 (3-4.25) | 0.165 |
| I have an understanding of the process through which a refugee must undergo to be resettled in the United States. | 4 (2-5) | 4 (4-5) | 0.003 | 4 (2.5-4) | 4 (4-5) | 0.267 |
| I am able to clearly differentiate between an individual with refugee status and an asylum seeker. | 2 (2-4) | 4 (3.75-5) | 0.001 | 3 (2-4) | 4 (3-5) | 0.057 |
| I believe I am aware of and am able to reflect on my own cultural biases. | 4 (4-4.25) | 4.5 (4-5) | 0.005 | 4 (4-5) | 5 (4-5) | 0.038 |
| I understand what is meant by the term "cultural humility." | 4 (4-4.5) | 5 (4-5) | 0.006 | 4 (4-5) | 5 (4-5) | 0.114 |
| I am aware of the components of refugee medical intake, including the overseas and domestic exams. | 2 (1-3.25) | 4 (4-5) | 0.001 | 3 (2-4) | 4 (4-4.25) | 0.007 |
| I am aware of the role that the federal government plays in the refugee resettlement process. | 3.5 (2-4) | 4 (4-5) | 0.001 | 3 (2-4) | 4 (4-5) | 0.005 |
| I am aware of the role that state and local government plays in the refugee resettlement process. | 2.5 (2-4) | 4 (4-5) | 0.001 | 4 (2-4) | 4 (4-5) | 0.001 |
| I am aware of the organizations and community groups that provide services to refugees in the Milwaukee area. | 2 (2-4) | 5 (4-5) | 0.001 | 3 (1.25-4) | 4 (4-5) | 0.002 |
| I have had dedicated class time to learning about issues specific to refugees. (Presurvey only) | 2 (1-3) | | - | 2 (2-3) | - | - |

Abbreviation: IQR, interquartile range.
[a]Wilcoxon Signed Rank test.
[b]Mann Whitney U test.

the applicability of this intervention to practicing physicians. Though attending physicians have never been polled, resident physicians have. Their responses have affirmed a deficiency in education and comfort in providing care to refugees. Given that cross-cultural training is a relatively new addition to medical education, older physicians may, in fact, feel less prepared. It is likely that similar, if not better, results would be seen if practicing physicians were to complete the intervention.

Even considering these limitations, our session did greatly improve participants' knowledge of refugee health and deepened their appreciation of the refugee experience, providing a firm foundation upon which participants can continue to build.

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BRIEF REPORT

# A Health Needs Assessment Among Milwaukee's Homeless

Joshua Matzke, MD; Bryan Johnston, MD; Thomas Schneider, BS; David Nelson, PhD

## ABSTRACT

**Background:** This project aims to assess the needs and barriers to care from the people experiencing homelessness in a large Midwestern city from their perspective.

**Methods:** This survey was advised by those with lived experience of homelessness and those who work in the space. Surveys were disseminated during outreach around the city of Milwaukee, Wisconsin. Data were transcribed, reviewed, and analyzed.

**Results:** Results indicated that 68% of participants perceive their health as "poor" or "fair." Fifty-five percent indicated they had primary care, and 64% reported possessing active health care insurance. There were many perceived barriers to care, including lack of transportation, money, and inadequate clinic hours.

**Conclusions:** Survey results indicate that the needs and barriers to care for those experiencing homelessness are broad and complex and should be factored in when considering solutions and aiming to provide more equitable care.

## BACKGROUND

Homelessness can result from an array of reasons, including unemployment, substance abuse, and a lack of affordable housing, which results in a broad range of needs in this population. Each January, the US Department of Housing and Urban Development (HUD) completes its annual Point-in-Time Count of all those experiencing homelessness on a single night.[1] In January 2019, there were 567,715 people experiencing homelessness in the United States, of which 4,538 were in Wisconsin and 885 were in Milwaukee County.[1]

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People experiencing homelessness often find themselves in scenarios where health needs compete with their immediate needs, like food and housing.[2] As a result, they both underutilize primary care and present at a late stage of disease.[3] This has led to mortality rates among homeless adults that are 3 or more times greater than the general population.[4] Although resources for this population have improved over the last decade, additional resources are still needed.[5] Community-wide needs assessments in Milwaukee have been completed by health systems and the county, but none are specific to people experiencing homelessness.[6] Ake et al published a needs assessment in 2018 that focused on a population of homeless pregnant women in Milwaukee, to help establish a program of care to improve the health outcomes of newborns and their mothers.[7] A health assessment among Milwaukee's general homeless population is necessary to identify the needs of all those experiencing homelessness in the city. This study sought to identify gaps in current care and resources from the perspective of people experiencing homelessness to influence possible solutions needed to improve health equity and access, health outcomes, and perceived health in this population.

## METHODS
### Survey Design
A survey tool was developed in collaboration with a group of 7 key informants with current or past personal experience with homelessness and those who work closely in the space. An important component of this study was to obtain input from those experiencing unsheltered homelessness, a population often missed by study

**Table 1.** Responses to Health Needs Assessment Among Milwaukee's Homeless

| Variable | % | Variable | % |
|---|---|---|---|
| Race (N=77) | | Age (N=77) | |
|   Non-Latinx White | 52 |   18 – 25 | 6 |
|   Non-Latinx African American | 26 |   26 – 35 | 20 |
|   Latinx | 22 |   36 – 45 | 29 |
| Sex (N=77) | |   46 – 55 | 25 |
|   Male | 61 |   56 – 65 | 14 |
|   Female | 39 |   66 – 75 | 6 |
| Overall how do you feel your health is? (N=77) | | (For females) Are you currently using birth control? (N=30) | |
|   Poor | 48 |   Yes | 30 |
|   Fair | 25 |   No | 70 |
|   Good | 23 |   I don't know/unsure | 0 |
|   Very good | 4 | Do you have any chronic illnesses you are | |
|   Excellent | 0 | prescribed medicines for? (diabetes, high blood | |
| Do you have a primary care physician or | | pressure, heart disease, asthma, etc) (N=61) | |
| clinic you regularly visit? (N=77) | |   Yes | 61 |
|   Yes | 58 |   No | 39 |
|   No | 42 | Do you have a mental health diagnosis? (N=54) | |
| Do you have a dentist you regularly visit? (N=77) | |   Yes | 35 |
|   Yes | 12 |   No | 65 |
|   No | 88 | Within the past 12 months, did you worry | |
| Do you use any mental health counseling | | that your food would run out before you | |
| services, including substance use counseling? | | got money to buy more? (N=77) | |
| (N=77) | |   Never | 0 |
|   Yes | 17 |   Rarely | 6 |
|   No | 83 |   Sometimes | 22 |
| Do you have health insurance? (N=77) | |   Fairly often | 38 |
|   Yes | 64 |   Frequently | 34 |
|   No | 36 | How often does anyone, including family, | |
| Who is your insurance provider? (N=77) | | threaten you with harm? (N=77) | |
|   BadgerCare or Medicaid | 80 |   Never | 88 |
|   Private | 4 |   Rarely | 8 |
|   Medicare | 16 |   Sometimes | 4 |
| Do you have access to harm reduction | |   Fairly often | 0 |
| (clean needles, Narcan, etc)? (N=64) | |   Frequently | 0 |
|   Yes | 31 | Where do you usually sleep? (N=77) | |
|   No | 69 |   Shelter | 20 |
| In the past year, have you had unprotected | |   Outside | 45 |
| sex? (N=58) | |   Car | 12 |
|   Yes | 59 |   Couch or friends | 18 |
|   No | 41 |   Own place | 5 |
| (For females) In the past year, have you been | | | |
| pregnant or been worried about becoming | | | |
| pregnant? (N=30) | | | |
|   Yes | 37 | | |
|   No | 63 | | |

teams due to inconvenience. The final survey focused on assessing perceived health status, health resource utilization, and perceived barriers to accessing care. It received Institutional Review Board (PRO00036564) approval on August 11, 2020.

### Procedures

This project was conducted in partnership with StreetLife Communities, a nonprofit organization engaged in homeless outreach throughout Milwaukee. Research team members joined StreetLife to conduct surveys during their longstanding outreach programming, including a weekly city gathering and well-established biweekly routes visiting major outdoor encampments and informal gathering places. Voluntary participation and data privacy were explained, and verbal consent was obtained prior to the administration of each survey. Participants completed the paper survey, and collected surveys were stored by the student investigator prior to data analyzation.

### RESULTS

A total of 77 surveys were disseminated, of which 61 were fully completed. Questions from the survey and results are shown in Table 1. The demographics of this project included 52% non-Latinx White respondents, 26% non-Latinx African American respondents, and 22% Latinx respondents. This is of note, as only 19% of Milwaukee's population identifies as Latinx. The most common age group was 36 to 45 and 61% were men. Overall perceived health in study participants was poor. Participants were asked to indicate how often they utilized health services in the last 12 months (Table 2); this revealed that emergency departments (ED) were the highest utilized health resource, and 43% of respondents accessed an ED at least 4 times. Only 13% of respondents saw a dentist and 23% saw a mental health provider. Fifty-five percent of respondents had a primary care physician, and 64% had active health care insurance.

Using a Likert scale, participants were given a list of barriers and asked to rate the perceived level of impact each had on accessing care or resources (Table 3). Transportation was the most common barrier, as 85% of respondents indicated that it was a significant factor—4 or 5 on the scale—in preventing them from accessing resources. Another 74% and 69%, respectively, described inadequate clinic hours and money as significant barriers, while 30% perceived disrespectful care as one of their barriers to care. Thirty-nine percent indicated that substance use hindered their access. Tobacco/cigarettes and alcohol were the most common substances used (77% and 68%, respectively) on at least a weekly basis. Thirty percent of participants said they use opiates/heroin on a weekly basis and 18% on a daily basis. Additional results regarding barriers to care, including food security and housing, are shown in Table 1.

### DISCUSSION

As expected, there were wide variations in health resource utiliza-

tion. Specifically, reported ED utilization was very high in this study compared to the general population.[4] One participant presented to an ED 122 times in 2020, most often for anxiety and frostbite. Meanwhile, only 6.5% of the general population used an ED twice or more in 2017.[8] Individuals who experience homelessness not only have higher rates of hospital admission, but they also have longer stays once admitted—at least 2 days longer for acute admissions.[9]

While primary care access was reported more than expected, many still lacked consistent care. A lack of regular primary care may contribute to the overutilization of EDs, leading to poor outcomes and experiences for both patients and clinicians. Many homeless patients relying on seeing different clinicians in acute settings are denied access to the patient-provider relationship and continuity of care that are essential for solutions to their complex health challenges—not just acute issues.

The ability to address health concerns also is hindered by perceived barriers. Respondents often suggested that even if they were able to schedule an appointment to see their primary care physician, transportation was a significant barrier. If they did not have money for a bus and the weather was not amenable to walking, they were unable to attend their appointment. Inadequate clinic hours also were frequently indicated as a barrier to accessing care, which suggests that either clinics truly do not have hours that align with this population's availability or that there is a lack of familiarity with available clinics and primary care coordination.

A common theme was lack of awareness regarding access and resources. It is often forgotten that many resources are designed from the lens of privilege or by those who have few barriers, which makes it easier to overlook the logistics that may be involved for those who face these barriers to care. For example, many respondents were unaware of clean needle exchanges in Milwaukee or conveyed they had heard about them but did not know how to access them. A similar sentiment was found regarding housing. While not formally collected during the survey process, many survey respondents and other people experiencing homelessness indicated awareness of the centralized 2-1-1 resource used to seek housing resources, but lack of a cell phone or poor experiences in the past were common barriers to successful connection.

There certainly is a connection between these barriers and overall health status. As a result of the barriers and lack of resources or access to services, nearly half of the respondents perceived their health as poor. Sixty-one percent endorsed having 1 or more chronic health conditions, which is a 9% higher prevalence than the noninstitutionalized adult US civilian rate.[10] These data alone suggest that this cohort requires more resources per capita to help manage chronic disease than the general population. Addressing this issue will require research, policy, and resources for health services. Steps that can be taken might include primary care coordination, multidisciplinary teams performing regular outreach, improved food and housing stability screening and resources, and harm reduction resources.

**Table 2.** Health Services Utilized in the Last 12 Months (N = 77)

| Health Resource | 0 | 1–3 | 4–6 | 7–9 | ≥10 |
|---|---|---|---|---|---|
| Emergency department | 18 | 26 | 22 | 8 | 3 |
| Mental health provider | 59 | 12 | 6 | 0 | 0 |
| Dental | 67 | 10 | 0 | 0 | 0 |
| Urgent care | 40 | 19 | 15 | 3 | 0 |
| Primary care provider | 35 | 33 | 9 | 0 | 0 |
| Free clinic | 61 | 16 | 0 | 0 | 0 |
| Overnight hospital stay | 38 | 35 | 4 | 0 | 0 |

**Table 3.** Likert Scale of Perceived Barriers to Accessing Health Resources (N = 61)

| Barrier | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Inadequate hours | 7 | 0 | 9 | 8 | 37 |
| Money | 4 | 1 | 14 | 10 | 32 |
| Transportation | 6 | 0 | 3 | 10 | 42 |
| Substance use | 31 | 1 | 5 | 9 | 15 |
| Safety | 51 | 6 | 3 | 1 | 0 |
| Language barrier | 53 | 0 | 7 | 0 | 1 |
| Ability to read or write | 45 | 5 | 7 | 4 | 0 |
| Housing | 15 | a7 | 20 | 6 | 13 |
| Child care | 41 | 6 | 5 | 5 | 4 |
| No mailing address | 57 | 0 | 0 | 0 | 4 |
| Disrespectful care | 36 | 4 | 3 | 6 | 12 |

1 = not a barrier; 5 = significant barrier.

Improving access, resources, and awareness of resources will be vital to improving the overall health and well-being of people experiencing homelessness in the future.

Limitations of this study include participants being excluded if they were unable to read and complete the English survey, as no Spanish speaking translators were available. Another limitation was that the participants included were those who gather at a community lot each Saturday, along with those encountered during street outreach by StreetLife Communities. While this outreach method covers commonly utilized unsheltered sites of habitation in the Milwaukee area, it does not encompass the entire homeless population. There are certainly pockets of extreme poverty and homelessness that are undiscovered and not included in this project. Additionally, the survey was independently completed by participants, so data were unable to be verified. Independent completion also may have led to confusion on some wording of questions. For example, 5% of respondents indicated they owned a place to sleep, although they were homeless.

## CONCLUSIONS

Those presently and at risk for homelessness make up some of the most vulnerable members of our community. Not only is this population sicker than those more stably housed, but they die sooner. In addition to access to care, the other social determinants of health need to be considered as solutions are discussed. Only when we address the entire system will we begin to see progress to eradicate the issues of homelessness.

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# A Culture and Wellness Pilot to Guide Community Engaged Public Health Research in Native American Populations

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## ABSTRACT

**Background:** Alaskan Native/American Indian (AI/AN) participation in biomedical sciences is often hindered by cultural miscommunication regarding concepts and definitions of health. Identifying culturally contextualized health priorities is crucial to building research collaborations between academic institutions and AI/AN consortia.

**Methods:** This article describes pilot data from the development of a culture and wellness questionnaire deployed by the Great Lakes Native American Research Center for Health at cultural events and community engagement meetings. The questionnaire was designed in collaboration with AI/AN members to assess performance indicators of public health promotion in AI/AN populations who are culturally inclined to interpret health holistically.

**Results:** There were 25 completed questionnaires. Connection to the land (88%) and "giving thanks" (96%) were the most prominently affirmed health and wellness concepts. Participants were least confident (33%) in the ability to support the next generation culturally (language, stories, etc).

**Discussion:** These results comport with anecdotal data that AI/AN concepts of health and wellness should be co-developed with AI/AN cultural leaders and community members. Future implications for academic partnerships are discussed.

## INTRODUCTION

This paper reports the findings of a novel assessment of health and wellness contextualized to American Indian/Alaska Native (AI/AN) culture in the service area of the Great Lakes Native American Research Center for Health (GLNARCH). The NARCH centers pursue a mandate to improve Native American participation in

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biomedical sciences, broadly defined for our purposes as any research initiative that addresses a health issue in these communities, including clinical, applied, and community-engaged research. NARCH also supports AI/AN (sometimes referred to as tribal) health priorities via training, public health promotion, and education. The National Institute of General Medical Sciences and several other National Institutes of Health (NIH) institutes and centers partner with the Indian Health Service to support the NARCH program. A detailed description of GLNARCH, the founding principles, and its development was reviewed by Jackson et al.[1] These programs are responsive to the NIH Tribal Research Office stated goal "to promote an authentic, inclusive, and equitable partnership with American Indian and Alaska Native communities by improving cultural awareness and respect across the NIH and its intramural and extramural research."[2]

As alluded to by the NIH Tribal Research Office priorities, academic partners must interface with AI/AN culture and traditions to pursue community-engaged research. An equitable, inclusive, and authentic health research interface will require cultural contextualization of health outcomes and indicators. All NARCH centers throughout the United States face challenges interpreting their health-related initiatives across cultural contexts. The unique circumstances of AI/AN health promotion have been discussed by our GLNARCH team[1,3,4] and others extensively.[5] Specifically, we recently postulated that complex public health challenges, such as inadequate access to health care, can be addressed by interpreting health research and information in the context of traditional knowledge (sometimes referred to as "Tribal Ways of Knowing").[6]

**Table 1.** Current GLNARCH Program Evaluation Metrics

| Metric Topic | Data Source |
| --- | --- |
| 1. Is GLNARCH operating with fidelity? | Participant satisfaction questionnaires, attendance counts, event counts |
| 2. Is GLNARCH fostering partnerships? | Number of partnerships initiated and maintained |
| 3. Are GLNARCH research activities contributing to health science fields? | Yearly counts of academic outputs (abstracts, reports, publication, grants, presentations, etc) |
| 4. Is GLNARCH fostering community-based participatory research? | Yearly counts of community-engaged academic outputs; mentor and student satisfaction questionnaires |
| 5. Is GLNARCH research serving the community and addressing health disparities? | Mentor and student satisfaction questionnaires, key informant interviews |
| 6. Are AI/AN students successfully mentored and supported through each phase and progressing through phases? | Mentor and student satisfaction questionnaires, student progress tracking (degrees, job attainment, program completion, etc) |

Abbreviations: GLNARCH, Great Lakes Native American Research Centers for Health; AI/AN, American Indian, Alaska Native.
Examples of specific metrics and outcomes from recent reports can be viewed at the GLITC.org website.[1,7]

**Table 2.** Specific Questions and Scales Used to Assess Either Wellness, Sentiments Towards Cultural Resilience, or Health Status

| Question | Scale |
| --- | --- |
| I feel connected to the land around me | Likert (5) |
| I feel connected to my community | Likert (5) |
| My culture is respected by members of my community | Likert (5) |
| My culture is respected by individuals outside of my community | Likert (5) |
| I feel healthy | Likert (5) |
| My community participates in cultural activities that promote well-being | Likert (5) |
| I am optimistic when I think about passing on our culture to the next generation | Likert (5) |
| I am in the habit of giving thanks | Likert (5) |
| My community has the ability to support and provide for the next generation in a monetary sense (clothing, housing, etc) | Likert (5) |
| My community has the ability to support the next generation culturally (language, stories, etc) | Likert (5) |
| Would you say that, in general, your health is: | Excellent – Poor |

For example, our community partners, colleagues, and Elders teach that the key to promoting wellness is by democratizing health capacity. This can be accomplished through cultural vectors of community, education, and inclusivity.

We summarized some main cultural themes for improving tribal health as follows: (1) helping my people, (2) honoring our elders, (3) self-determination, (4) living in a good way.[6] The latter is of particular relevance to the current pilot. This work is unique as a health research topic since the starting point is traditional knowledge that was accumulated over generations and codified in culture. Thus, we report here the beginning of a formalized process to translate this information into a format that can interface with biomedical research. The best practices for meeting these challenges may overlap with other ambitious health- and wellness-promoting efforts. This article describes pilot data from the devel-

opment of a culture and wellness questionnaire deployed by the GLNARCH staff at cultural events and community engagement meetings.

GLNARCH currently provides a Community Scientific Advisory Committee with established performance indicators (Table 1)[7] focused on the experiences, accomplishments, and satisfaction of students, community advisors, researchers, and mentors. This has provided valuable data to track the Center's progress towards stated goals. However, these historical program evaluation priorities were noted to lack key insights regarding health status, wellness, and concepts of health based in local culture. A new metric category is in development for future reports: Do GLNARCH activities promote health and wellness as defined by the culture of the community? This new metric category—and the broader implications for NARCH initiatives—is the focus of this report.
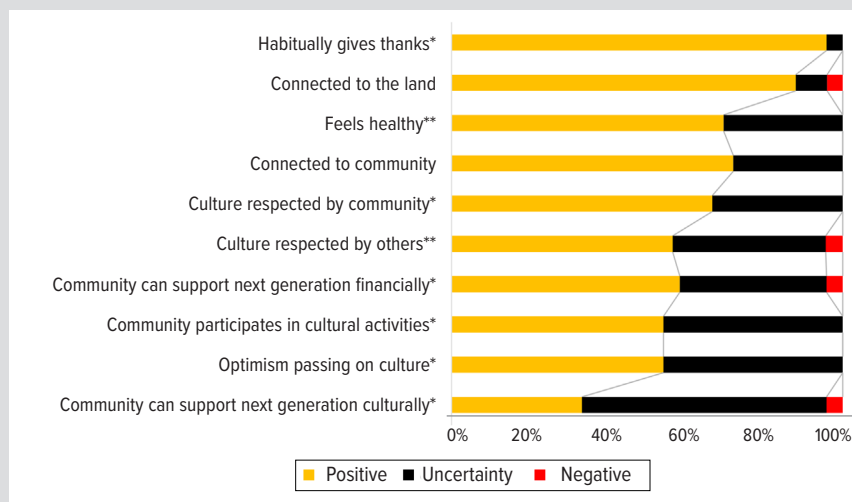
## METHODS
### Study Participants and Recruitment
GLNARCH personnel piloted a new culture and wellness questionnaire at 2 events in 2019: (1) an "open house" center grant meeting to report out progress and future directions in dialogue with educational, community, and research partners, and (2) the Bear River Powwow, in which the team engaged directly with tribal community members. Both events were held onsite in Lac du Flambeau, Wisconsin. Participants were from the Bemidji area, and most participants were AI/AN, though non-Native event participants were not excluded. Based on input from tribal partners, it was important to include non-Native spouses or adopted children of tribal members living in tribal communities and those who live and/or work in the Bemidji region. Only those who did not engage in GLNARCH activities within the time frame were excluded. Questionnaires were conducted in English since that is an in-common language among AI/AN populations in the region.

GLNARCH coordinators conducted site visits to tribes, tribal colleges, universities, and tribal health fairs as part of normal center grant activities. This included meetings, booths at events, etc. During this time, subjects were asked to participate in questionnaires and/or on-camera interviews (digital stories). Individuals also were recruited in person at GLNARCH events. Participants were provided with an information letter about GLNARCH projects and signed a waiver to participate in digital storytelling if being interviewed on camera. Participants at the powwow were incentivized to complete questionnaires and interviews with various gift items, such as Medical College of Wisconsin (MCW) and Great Lakes Inter-Tribal Council (GLITC) water bottles, shirts,

**Figure.** Wellness Pilot Survey Results

Likert scale responses are compiled to reflect positive, negative, or ambivalent responses.
n = 25, *n = 24, **n = 23.

ness. The wellness questionnaire pilot was conducted on a subset of GLNARCH participants starting in spring 2019 (n = 25).

## RESULTS

The Figure summarizes the findings from the wellness and culture pilot. Respondents most frequently reported feeling connected to the land and habitually giving thanks. Broadly, the responses illustrate the importance of culture when interpreting concepts of health and wellness. Findings aligned with perspectives espoused in digital storytelling sessions, which can be viewed in the aforementioned link for further context.

Many respondents reported that they feel healthy. Many participants reported a culturally specific term for health and wellness. "Minobimaadaziiwin" and "Ni Mino Ayaa" were commonly reported and translate from Ojibwe roughly to "living in a good way." This highlights the prominence of holistic conceptions of health and wellness. The most prominently affirmed statements were: "I feel connected to the land around me" (88%) and "I am in the habit of giving thanks" (96%). In the context of Ojibwe culture, these both present spiritual implications of wellness. The Anishinaabe members of the questionnaire development team developed the wording of the item on giving thanks to assess the level of respect for cultural and spiritual traditions.

Despite positive sentiments regarding the importance of culture and spirituality, a pattern of uncertainty towards the future of cultural practices emerged. Respondents seemed less confident that their culture could be perpetuated and passed on to the next generation (Figure). The respondents also expressed less certainty that their culture was respected by others. Among the wellness pilot metrics, GLNARCH and powwow participants expressed the least confidence in response to the question: "My community has the ability to support the next generation culturally (language, stories, etc.)." Only 33% of respondents expressed confidence in this item.

## DISCUSSION

Health can be a difficult term to define for different cultures, since it can often refer to more than simply the presence or absence of disease. Concepts of "health" have evolved throughout history and remain a topic of bioethical and philosophical discussion.[10] Many respondents reported that they feel healthy but were less sure of their ability to pass on cultural teachings to the next generation. The data suggest that many were concerned about the perpetuation of culture. It was clear from discussions with these participants that longevity of the culture was a priority. This theme also

or bags. All participants provided written and verbal informed consent, and all protocols were reviewed and approved by the MCW Institutional Review Board. Digital stories are posted on the GLITC website (https://www.glitc.org/programs/education-health-and-research/native-american-research-center-for-health-narch/publications-and-media/). These stories provide further context for the questionnaire development but are not the focus of this report.

### Wellness and Culture Questionnaire Development

To explore health and wellness, contextualized broadly to Bemidji region culture, questions were developed in consultation with members of the GLNARCH team (current co-authors) who themselves are Anishinaabe and/or work and live at the Salish Kootenai or Lac du Flambeau reservations. The questionnaire was developed iteratively with team discussions, based on decades of stakeholder feedback from GLNARCH programs ranging from elder teachings to student interviews. Much of that information also appears in previous publications and reports covering 18 years of GLNARCH programming.[1,3,7,8] Though somewhat informal, this served as an efficient way to synthesize decades of experience, advisory committee feedback, and stakeholder engagement into an emerging pilot assessment of important health phenomena. Critiques of the questionnaire items were collected and reviewed for common and conflicting viewpoints, and best practices for questionnaire development were followed.[9]

The final questionnaire consisted of 18 questions, four of which focused on basic demographic information, including tribal affinity. Ten questions concerning wellness and culture used a Likert-type scale to rate level of agreement, while 1 question asked about general health status (Table 2). Participants also were asked about traditional words or phrases to describe well-

was identified in digital storytelling sessions with GLNARCH participants over the years.[3]

Questionnaire data were collected via convenience sampling and are not intended to generalize the sentiments of any given population. The sample size was small and provided preliminary pilot data. Furthermore, tribal membership and participation in tribal culture create overlap that challenges our ability to distinguish between cultural insiders vs outsiders. Many individuals are full participants of the culture and the community, yet do not or cannot identify as tribal members. Nevertheless, these experiences demonstrate important candidate phenomena for conceptualizing health for the purpose of improving research inclusivity for underrepresented populations,[11] such as AI/AN. These phenomena include connectedness to land, routine spiritual customs, and Minobimaadaziiwin. The importance of "living in a good way" has been emphasized throughout our affiliated research efforts—particularly as important context for understanding environmental research in Anishinaabe territories.[6]

These questionnaire results provide an outline for the prominent perceptions regarding Anishinaabe concepts of health. The highly affirmative responses demonstrate agreement between the concepts identified by key informants when developing the questionnaire and the surveyed community members. The context in which the questions were asked may have produced a favorability bias towards answering positively to questions regarding culture. Despite a potential favorability bias, the noted ambivalence indicates anxiety towards promoting culture in an uncertain future.

It seems likely that all human beings feel a desire to maintain their traditions and cultures as an important component of their wellness. The AI/AN communities present an instructive example of how the organism (humans) cannot be fully removed from the environment (culture). The GLNARCH culture and wellness pilot data are intriguing because the trends affirm the a priori insights of the GLNARCH advisory committee and culturally AI/AN staff: environmental health is tribal health, tracking morbidity and mortality data alone misses the bigger picture, and health encompasses how a life is lived ("living in a good way"). The concept of health is active and dynamic in the minds of these participants, as opposed to a passive state represented by a morbidity prevalence or rate.

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# Alcohol Use During Chemotherapy: A Pilot Study

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## ABSTRACT

**Introduction:** Alcohol use increases the risk for some cancers and can cause complications during treatment. The prevalence of alcohol use during chemotherapy has not been well documented in current literature. This pilot study aimed to examine self-reported alcohol use during chemotherapy among cancer survivors as a basis for future research and interventions.

**Methods:** We surveyed Wisconsin cancer survivors (N=69) who participated in the ongoing population-based research study, Survey of the Health of Wisconsin (SHOW), on alcohol use during chemotherapy.

**Results:** Of the cancer survivors who reported receiving chemotherapy, 30.4% (N=21) reported consuming alcohol while receiving chemotherapy, and 38.1% (N=8) of those who drank reported complications. Alcohol use during chemotherapy was higher among older adults (age 65+, rate ratio [RR], 1.9; 95% CI, 0.7-4.9), men (RR, 2.7; 95% CI, 1.3-5.4), former and current smokers (former: RR, 1.6; 95% CI, 0.7-3.8, current: RR, 2.5; 95% CI, 1.1-5.8), and those with non-alcohol-related cancers (RR, 2.0; 95% CI, 0.9-4.2.)

**Conclusions:** Alcohol use during chemotherapy is common and may increase the risk of complications. More research is needed to better understand this problem and to design effective interventions.

## BACKGROUND

Alcohol is a well-established risk factor for the development of cancers, including upper aerodigestive tract cancer, hepatocellular carcinoma, breast cancer, and colorectal cancer.[1] Cohort studies demonstrate an 8% increase in overall cancer-related mortality

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and a 17% increased risk for cancer recurrence in the highest versus lowest alcohol consumers.[2] Despite this, a significant proportion of cancer survivors continue to consume alcohol.[1] Epidemiologic studies to inform alcohol surveillance and counseling guidelines for cancer patients are currently lacking.[3]

Cancer treatments like chemotherapy can cause severe adverse side effects and stress in cancer patients. Some documented side effects include severe gastrointestinal complications (nausea, vomiting, mucositis, constipation, and diarrhea), cardiotoxicity, and central and peripheral neuropathy.[4] Little is known about how concurrent alcohol use affects chemotherapy delivery and efficiency and how persistent drinking during treatment affects long-term cancer risk. This study aimed to examine preliminary evidence of self-reported alcohol use during chemotherapy among cancer survivors as a basis for future research and evidence-based intervention design. In this study, a person is considered to be a cancer survivor from the time of diagnosis until the end of life.

## METHODS

This was a cross-sectional analysis of a geographical cohort of patients participating in the Survey of the Health of Wisconsin (SHOW) from 2009 to 2019. Details of SHOW methods have been described previously by Malecki et al.[5] Participants who reported a previous diagnosis of cancer (n = 337) were sent a cancer survivorship survey by mail; the study sample for this analysis included only a subset (n = 69) who indicated chemotherapy and completed an alcohol questionnaire (Figure).

**Figure.** Flow Diagram of Study Participants, Alcohol Use During Chemotherapy Pilot Study, Survey of the Health of Wisconsin (SHOW)
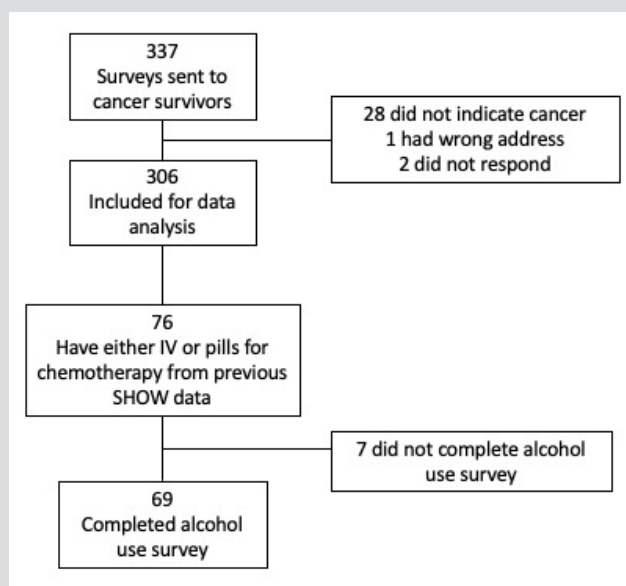
Participants who reported a previous cancer diagnosis (n = 337) were sent a cancer survivorship survey by mail; the study sample for this analysis included only a subset (n = 69) who indicated chemotherapy and completed an alcohol questionnaire.

**Table.** Prevalence of Alcohol Use During Chemotherapy, Survey of the Health of Wisconsin (SHOW)

| | Total Participants (N = 69) | Prevalence of Alcohol Use | Rate Ratio (95% CI) | *P* value |
|---|---|---|---|---|
| Total | 69 (100%) | 21 (30.4%) | – | |
| Age[a] | | | | |
| <65 years | 21 (31.8%) | 4 (19.0%) | Ref | |
| 65+ years | 45 (68.2%) | 16 (35.6%) | 1.87 (0.71 – 4.90) | *P* = 0.18 |
| Sex | | | | |
| Female | 46 (66.7%) | 9 (19.6%) | Ref | |
| Male | 23 (33.3%) | 12 (52.2%) | 2.67 (1.32 – 5.39) | *P* = 0.006 |
| Smoking status[b] | | | | |
| Never | 41 (61.2%) | 9 (22.0%) | Ref | |
| Former | 17 (25.4%) | 6 (35.3%) | 1.61 (0.68 – 3.82) | *P* = 0.30 |
| Current | 9 (13.4%) | 5 (55.6%) | 2.53 (1.11 – 5.75) | *P* = 0.04 |
| Cancer type | | | | |
| Alcohol-related[c] | 38 (55.1%) | 8 (21.1%) | Ref. | |
| Non-alcohol-related[d] | 31 (44.9%) | 13 (41.9%) | 1.99 (0.95 – 4.18) | *P* = 0.06 |

[a]Three participants did not report their age.
[b]Two participants did not report their smoking status.
[c]Alcohol-related cancers include breast, colorectal, esophageal cancer, and both breast and colorectal.
[d]Non-alcohol-related cancers include bladder, bone, brain, leukemia, lymphoma, lung, ovarian, prostate, skin, testicular, thyroid, uterine.

All participants were asked a general question about consuming alcohol during chemotherapy (yes, no, never). For those reporting alcohol use, general information about complications from chemotherapy were also collected (yes, no). Other alcohol consumption questions were asked but were not reported in our results due to the small sample size, including the amount of alcohol used per day (1 to 5 or more drinks), binge drinking behavior (yes, no), and hospitalization due to chemotherapy complication (yes, no).

Self-reported demographic characteristics included age (at time of survey), sex (male, female), smoking status (current, former, never), and self-reported type of cancer at diagnosis (eg, breast, colorectal).

Data analyses were completed using SAS University edition. Prevalence of alcohol consumption among cancer survivors receiving chemotherapy and prevalence of chemotherapy complications among cancer survivors who drank and their 95% Clopper Pearson confidence intervals were calculated. Rate ratios and 95% confidence intervals were calculated using the Cochran-Mantel-Haenszel method.

All study protocols were approved by the University of Wisconsin Health Sciences Institutional Review Board, and all participants were provided written informed consent during the initial home visit.

## RESULTS

Cancer survivorship surveys were sent to 337 SHOW participants: 306 confirmed a history of cancer and 76 indicated chemotherapy use – the focus on this research; and 69 (90.8%) completed the alcohol consumption survey (Figure).

The average age of the study population was 68.4 years (range, 36-87) at the time of survey completion in 2019. Forty-six (66.7%) cancer survivors were women. Sixty-six (95.7%) were non-Hispanic White. Nine (13.4%) were current smokers, 17 (25.4%) were former smokers, and 41 (61.2%) reported never smoking. Thirty-eight (55.1%) of the cancer survivors were initially diagnosed with at least 1 cancer type where alcohol is a risk factor: esophageal cancer (n = 1), breast cancer (n = 28), colorectal cancer (n = 8), and both breast and colon cancer (n = 1).

Among the 69 cancer survivors, 21 (30.4%; 95% CI, 19.9%-42.7%) reported alcohol use while receiving chemotherapy. Alcohol use was higher among those who were older (age 65+, RR, 1.9; 95% CI, 0.7-4.9), male (RR, 2.7; 95% CI, 1.3-5.4), and former or current smokers (former: RR, 1.6; 95% CI, 0.7-3.8, current: RR, 2.5; 95% CI, 1.1-5.8). Alcohol use was higher among those who reported having a non-alcohol-related cancer compared with those who reported having had an alcohol-related cancer (RR, 2.0; 95% CI, 0.95-4.2). (See results in Table.) Among those who drank alcohol during chemotherapy, 8 (38.1%; 95% CI, 18.1%-61.2%) reported having chemotherapy complications.

## DISCUSSION

In this preliminary descriptive study, 30.4% cancer patients drank alcohol while receiving chemotherapy. Other studies have collected information about alcohol use among cancer survivors in general but have not specifically examined alcohol use during chemotherapy. Miller et al reviewed 3 studies on alcohol use after oral cancer diagnosis and concluded that 34% to 57% of upper aerodigestive tract cancer patients continue to drink after diagnosis.[6] Sanford et al found that the current prevalence of alcohol use among cancer survivors after recovery was 57%.[7] Penfold et al also showed that the prevalence of high alcohol consumption in cancer survivors of head and neck cancer reduced from 54% to 35% at 4 months after diagnosis but then increased to 41% at 12 months.[8] Combined with our data, this suggests that a high proportion of cancer survivors drink alcohol continuously after cancer diagnosis—even during treatment—despite the risk and side effects associated with alcohol.

People's drinking patterns change as their social and environmental stress changes. A recent study based on an online survey among the general population found that 93% of adults reported alcohol consumption.[9] The same study found that there was an increase in frequency and quantity of alcohol use among people who drink while social distancing at home during the SARS-CoV-2 (COVID-19) pandemic. Combined with our finding that a high percentage of cancer survivors continue to use alcohol during treatment, we think that interventions for alcohol use should take into account the stress caused by cancer diagnosis and treatment.

In the current study, alcohol use during chemotherapy was higher among certain subgroups, such as men, smokers, and those with non-alcohol-related cancers. Several of these findings have been reported in studies that examine alcohol use among cancer survivors. Breast cancer is found to be associated with lower odds of drinking at all levels,[8] which explains our findings that both men and those with non-alcohol-related cancers have higher drinking rates. Our finding that alcohol use is higher among smokers is also supported by the literature.[8] The high co-occurrence of smoking and drinking means that ongoing tobacco cessation efforts for cancer survivors can also include alcohol reduction approaches.

Lastly, we found that 38.1% of those who drank during chemotherapy treatment reported at least some complications. In a similar study, 60% of patients who consumed more than the normal amount of alcohol determined by the American Heart Association (1 to 2 drinks per day for men and 1 drink per day for women) developed stage III osteoradionecrosis as a complication of radiation therapy.[10]

Limitations of our study include the small sample size of 69 patients for analysis, the cross-sectional survey design subject to recall bias, and the lack of a comparison group.

## CONCLUSIONS

This small sample of cancer survivors from an ongoing population-based research study sample of Wisconsin residents suggests that about one-third of cancer survivors report drinking alcohol while receiving chemotherapy. Larger and more powerful studies are needed to identify the risks and benefits of alcohol intake during cancer treatment. Researchers and clinicians must address the impact of alcohol use after cancer diagnosis, especially during cancer treatment.

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# Discharge When Medically Ready

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## ABSTRACT

**Quality Problem:** The timing and pace of patient discharges are not level-loaded throughout the day at many institutions including ours, an academic medical center and adult Level I trauma center located in Milwaukee, Wisconsin.

**Initial Assessment:** Only 4% of patients were being discharged with rooms marked dirty by 11 AM at our institution.

**Choice of Solution:** We put together a multidisciplinary team of approximately 30 stakeholders to develop a revised process that focused on coordination of discharge activities, plan of care awareness among team members, and communication with patients and families.

**Implementation:** The discharge process was piloted and iteratively adjusted on a single medicine floor.

**Evaluation:** Our interventions made a noticeable impact on median room "ready to be cleaned" (RTBC) time without having an adverse impact on length of stay. RTBC improved by a median of 39 minutes ($P = 0.019$), and the proportion of rooms ready to be cleaned by 11 AM increased from 4.19% to 8.13%.

**Lessons Learned:** Having a multidisciplinary team participate in the evaluation and development of a new process was critical. Additionally, implementing solutions on a single unit allowed for rapid iteration of changes.

## QUALITY PROBLEM

Acute care hospitals are experiencing increased inpatient census with a need for early bed availability during the morning hours to accommodate incoming patient flow.[1] Prioritizing discharges

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in the morning can be challenging given elements of patient care that need to be addressed on the morning of discharge. When census begins to rise, patients begin to board in the emergency department (ED) and length of stay begins to increase, discharge distribution concentrates later in the day, and demand for inpatient space advances to earlier in the morning due to daily admissions outnumbering discharges.[2] The aim of this project was to develop a process that focused on early discharge for patients who are medically ready by applying process improvement principles.

Studies attempting to reduce total length of stay and streamline the discharge process have made interventions at multiple levels, including early discharge orders by physicians, twice a day multidisciplinary rounds, early transportation to nursing facilities, and creating websites to track daily discharges before noon.[3-5] Many institutions have examined the importance of multidisciplinary teams as a modality to create clinical microsystems to improve communication and patient outcomes and allow for optimized discharge planning.[6-8] While there is guidance on optimizing patient transitions from the inpatient to outpatient settings,[9] there is a paucity of data on a comprehensive set of tactics to facilitate early discharges.

## INITIAL ASSESSMENT

Similar to other academic medical centers,[10] the timing and pace of patient discharges are not level-loaded throughout the day within the inpatient platform in our institution, an academic medical center and adult Level I trauma center located in Milwaukee, Wisconsin.

A critical mass of discharges happens in the afternoon, with nearly 50% occurring between 1 PM and 5 PM. This creates an insufficient number of available beds for timely placement of patient admissions, with 50% of admissions occurring between 11 AM and 7 PM.

## CHOICE OF SOLUTION

We employed Institute of Healthcare Improvement's Model For Improvement (MFI). MFI frames an improvement project with 3 questions:[11] (1) What are we trying to accomplish)? (2) How will we know a change is an improvement? (3) What changes can we make that will result in improvement?

Our goal with this project was to open up inpatient beds earlier in the day. We decided to track our median bed "ready to be cleaned" (RTBC) time and the proportion of beds marked ready for cleaning by 11 AM as indicators of improvement in the number of inpatient beds available for new admissions. A 30-member team from medical and surgical floors was assembled to determine the changes needed to reach our goal. It included representatives from various disciplines: attending and resident physicians, advanced practice providers, nursing, pharmacy, respiratory therapy, radiology, physical therapy, occupational therapy, speech therapy, patient flow, and transport. This team met 1 to 2 times per month over the span of 7 months and was facilitated by the institution's process improvement department.

The team first developed a current state process map that represented the discharge planning process steps, from admission until discharge. The team then utilized Lean principles to analyze the process map and identify non–value-added activities within the current process. Lean originated in the business world as a cost reduction mechanism employed by all members of the organization to systematically reduce waste.[12] Lean principles are routinely used in health care to maximize value by reducing waste and wait.[13] The root causes for the non–value-added activities in our discharge planning process were identified and solutions were developed to address them. Root causes were grouped into 19 categories, each of which was further divided into subcategories. A total of 91 solutions were identified and eventually solidified into 53 discrete action items, with several items targeting each root cause. These solutions were prioritized by using scores assigned by the team for "impact to project goals" and "effort to implement." These scores were used for pilot implementation priority to maximize impact and ensure stewardship of resources. The 19 categories and subcategories of barriers identified and solutions with highest score in each subcategory are presented in the Table. These solutions led to the development of multiple interventions throughout the patient's stay (Table and Appendix). Some solutions were not implemented during the pilot, mostly due to informational technology or budgetary constraints (Table). We decided to move forward with the pilot while continuing to work with project sponsors on implementing these solutions at a later date. Key behavioral items implemented during the pilot are summarized below.

On the day of admission, the clinician and nurse discussed the goals of care with the patient, and the clinician established the anticipated date of discharge, if known.

At T-48 (48 hours prior to discharge), the clinician assessed the patient's progress to the discharge milestones. The anticipated discharge date was established or updated. Nursing staff assessed the patient's and family's understanding of the care plan and discharge needs.

At T-24 (24 hours prior to discharge), the clinician assessed the patient's progress to the discharge milestones. Remaining activities were ordered and/or completed, including imaging/procedures, medication reconciliation, home oxygen evaluation, therapy, consults, and discharge teaching. Additionally, durable medical equipment, home care, and transportation were arranged.

On the day of discharge, the clinician reviewed the planned discharge, final discharge medication list, and after-visit summary. The care team completed remaining items for patient discharge, including providing final education, prescriptions, and durable medical equipment.

## PILOT IMPLEMENTATION

The solutions were planned for pilot on a single medicine unit for 2 months. The education methods used for the new process were department meetings, leader emails to staff, the hospital intranet, and an internal podcast. Posters summarizing the changes were posted on the pilot unit and in staff workrooms.

After completion of education, we conducted the pilot. Compliance with various elements of the pilot was determined by nurse manager audits. This involved the nurse manager rounding with patients throughout their stay to determine what aspects of the care plan had been discussed with them and also auditing patient's whiteboards for the presence of a care plan and estimated discharge date. This information, along with observations by members of the care team related to the pilot, was reviewed at weekly multidisciplinary meetings and adjustments were made. The main points of adjustment during pilot implementation included members of the multidisciplinary team gathering information from their respective frontline staff regarding compliance with tactics, increasing awareness among staff members by sharing tactics at staff meetings on an ongoing basis, and coaching staff members through one-on-one interactions with unit leaders.

## EVALUATION

We assessed performance of the process by evaluating the percentage of beds marked RTBC by 11 AM and median RTBC time. A previous study showed an association between increase in the proportion of patients discharged before noon and length of stay, presumably driven by the perverse incentive of keeping the patient an additional midnight and discharging them early the next day.[14] Therefore, we also monitored length of stay as a balancing measure to ensure it was not adversely influenced by the efforts to improve the RTBC metrics.

**Table.** Barriers and Solutions to Discharge When Medically Ready

| Category | Subcategory | Highest-Ranked Solutions in Each Subcategory[a] (Score out of 100) |
|---|---|---|
| Imaging studies | Scheduling outpatient exams | *Exams that do not change the disposition of the patient should be scheduled as outpatient (65)* |
| | Update SPOK[b] provider list | *Add intern/resident to SPOK[b] paging list to make it easier to determine who to page (41)* |
| EPIC (EHR) | Imaging preparation | Have all imaging preparations be on EPIC for nurses (62) |
| | Home care/DME orders | *Link templates of needed information to home care/DME orders in Epic (47)* |
| | Home oxygen orders | *Information services to work with home care medical to create a comprehensive template for home oxygen ordering (45)* |
| | Discharge checklist | *Transition to standardized needs flowsheet (discharge check off) that all disciplines can see (42)* |
| | Discharge order alert | EPIC alert to flag patients 24 (T-24) and 48 (T-48) hours prior to discharge and day of discharge (40) |
| | Physical therapy/occupational therapy | When team places a consult, there should be a prompt in EPIC to ensure activity order is in place (50) |
| | Swallow evaluation | Create an order set to include bedside swallow evaluation and video swallow if indicated (46) |
| | Security-personal property | Alert on discharge navigator of possession of personal property by security (41) |
| Clinician | Clinician plan of care updates to the team | *Clinicians enter anticipated discharge date and discharge plan in their daily progress note and attend care coordination rounds (64)* |
| | After-visit summary | *Clinicians to enter discharge instructions on day of discharge (52)* |
| | Order entry | *Provide WOW (Workstation On Wheels) to providers (61)* |
| | Controlled substances | *Educate clinicians to "sign" controlled substances in Epic instead of "sign and hold" (45)* |
| | Attending to see patient | *Attending on house-staff team to see ready for discharge patients prior to rounds (41)* |
| | Team rounds | *House-staff teams, when not post call, to start rounds by 8.30 ᴀᴍ (51)* |
| | House staff | *Better education for house staff on discharge process (33)* |
| Pharmacy | Priority lane | *Have a fast-track process in pharmacy to fill medications faster for discharged patients (50)* |
| | Test script | *Create policy giving pharmacist the ability to run test prescriptions under attending's name (54)* |
| | Fill preference | *Pharmacist to ask about where to get prescription filled after DC (51)* |
| | Antibiotic script | Policy allowing pharmacist to print antibiotic script once Infectious Disease note is in (43) |
| | Printed scripts | *Have prescriptions completed and given to pharmacy as soon as possible (43)* |
| | Additional staff | Hire additional staff to complete test prescriptions/prior authorizations (27) |
| | Fill alert | Patient to receive text message when prescription is ready for pick up at pharmacy (35) |
| | Discharge medication reconciliation | Create a process to keep discharge medication report separate from other AVS documents (47) |
| Physical therapy | Admission assessment | *Nursing to screen for need for PT/OT assessment using Activity Measure for Post-Acute Care( 34)* |
| | Additional staff | Increase physical therapy/occupational therapy daily staffing (30) |
| CCRs | Clinical milestone focus | *Transition CCRs to being clinical milestone-focused from date-focused (45)* |
| Education | Managing patient expectations | *Create scripting to educate patients and families in discharge process throughout admission (39)* |
| | Wound/ostomy teaching | Create standardized videos for wound/ostomy care (41) |
| | White boards | *Utilize white boards in patient rooms to improve communication with patients/families (51)* |
| Follow-up | Follow-up appointments | Priority line to clinic scheduler to set up post discharge appointments (41) |
| | Identification of PCP | Nursing to flag patients without PCP at admission assessment and communicate with health care unit coordinators on floors to set up PCP (40) |
| Case management/ social work | Ride home | Arrange Uber/Lyft prepaid cards for payment to patients for ride home (31) |
| | Difficult discharge team | *Create team to discharges where patient has been medically ready for more than 24 hours but there is no safe discharge plan (30)* |
| | DME supplier | *Provide feedback and assign consequences to DME supplier for delays (21)* |
| Dietary | Home nutrition support | *Determine need for home nutrition support on post-operative day 1 and determine insurance coverage greater than 24 hours prior to discharge (37)* |
| Transport | Staffing model | *Transport to provide adequate staffing during peak hours and support 15-minute maximum wait time (36)* |
| ICU | Early discharge planning | *Initial discharge assessment and planning to begin in the ICU (51)* |
| Consults | Timely communication | *If day of discharge consult cannot be avoided, inform consulting team when calling consult and consulting team to prioritize (43)* |
| | Diabetes education | Diabetes education to schedule time for education with patient's family (41) |
| | Diabetes education consults | Empower RNs to place diabetes education consult (44) |
| Nursing | Additional staff | *Expand hours of patient free charge nurse to round with teams and coordinate discharge needs (35)* |
| | Rounding with primary team | *Include RN in bedside rounds with primary team (53)* |
| | Plan of care | *Charge RN to page clinician to clarify discharge plan in the afternoon if unclear (44)* |

Abbreviations: EHR, elecontronic health record; DME, durable medical equipment; PT, physical therapy; OT, occupational therapy; CCR, care coordination rounds; PCP, primary care provider; ICU, intensive care unit; RN, registered nurse.

Italicized Items were implemented during the pilot.

[a]Score out of 100, calculated as {Anticipated impact X (10-anticipated effort)}; anticipated impact and anticipated effort both scored on a scale of 1 to 10 with 10 being maximum impact/effort.

[b]SPOK is the clinical communications system used at our institution.

The pilot unit metric performance was evaluated by utilizing data from 2 months of patient discharges preintervention (N = 167) and 2 months postintervention (N = 160). There was a statistically significant ($P = 0.017$, Mann-Whitney test) favorable shift in the median RTBC time of 39 minutes earlier in the day from 15:32 to 14:53. There was no significant change in median length of stay ($P = 0.444$) from 3.33 to 3.42 days, which was consistent with the project's deliverable expectations. Length of stay was calculated based on the number of midnights a patient spent in the hospital. While we saw a slight increase of 0.09 days in the length of stay, we do not think the change was clinically meaningful. The data indicated a favorable 94% improvement (from 4.19% to 8.13%) for rooms RTBC by 11 AM; however, analysis did not indicate statistical significance ($P = 0.168$). Finally, there was no significant change in the 30-day readmission rate (17.2% to 16.9%, $P = 0.13$).

Based on these results, the interventions made a noticeable impact on early discharge planning without having an adverse impact on length of stay. In a study done at a pediatric hospital, a 79% increase in discharges by 11 AM (8.8% to 15.8%) reduced wait times in the ED from 221 minutes to 133 minutes.[15] While we did not study the change in our ED wait times with the improvement in proportion of rooms marked RTBC by 11 AM, we anticipate a similarly positive impact.[10] Reduction in ED overcrowding has the potential to improve patient and staff satisfaction[16] and improve patient safety.[17]

## LESSONS LEARNED

The team reported the value in bringing various roles together during process development to aid in understanding tasks and challenges faced by other members of the care team. Many new insights were unexpected and allowed understanding beyond what was understood within the context of busy day-to-day observation. Additionally, piloting solutions on a single unit allowed for rapid iteration of changes, since the number of stakeholders to involve in assessment of performance and implementation of incremental changes was minimized. Another key learning is the need for formal electronic health record-generated reports on compliance with tactics included in the pilot.

The next step is to implement this process on all hospital units, while utilizing successive "plan-do-study-act" cycles. Solutions that were not implemented during the pilot will be incorporated in the next phase as they become available.

Two additional interventions are being considered based on learnings from the pilot. Lack of team awareness of readiness for discharge is a key barrier to early discharges. We addressed this by asking clinicians to enter expected discharge date on whiteboards in patient rooms and filling out the expected discharge date in the electronic health record during our multidisciplinary care coordination rounds. Based on input from unit nurse managers, we are considering highlighting readiness for next day discharge on a whiteboard placed in multidisciplinary work areas on the floor.[15] In addition, our clinicians reported a need for an afternoon huddle with social work and case management to prepare patients for early discharges the following day.[3] We plan to discuss the logistics of this change with our care management colleagues and hospital administration.

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# The Effect of Weather and Sporting Events on Ambulatory Visits and Hospitalizations at a Veterans Affairs Medical Center

Cynthia Kay, MD, MS; Jeffrey L. Jackson, MD, MPH

## ABSTRACT

**Background:** We explored the impact of weather and sporting events on clinic and emergency department (ED) visits and hospitalization.

**Methods:** Weather, dates of sporting events, ED visits, hospitalizations, clinic visits, no-shows, and same-day patient cancellations from 2015 to 2018 were abstracted from Milwaukee's Veterans Affairs (VA) medical system.

**Results:** Inclement precipitation increased clinic cancellations. Snowfall reduced ED visits. Green Bay Packer football games, University of Wisconsin-Madison football games, and the Super Bowl reduced ED visits but not hospitalizations. Milwaukee Brewers baseball home games did not affect ED visits, but hospital admissions increased slightly. Basketball events (Milwaukee Bucks, University of Wisconsin – Madison, University of Wisconsin – Milwaukee, Marquette University)had no impact.

**Conclusions:** Inclement weather increased clinic cancellations, and snow reduced ED visits. Football games reduced ED visits, while baseball increased hospitalizations, probably because the Milwaukee Brewers stadium is located on the VA property.

## BACKGROUND

Health care professionals often carry various superstitions and preconceptions, such as a full moon brings in unusual cases, and severe weather or major sporting events cause fewer admissions and more clinic cancellations. However, previous research on the influence of weather and sporting events on emergency department (ED) visits, urgent care visits, and hospitalizations has been mixed.[1-3] There are numerous studies that demonstrate a modest effect of weather on ED visits,[4,5] with a larger impact from the day of week and season. ED visit prediction models that incorporate these factors have been developed for staffing purposes.[6] Some

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studies have found that sporting events reduce ED visits, mostly for low-acuity visits and among males, during the event.[7,8] There have been no studies examining the effect of weather and sporting events on veterans or in Wisconsin. Our purpose was to study the impact of these factors on ED and clinic visits and hospitalization among veterans.

## METHODS

For this study, the number of ED visits, hospitalizations, clinic visits, no-shows, and same-day patient cancellations from 2015 to 2018 from a Veterans Affairs (VA) medical system located in the Midwest region of the United States were obtained from electronic health records. Included VA primary care clinics were all located in Wisconsin: Green Bay, Cleveland, Appleton, Union Grove, and Milwaukee. ED visits and hospitalizations were to the Clement J. Zablocki VA Medical Center in Milwaukee. These data are aggregated on a daily basis and were abstracted by day but did not include hourly information. From the National Oceanic and Atmospheric Administration, we abstracted daily minimum and maximum temperatures and type and amount of precipitation. From team websites, we abstracted the days the state's professional baseball (Milwaukee Brewers), basketball (Milwaukee Bucks), and football teams (Green Bay Packers) played, as well as nonprofessional football (University of Wisconsin-Madison) and basketball (University of Wisconsin – Madison, University of Wisconsin – Milwaukee, and Marquette University), as well as Super Bowl dates. For teams that play home games in Milwaukee (Marquette, Brewers, Bucks), we abstracted whether games were at home or away. Multivariable regression assessed the relationship between continuous outcomes

**Table 1.** Impact of Weather on Clinic Visits, Emergency Department (ED) Visits, and Hospitalizations

| | Clinic Visits<br>ß (95% CI) | Clinic Cancellations<br>ß (95% CI) | Clinic No-Shows<br>ß (95% CI) | ED Visits<br>ß (95% CI) | Hospitalizations<br>ß (95% CI) |
|---|---|---|---|---|---|
| Rainfall (inches) | 135.6 (-19.2 to 290.4) | 18.1 (3.2 to 33.0)[a] | 9.0 (-4.1 to 22.2) | 0.21 (-2.5 to 2.9) | 1.4 (-3.5 to 0.72) |
| Snow (inches) | -91.8 (-215.4 to 31.8) | 23.1 (11.2 to 34.9)[b] | -1.1 (-11.7 to 9.4) | -2.9 (-5.0 to -0.67)[c] | -0.15 (-1.8 to 1.6) |
| Snow on ground (inches) | 13.0 (-32.8 to 58.9) | 0.36 (-4.1 to 4.8) | 0.54 (-3.4 to 4.5) | 0.20 (-0.61 to 1.00) | -0.001 (-0.63 to 0.63) |
| Temperature (Minimum) | -3.8 (-11.2 to 3.6) | 0.14 (-0.51 to 0.80) | 0.35 (-0.23 to 0.93) | -0.06 (-0.19 to 0.07) | -0.006 (-0.11 to 0.10) |
| Temperature (Maximum) | 13.0 (-32.8 to 58.9) | -0.3 (-1.0 to 0.40) | -0.28 (-0.92 to 0.35) | 0.10 (-0.02 to 0.22) | 0.01 (-0.08 to 0.11) |

[a] $P=0.02$, [b] $P<0.005$, [c] $P=0.01$

and dependent variables (Stata 16.1). This study was approved by the Clement J. Zablocki VA Medical Center Institutional Review Board.

## RESULTS

Over the 3 years, there was an average of 1695 clinic visits, 69 ED visits, and 30 hospital admissions on nonholiday weekdays. There were fewer ED visits on weekends and holidays (69 vs 49, $P<0.001$) but no difference in daily admissions (28.1 vs 27.6, $P=0.50$). The temperatures ranged from -10 °F to 95 °F. Snow was on the ground for 134 days (12.3%). It snowed on 58 days (5.3%), with more than 1 inch of accumulation on 21 days during the study period.

On average, there were 100 same-day clinic cancellations and 94 clinic no-shows. There were significantly more same-day clinic cancellations when there was rain or snow (Table 1), with a stepwise increase in clinic cancellations with greater rain (none: 96 cancellations, ≤1 inch: 106 cancellations, >1 inch: 140 cancellations) or snowfall (none: 98 cancellations, ≤1 inch: 122 cancellations, >1 inch: 179 cancellations) ($P<0.001$ for both).

Temperature, rain, and snow did not affect the total number of clinic visits or rates of hospitalizations, although snow reduced the number of ED visits (Table 1). There were fewer ED visits on days the Packers or the University of Wisconsin-Madison (UW-Madison) football team played, or the Super Bowl was held (Packers: 49 vs 63, $P<0.0005$; UW-Madison: 52 vs 63, $P<0.0005$; Super Bowl: 48 vs 63, $P=0.04$). However, there was no difference in hospitalizations (Packers: 27.9 vs 28.6, $P=0.63$; UW-Madison: 27.9 vs 27.2, $P=0.65$; Super Bowl: 27.9 vs 20.4, $P=0.22$). Brewers home games did not affect ED visits (49 vs 50, $P=0.98$), but admissions increased (27.9 vs 30.3, $P=0.002$). Basketball games (Marquette, UW-Madison, UW-Milwaukee, Bucks) had no impact on ED visits or admissions (Table 2), whether in-town or away (data not shown).

## DISCUSSION

This is the first study to our knowledge that has examined clinic

**Table 2.** Impact of Sporting Events on Emergency Department (ED) Visits and Hospitalizations

| | ED visits<br>(95% CI) | P value | Hospitalizations<br>(95% CI) | P value |
|---|---|---|---|---|
| Green Bay Packer games | -15.3 -18.9 to -11.6) | <0.005 | 0.73 (-2.2 to 3.6) | 0.62 |
| Super Bowl | -15.8 (-30.7 to -0.85) | 0.04 | 7.5 (-4.5 to 19.4) | 0.22 |
| Milwaukee Brewers games | 0.03 (-1.9 to 1.9) | 0.98 | 2.4 (0.99 to 3.9) | .002 |
| Milwaukee Bucks games | 0.54 (-1.9 to 3.0) | 0.67 | 2.4 (0.99 to 3.9) | 0.27 |
| Marquette University games | -0.67 (-3.5 to 2.1) | 0.64 | -1.1 (-3.0 to 0.85) | 0.65 |
| UW – Madison football | -12.7 (-16.8 to -8.6) | <0.005 | -0.51 (-2.7 to 1.7) | 0.65 |
| UW – Madison basketball | -1.3 (-4.0 to 1.5) | 0.36 | -0.79 (-2.9 to 1.3) | 0.47 |

Abbreviation: UW, University of Wisconsin.

visits, same-day cancellations, and no-show rates due to weather and sporting events. Temperature had no impact on any outcomes. There were more clinic cancellations when it was raining or snowing, with cancellations increasing with greater amounts of precipitation. Snow, Packer games, and the Super Bowl reduced ED visits. At our facility, the decrease was clinically meaningful, with nearly a quarter fewer visit on those days. There was a statistically, but not clinically meaningful, increase in hospitalization rates when the Brewers played at home. The paradoxical finding of no increase in ED visits but increased hospitalizations may be due to most home games being played on weekends. Previous studies have found that low-acuity ED visits were less likely during sporting events. This also might help explain why admissions increased without an increase in the number of visits. American Family Field (the Brewers' home stadium) is located on the VA campus. With an average attendance of nearly 32,000, the proximity might explain the increase in game-day admissions.

The discordant finding of fewer ED visits with unchanged hospital admissions over the weekend suggests that those who present over the weekend may be more ill. This has been mentioned as a possible explanation for the increased mortality rate seen for weekend admissions.[9]

A limitation of this study is that it uses data from a single VA medical center, limiting generalizability to other medical centers. While the demographics of our VA are similar to other VAs (93% male, median age 64, 78% White), veterans are older, more likely to be male, and more likely to be White than nonveteran popula-

tions.[10] Previous research has shown that sporting event impact on ED visits was largely limited to males. Our results may not generalize to health systems with more women. Another limitation is that the retrospective nature of this study limits any comments on causality. Further, we have no information on the specific types of admissions increased by Brewers games, and we do not have hourly data. Based on other studies, it is likely that there would be a lull in ED visits immediately before and during games with a spike afterwards. Finally, we do not have detailed demographic information. Older adults may be more susceptible to weather than other populations. Future studies should gather hourly data, obtain patient-level information, and include non-VA health facilities.

## CONCLUSIONS

Snow and rain increased clinic cancellations, and snow decreased ED visits. There were fewer ED visits with football games and more admissions with baseball games. Temperature had no impact.

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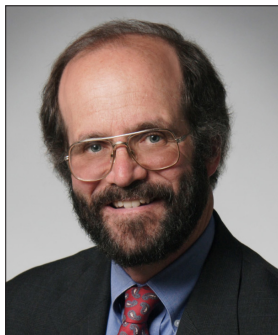
# New Developments in Our Understanding of the Origins and Treatment of Asthma

**Daniel J. Jackson, MD**

**Robert N. Golden, MD**

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Asthma is the most common chronic disease of childhood. While asthma is a highly heritable condition, the dramatic increased prevalence of disease over the past half-century strongly suggests that the environment plays an important role in disease expression. Asthma disproportionately affects children in urban communities in the United States and imposes a great personal and health care burden. Despite treatment advances, a significant proportion of patients do not achieve control of their disease and continue to experience high levels of morbidity. Unfortunately, tremendous health care disparities exist in asthma, with Black and Hispanic children in the United States bearing the greatest disease burdens. While children raised on farms have reduced risk of developing asthma, rural children who develop asthma often experience worse disease outcomes. Thus, the factors underlying differential burdens of disease across urban, suburban, and rural environments are an important area of study.

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## What has been learned about asthma from birth cohort studies led by UW-Madison investigators?

University of Wisconsin-Madison has a long-standing track record of internationally recognized contributions to asthma research. One area in which we have led the way is with birth cohort studies performed in diverse environments. The Childhood Origins of Asthma (COAST) birth cohort study, initiated in 1998 and comprising predominantly suburban Madison children/families, has identified the critical synergistic contributions of early-life respiratory allergies and wheezing with the common cold virus, rhinovirus, to the inception of asthma. The Urban Environment and Childhood Asthma (URECA) birth cohort study, initiated in 2004 at four urban centers in the United States, seeks to identify the specific components of urban environments that impact the development of asthma. URECA has identified both environmental exposures and distinct patterns of gene expression in the airways that are linked to clinical phenotypes of disease during later childhood. The Wisconsin Infant Study Cohort (WISC) began in 2013 as a partnership between UW-Madison and Marshfield Clinic research-

ers to understand the components of rural farm environments, such as early-life microbial exposures, that can reduce the risk for allergic disease and asthma, with a long-term goal of identifying preventive strategies for the broader population. To address the importance

> ...tremendous health care disparities exist in asthma, with Black and Hispanic children in the United States bearing the greatest disease burdens.

of studying diverse populations and the difficulty in extrapolating findings from one study population to another, UW-Madison investigators are leading the Children's Respiratory and Environment Workgroup (CREW), a consortium of researchers from 12 birth cohort studies, in the Environmental Influences on Child Health Outcomes (ECHO) program.

## Why do children in urban environments have increased asthma morbidity, and how can we reduce disparities?

The National Institute of Allergy and Infectious Diseases (NIAID), part of the National Institutes of Health (NIH), has been funding research to address asthma disparities in urban communities for more than 30 years. The UW School of Medicine and Public Health has led the NIAID-funded Inner City Asthma Consortium (ICAC) since 2002. These studies have implicated exposures common to urban environments—

such as pollution, cockroach and mouse allergens, stress, and violence—to variable phenotypes and severity of asthma. ICAC has demonstrated that guideline-based asthma care can significantly improve outcomes, although many children continue to have uncontrolled disease despite these evidence-based approaches. Recently, ICAC has leveraged airway transcriptomics, an assessment of gene expression, to identify how different triggers such as viruses and pollution provoke asthma attacks. We have identified both common and distinct pathways according to the trigger(s) of an episode, and we have further identified the incomplete impact of systemic corticosteroids, the current standard therapy for these episodes, which carry significant short- and long-term adverse effects. Recent studies have shown that even a single course of systemic corticosteroids can increase the risk of fracture, sepsis, GI bleeding, and other consequences. We can do better!

In 2021, we received new NIAID funding to lead the next iteration of this program called the Childhood Asthma in Urban Settings (CAUSE) Network, a group of multiple clinical sites and scientific centers that work collaboratively to better understand disease mechanisms and improve asthma outcomes. The overall goal of our CAUSE Leadership Center at UW-Madison is to address high-priority, unmet needs for childhood asthma in disadvantaged children in urban communities, including: (a) developing strategies to prevent asthma; (b) improving treatment and inhibiting disease progression; (c) reducing severe asthma attacks; and d) defining endotypes of respiratory health and disease. In this program, we link cutting-edge, mechanistic investigations to clinical trials and observational studies, with an aim of developing novel and targeted therapies for the prevention and treatment of asthma in urban communities and beyond.

### What is new in the treatment of asthma?

The Global Initiative for Asthma (GINA) recently put forth paradigm-changing recommendations for the treatment of asthma. GINA has strongly encouraged the use of inhaled corticosteroids (ICS) in combination with a reliever therapy (beta agonist) for the treatment of asthma symptoms, even in patients with mild asthma. Multiple recent studies have shown that an ICS in combination with either albuterol or formoterol is superior to albuterol alone as a reliever therapy. Implementation of these recommendations has been challenging in clinical practice and is an example of where we can do better as a health care system to improve patient outcomes. Furthermore, the vast majority of these studies have been performed in adult patients, and more evidence is needed to clearly determine the effectiveness of these approaches in children.

Targeted biologic therapies have dramatically improved the treatment of severe asthma patients with a "Type 2" phenotype (elevated biomarkers such as peripheral blood eosinophils and/or fractional exhaled nitric oxide). However, studies of these therapies in children and Black and Hispanic populations have been more limited to date and represent an unmet need. Further, treatments are still tremendously lacking for asthma patients who do not have evidence of Type 2 inflammation. UW-Madison investigators are addressing these gaps within ongoing collaborative research programs such as the NIH National Heart, Lung, and Blood Institute's Precision Interventions for Severe and Exacerbation-Prone Asthma (PrecISE) Network and the NIAID's CAUSE Network.

### CONCLUSION

Much has been learned about the origins and treatment of asthma over the past several decades. UW-Madison investigators are at the forefront of an exciting time in asthma research, leveraging environmental, genomic, epigenetic, metabolomic, and other "big data" to reduce asthma disparities with tangible goals of asthma precision treatment and disease prevention.

# Thank You!
## to our Reviewers

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