PREVENTING CHRONIC DISEASE

PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

ADVANCING HEALTH EQUITY, ELIMINATING HEALTH DISPARITIES, AND IMPROVING POPULATION HEALTH

U.S. Department of
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About the Journal

Preventing Chronic Disease (PCD) is a peer-reviewed public health journal sponsored by the Centers for Disease Control and Prevention and authored by experts worldwide. PCD was established in 2004 by the National Center for Chronic Disease Prevention and Health Promotion with a mission to promote dialogue among researchers, practitioners, and policy makers worldwide on the integration and application of research findings and practical experience to improve population health.

PCD's vision is to serve as an influential journal in the dissemination of proven and promising public health findings, innovations, and practices with editorial content respected for its integrity and relevance to chronic disease prevention.

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EDITORIAL

Advancing Health Equity, Eliminating Health Disparities, and Improving Population Health

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In June 2017, *Preventing Chronic Disease* (PCD) invited a panel of 7 nationally recognized experts in scientific publishing to respond to key questions about the journal's mission, quality of scientific content, scope of operations, intended audience, and future direction (1). PCD and the panel of experts recognized that chronic disease is a major contributor to poor health outcomes, an increase in health care costs, and a reduction in quality of life. Reducing the burden of chronic disease is a challenge requiring diverse collaborations and dissemination and adoption of effective interventions in multiple settings. The expert panel strongly encouraged the journal to focus more on complementing its rich body of published work on epidemiological studies with content that is attentive to evaluating population-based interventions and policies.

Since its inception in 2004, PCD's mission has been to promote dialogue among researchers, practitioners, and policy makers worldwide on the integration and application of research findings and practical experience to address health disparities, advance health equity, and improve population health. To better advance that mission, PCD used the panel's recommendations to refine the journal's focus, addressing 4 main areas of public health research, evaluation, and practice:

- Behavioral, psychological, genetic, environmental, biological, and social factors that influence health
- Development, implementation, and evaluation of population-based interventions to prevent chronic diseases and control their effect on quality of life, illness, and death
- Interventions that reduce the disproportionate incidence of chronic diseases among at-risk populations
- Development, implementation, and evaluation of public health law and health policy–driven interventions

Refining the focus on these 4 areas has allowed PCD to receive a wide range of content from authors around the world. In addition to manuscripts received through the journal's regular submission process, PCD has issued calls for papers on topics that bring to the forefront timely public health issues and targeted public health responses to improve population health.

Advancing health equity and eliminating health disparities have been and continue to be critical factors to PCD in addressing these topic areas. Healthy People 2020 defines health equity as the attainment of the highest level of health for all people (2). According to Healthy People 2020, "Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities" (2). Healthy People 2020 defines health disparities as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage" (2).

As part of its mission to address these important issues, PCD is excited to release this collection, "Advancing Health Equity, Eliminating Health Disparities, and Improving Population Health." Of the 17 articles in the collection, 10 were submitted in response to PCD's call for papers for the collection and 7 were previously published in the journal. All articles underwent the journal's rigorous peer-review process. In addition, this collection features a position statement on the journal's commitment to advancing diversity, equity, and inclusion in its scientific leadership, peer review process, research focus, training, and continuing education (3).

Over the past decade, there has been a range of community-based, technically innovative, and clinically driven prevention strategies in public health to prevent and reduce the burden of chronic conditions among diverse populations worldwide. Articles in this collection describe innovative and successful work to address factors contributing to advancing health equity, eliminating health disparities, and improving population health. They provide the latest information on ways to better understand contextual factors responsible for influencing health outcomes (both negatively and positively) and effective approaches to improve population health among diverse populations in various settings. The 18 articles address these core themes from multiple perspectives:

1. PCD's Commitment to Advancing Diversity, Equity, and Inclusion in Its Scientific Leadership, Peer Review Process, Research Focus, Training, and Continuing Education (3)
2. Engaging With Communities — Lessons (Re)Learned From COVID-19 (4)
3. Global Perspectives on Improving Chronic Disease Prevention and Management in Diverse Settings (5)
4. Reaching the Hispanic Community About COVID-19 Through Existing Chronic Disease Prevention Programs (6)
5. Community Engagement of African Americans in the Era of COVID-19: Considerations, Challenges, Implications, and Recommendations for Public Health (7)
6. Addressing Racial and Ethnic Disparities in COVID-19 Among School-Aged Children: Are We Doing Enough? (8)
7. A Framework for Mobilizing Health Care to Respond to the Community Within the COVID-19 Pandemic (9)
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9. COVID-19 and Chronic Disease: The Impact Now and in the Future (11)
10. Screening and Referral Care Delivery Services and Unmet Health-Related Social Needs: A Systematic Review (12)
11. Community and Research Perspectives on Cancer Disparities in Wisconsin (13)
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17. Oral Health Behaviors in Very Young Children in Low-Income Urban Areas in Chicago, Illinois, 2018–2019 (19)
18. A Randomized Trial to Improve Adherence to Follow-up Eye Examinations Among People With Glaucoma (20)

Positioning a scientific journal to address matters related to diversity, equity, and inclusion requires careful and intentional thinking and action. Going back to PCD's inaugural issue in 2004, featuring an essay on social determinants of health by Dr Leonard Symes, professor emeritus of epidemiology at the University of California, Berkeley, the journal has created a space to highlight the importance of these topics in chronic disease prevention and health promotion. Since that first issue, PCD has continued to demonstrate a dedication to these issues at all levels: through its leadership and staff, the content it publishes, its expanding pool of talented volunteers (PCD's external review panel, editorial board, associate editors, statistics review committee), the rigorous peer-review process, a comprehensive and inclusive variety of article types, calls for papers related to these issues, and more. In its 18 years of publication, PCD has consistently worked to assure the public of its commitment to achieving diversity, equity, and inclusion.

Peer-reviewed journals around the world are also focusing attention on these issues. In keeping with this movement, as PCD's editor in chief I have authored the first article featured in this collection, which is a position statement on the steps already taken by the journal, steps planned for the next 5 years, and key measurable outcomes (3). PCD hopes to serve as a model in identifying and implementing best practices for diversity, equity, and inclusion to build an even stronger trust with the public.

And trust is needed: mistrust of the health care system has emerged as a primary barrier among members of communities of color to seeking care in health care systems (21). Mistrust stems from historical events, including the Tuskegee syphilis study, and is reinforced by health system issues and discriminatory events that continue to this day (21). This collection includes an article by Michener and colleagues, which posits that COVID-19 has underscored long-standing societal differences in drivers of health (4). The authors offer insights into this historical reality and suggest using a health equity lens to engage communities at risk of poor health outcomes, improve bidirectional communication, establish data sharing, and improve involvement in program implementation, dissemination, and evaluation. Authors share concrete ways these can be achieved by presenting successful examples around the US.

The global impact of COVID-19 among people at risk or living with a chronic condition in multicultural communities necessitates that health communication messages are created and delivered from a health equity perspective (22). Airhihenbuwa and coauthors, in their commentary, discuss the importance of culture in unpacking messages that may be the same globally (eg, physical/social distancing) yet different across cultures and communities (individualist vs collectivist) (5). Authors discuss how use of the PEN-3 framework can facilitate a community-engaged communication response to COVID-19.

Populations with low socioeconomic status and certain racial and ethnic groups (eg, Native American, Hispanic, and African American people) have historically been disproportionately affected by chronic disease, COVID-19 diagnosis, hospitalization, and mortality (23). Calo and associates discuss how COVID-19 has disproportionately affected Hispanic communities throughout the US (6). This commentary describes how Better Together REACH, a community–academic coalition promoting chronic disease prevention, and Project ECHO (a telementoring program based at Penn State University), were adopted to support a coordinated COVID-19 response in the Hispanic community in Pennsylvania. Authors provide insights into how the existing infrastructure of chronic disease programs can be used to leverage resources and provide trusted and continuous services to reach Hispanic populations during the pandemic.

African Americans, like the Hispanic population, are more likely to contract COVID-19, be hospitalized, and die of the disease (24). Akintobi et al describe how psychosocial, sociocultural, and environmental vulnerabilities, compounded by preexisting health conditions, exacerbate the burden of COVID-19 among African Americans (7). Authors share important information based on their years of experience on ways to create and implement approaches to intentionally engage African Americans at higher risk of COVID-19. Insights and recommendations can advance community leadership and be used to prepare public health practitioners, researchers, and evaluators for future pandemics — both assisting in advancing health equity and addressing historical aspects of health disparities among African Americans.

The disproportionate impact of COVID-19 and associated disparities among Hispanic, non-Hispanic Black, and non-Hispanic American Indian/Alaska Native children and teenagers has been widely reported (25). Children from some racial and ethnic minority groups have a higher prevalence of obesity, asthma, type 2 diabetes, and hypertension; were diagnosed more frequently with COVID-19; and had more severe outcomes compared with their non-Hispanic White counterparts (26). In addition, a higher proportion of children from some racial and ethnic minority groups, compared with White children, live in families with incomes less than 200% of the federal poverty level or in households lacking secure employment (8). White et al argue that the COVID-19 pandemic reemphasizes the importance of implementing policy, systems, and environmental changes in school systems to support emergency preparedness and recovery, as well as resilience, through collaborations among local health departments, local school systems, and other public and private organizations (8). Topics addressed in this article include disparities in underlying medical conditions and social determinants of health, inequities in social determinants of health, and community-based approaches to reducing COVID-19 disparities. The article concludes by discussing ways to implement strategies to advance health equity through partnership.

It has long been recognized that disparities in health care access and patient outcomes are associated with factors related to race, sex, gender, sexual orientation, primary language, and socioeconomic status (27). Epps and coauthors recognize that African Americans and other underrepresented racial and ethnic groups are often not included in health decision making and policy development (9). As a result, these public health experts describe steps undertaken to improve participation, joint decision making, and capacity building between an integrated academic health system and a community coalition to address complex health challenges with the aim of increasing the capacity of health systems to reduce the burden of COVID-19. This article describes a call to action by the chair of a health care board of trustees to its board members consisting of clinicians, researchers, educators, and health advocates to identify ways to mitigate disparities and determine how the health care system could play a role in advancing and implementing effective strategies to reduce the disproportionate burden of COVID-19 among communities of color. Authors provide insight into the organizational planning process to generate a community outreach and health disparities collaborative with goals for governance, messaging and education, community partnerships, data, and research and evaluation.

COVID-19 has exacted a tremendous toll on the physical, emotional, and psychological well-being of many Americans, thus requiring a population health response (28). The disproportionate impact of the COVID-19 pandemic on Hispanic communities has resulted in a greater burden of depression, anxiety, and stress along with the need for increased assistance with housing, access to food, and supplemental income (29). Moon and colleagues offer original research that reports findings on demographic characteristics and factors associated with service volume, types of services, and referrals in the pre-COVID-19 and COVID-19 periods (10). They report that referrals shifted from primarily mental health services and disease management during the prepandemic period to affordable housing support, food assistance, and supplemental income during the COVID-19 period. This study presents findings on how a community-based organization with a longstanding presence in the Hispanic community effectively expanded its emotional wellness program, using *promotores* to provide integrated mental health care and social services to clients disproportionately affected by COVID-19.

Hacker et al discuss the problem of COVID-19 and chronic disease in their essay (11). They describe 3 categories of challenges facing public health professionals and identify solutions needed to improve health outcomes and lessen health inequities among people at risk or living with a chronic disease. Authors also discuss the evolving response by the Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion to implement a multipronged approach to enhance access to data at the local level, focus on addressing social determinants of health through a health equity lens, and expand partnerships and communication about the impact of COVID-19 on chronic disease.

Unmet health-related social support needs among people being served by health care systems can contribute to high patient morbidity and poor population health (30,31). However, little is known about the overall impact of screening and referral programs that address unmet health-related social needs on outcomes related to experience of care, population health, and cost. Ruiz Escobar et al conducted a systematic review of peer-reviewed articles in PubMed published over the past 10 years (as of March 2020) to determine the impact of screening and referral care delivery services on unmet health-related social needs (12). Thirty-five articles met the systematic review's inclusion criteria. After conducting their review, the authors concluded that although evidence exists of a positive influence of screening and referral program outcomes related to experience of care and population health, no definitive conclusions could be made on the overall impact on changes in patient connection to resources, patient satisfaction, and patient-reported outcomes because of the potential high risk of bias across studies. Their findings can inform the use of screening and referral programs in health care organizations, including ways to strengthen future studies to examine their effectiveness.

Qualitative research is an important methodological tool that provides critical insights in identifying subjective meaning in the context of health (32). Qualitative research is a necessary exploratory approach that can be used to better understand and improve health equity research and practice. Olson and her team of researchers conducted 10 listening sessions and 28 interviews with people from diverse backgrounds to identify themes in causes, solutions, and opportunities to collaborate across sectors to address cancer disparities (13). Researchers validated the use of qualitative approaches to engage diverse participants representing many different sectors. Qualitative findings identified medical mistrust, the need for equitable multilevel partnerships, influences of environmental threats on cancer burden, and location of cancer disparities as key concerns among people participating in the listening sessions and interviews. The researchers describe how these findings will be used to form multisector teams to address local social, cultural, and biological influences of cancer disparities and achieve health equity in Wisconsin.

Geographic location continues to be an important contributor in shaping access to timely and necessary screening and treatment options (33). Rohatgi et al conducted original research examining relationships among rurality, sociodemographic characteristics, and access to low-dose computed tomography (LDCT) screening for lung cancer and screening access and lung cancer mortality (14). This study revealed that more than 97% of metropolitan residents had access to LCDT screening, compared with just over 40% of nonmetropolitan residents. Researchers learned that residents of southeastern Missouri, a rural and impoverished area, had low screening access, high smoking prevalence, and high lung cancer mortality. Researchers concluded that targeted strategies to implement rural LDCT screening could reduce geographic disparities in access, and future research could help identify factors that increase access to screening to eliminate rural-related disparities in lung cancer mortality.

Breast cancer is the most frequently diagnosed cancer and a leading cause of cancer mortality among American Indian/Alaska Native (AI/AN) women (34). Despite having a lower incidence of breast cancer than White women, AI/AN women are more likely to be diagnosed at younger ages and later stages (35). Breast cancer incidence among non-AI/AN women has largely been quantified in large geographic regions in the US, and substantial regional variation in breast cancer inequities in non-Hispanic AI/AN populations has been reported. Zahrieh and colleagues conducted research to obtain a deeper understanding at a granular level to identify potential inequities in breast cancer incidence by applying county-level Bayesian disease mapping (a model-based approach that offers a means to improve county-level incidence estimates) to population surveillance data from 2005 through 2014 in New Mexico (30). They found a significant overall disparity effect across New Mexico, evidenced by the age-adjusted rate of breast cancer among non-Hispanic AI/AN women being appropriately 0.38 times the corresponding age-adjusted rate among non-Hispanic White women. Researchers also suggest that findings can be used to facilitate targeted statewide and county-level cancer control interventions to mitigate breast cancer disparities among AI/AN women in New Mexico.

Historically, type 2 diabetes has disproportionately affected racial and ethnic minority groups (31). To ensure accurate detection of type 2 diabetes, we must understand the ability of hemoglobin A_{1c} (HbA_{1c}) to correctly classify type 2 diabetes status and evaluate intra-ethnic variation. Toward this end, Khosla et al conducted a scoping review to determine HbA_{1c} performance in African descent populations in the US with normal glucose tolerance, prediabetes, and diabetes (16). Results included 7 studies that analyzed HbA_{1c} performance among African Americans, 1 study that analyzed HbA_{1c} performance in Afro-Caribbean people, and 4 studies that analyzed HbA_{1c} performance among Africans. Researchers found that current HbA_{1c} cutoffs for prediabetes and type 2 diabetes may overestimate glycemic status in African Americans and underestimate glycemic status in Afro-Caribbean and African people. Researchers indicated that alternating testing, such as the oral glucose tolerance test, fasting plasma glucose, and other glycated blood proteins in place of or in combination with HbA_{1c} may better assess glycemic status in populations of African descent.

Tobacco use remains the leading cause of preventable morbidity and mortality in the US (33). Livingston and colleagues evaluated changes in tobacco cessation benefits, patient access, and cigarette smoking prevalence before and after 16 coordinated care organizations began providing comprehensive cessation benefits for reducing tobacco use prevalence among Medicaid members in Oregon (17). This implementation evaluation identified changes in tobacco cessation benefits, patient–provider discussions of smoking cessation, and cigarette smoking prevalence before and after the introduction of statewide incentives for reducing cigarette smoking. Evaluators reported that statewide effort accelerated progress toward tobacco use reduction among members of coordinated care organizations.

Obesity among adults living in Appalachia continues to be a major problem, and policy, systems, and environmental interventions may help to address long-standing underlying factors that have historically contributed to this persistent public health concern (35). Cardarelli and associates reported findings from a qualitative study that used a grounded theory approach to identify barriers and facilitators for healthy food access in a rural county in Kentucky (18). The goal was to design interventions responsive to social, cultural, and historical contexts from an equity perspective. Focus group participants were asked, for example, if it was easy to get fruits and vegetable at locations where they purchase food, if many people in their community purchase food at farmers markets, and what factors in their community make it easier or harder to eat healthy. The authors concluded that efforts to address food access through policy, systems, and environmental interventions must be sensitive to characteristics of the rural setting, acknowledge social inequities in the region, and proactively engage community members throughout all stages of intervention planning, implementation, and evaluation.

Oral health disparities among children have been linked to socioeconomic inequalities, access to care, health systems barriers, and lack of access to foods that promote optimal oral health outcomes (39). Martin et al conducted original research that explored the frequency of tooth brushing among children with a mean age 21.5 months (19). Their results indicated that the frequency of brushing among children, as reported by guardians, was higher when the correct amount of toothpaste was used, brushing occurred for a longer duration, and other family members helped children with brushing. Their findings strongly suggest that parental and family support for brushing are critically important in promoting and sustaining tooth-brushing behaviors.

According to the *Lancet* Global Health Commission on Global Eye Health, women, rural populations, and racial/ethnic minority groups are more likely to have vision impairment, a pervasive inequality that needs to be addressed (40). This PCD collection on advancing health equity and reducing health disparities concludes with a research study by Leiby et al investigating the effectiveness of an enhanced intervention among people with glaucoma: using patient navigators and social workers to improve patient adherence to follow-up eye care in community settings (20). The study compared the intervention group with a group of patients in usual care. Participants in usual care were provided with a local ophthalmologist’s contact information and a copy of their eye examination results; they were not provided access to patient navigators or social workers. Study participants, who were randomly assigned to either the enhanced or usual care intervention, were a diverse group of participants aged over 40 with a family history of glaucoma or currently diagnosed with diabetes. Only participants who had not seen an ophthalmologist in the previous 12 months were permitted to enroll in the study. Study participants consisted largely of African Americans, followed by White, Asian American, and Hispanic residents of Philadelphia, Pennsylvania. The study found that the use of patient navigators and social workers doubled the rate of adherence to annual recommended eye care follow-up, compared with participants assigned to the study’s usual care intervention. The study highlights that formalized use of social support in partnership with local ophthalmologists can be an effective approach to increasing access to local ophthalmological services.

At the center of this collection of articles is a shared commitment to the goal of eliminating health disparities, particularly those that continue to persist despite aggressive efforts to ameliorate them. The collection describes a range of diverse and timely examples of efforts to eliminate health disparities and advance health equity among racial and ethnic groups in the US. Articles appearing here represent various types of PCD articles that encompass multiple perspectives, from original research and systematic reviews to implementation evaluation to expert commentaries to tools that can be used in public health practice. As a discipline, we have important work to do, not only to better understand how social determinants of health and other contextual factors impact health but also to design, implement, and evaluate effective multilevel systems approaches that create optimal conditions to promote health for all. PCD will continue to move forward in its commitment to these goals, and we encourage authors to visit the journal's Author's Corner website (https://www.cdc.gov/pcd/for_authors/index.htm) to learn more about article types that best fit their research addressing population-based approaches to eliminating health disparities and advancing health equity.

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POSITION STATEMENT

PCD's Commitment to Advancing Diversity, Equity, and Inclusion in Its Scientific Leadership, Peer-Review Process, Research Focus, Training, and Continuing Education

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PEER REVIEWED

This position statement expresses *Preventing Chronic Disease*'s (PCD's) commitment to continuously assess our focus, document our accomplishments, and identify new areas of growth. It begins with a brief overview of the burden of chronic diseases in the United States to emphasize why the journal remains committed to publishing peer-reviewed content that contributes new knowledge on innovative ways to ameliorate these long-standing public health challenges. Keeping PCD in the best position to publish relevant peer-reviewed articles requires that we continue our efforts to advance diversity, equity, and inclusion as well as best practices at all levels of operation. Hence, this position statement discusses the evolution of the journal's mission statement and its current topic areas of interest and proposes activities to advance diversity, equity, and inclusion (DEI) through scientific leadership, the peer-review process, research focus, and provision of training and continuing education.

Chronic diseases such as heart disease, cancer, diabetes, and obesity are among the leading causes of death, are the costliest to treat, and affect one-third of adults worldwide (1). Risk factors such as tobacco use, lack of physical activity, and poor nutrition have long been recognized as primary contributors to chronic disease prevalence and are, thus, the focus of public health efforts (2–12). These risk factors have historically helped to show where to implement public health interventions to address long-standing health disparities. For example, chronic disease prevention and management interventions may focus on behaviors such as healthy eating and physical activity and cessation of unhealthy practices such as tobacco and alcohol use (13–15). But there is also an awareness that these unhealthy behaviors exist within a larger context that goes beyond the individual.

The impact of chronic diseases is disproportionately evident in low-resourced areas and in communities of color (16,17). In these communities, chronic diseases are influenced by a combination of coexisting and interactive factors — race and ethnicity, psychological issues, socioeconomic status, culture and history, access to health care, racial discrimination, and environmental determinants of health (18,19). Furthermore, the COVID-19 pandemic demonstrated that these factors exacerbate chronic disease disparities in diverse communities that are also disproportionately affected by COVID-19. Responding to long-standing health inequities and health disparities requires scientific peer-reviewed journals to play a critical role in widening the scope of their content to acknowledge, explore, and report on less-studied factors, such as social determinants of health. These include forms of racism that have resulted in generational injustices, which also contribute to the rise of racial and ethnic health inequities (20). Broadening the definition of social determinants of health to include the influence of racism enables a better understanding of how these risk factors also affect where people live, learn, work, worship, and play. This expanded area of study can also highlight how racism contributes to inequities in access to a comprehensive range of social and economic benefits — including housing, education, wealth, and employment — that ultimately affect population health.

Since its establishment in 2004, PCD's mission has been to promote dialogue among researchers, practitioners, and policy makers worldwide on the integration and application of research findings and practical experience to address health disparities, advance health equity, and improve population health. We recognize that both the journal and the field of public health cannot effectively achieve this mission by doing things the same way and expecting different results; success requires an improved understanding of the factors that shape health along with knowing where, how, and when to intervene effectively. To be successful in this mission requires that PCD and other peer-reviewed journals adapt to a changing vocabulary and embrace areas of scientific exploration to include not only familiar terms and constructs, such as race and ethnicity, health disparities, health inequities, social economic position, and social determinants of health, but also all forms of racism, including structural and institutional racism.

PCD is well positioned to address chronic disease prevention and health promotion in this changing landscape. Over the past 5 years, we have taken intentional steps to identify ways to increase the participation of talented, experienced, and well-trained researchers, evaluators, policy makers, and practitioners who bring attention to new issues in the published literature. We took these steps long before DEI began receiving increased attention in scientific publishing. We took steps to ensure *diversity* among volunteers serving in every major group that provides feedback to the journal — external review panels, associate editors, editorial board members, Statistics Review Committee members, guest editors, peer reviewers, and PCD staff members. In doing so, we have consciously worked against unintentional promotion of one view or perspective at the exclusion of others, which can result in disengaging individuals and reducing participation among key players and community partners.

PCD continues to advance *equity* by proactively listening and then implementing feedback, recognizing the contributions of all volunteers, and providing a range of opportunities for others to lead and participate in key decision making. Our success in these areas is the result of creating an open dialogue among various partners — primarily those external to the Centers for Disease Control and Prevention — to generate the journal's mission and vision statements, identify topic areas for calls for papers, serve as guest editors of supplemental collections, refine the journal's peer-review processes, develop manuscript guidance documents, secure specialized peer reviewers, and more.

To ensure *inclusion*, we took proactive steps so that a range of individuals are and will continue to be part of discussions that help us present a broad spectrum of ideas and perspectives. PCD's purpose here is to prevent any one paradigm, belief, or perspective in the science and practice of public health to dominate decision making. We want to ensure that the journal's content areas help to advance the most comprehensive understanding of the range of both causes and solutions to long-standing public health challenges. For example, in 2017, we invited the journal's first panel of 7 nationally recognized experts (Appendix) in scientific publishing, population health, epidemiology and surveillance, social epidemiology, community health, health disparities, health equity, medicine, and community health to critique our focus, mission, publication content, and intended audience and offer recommendations on future directions (21). Based on recommendations from the expert panel, we decided to complement our publication of epidemiological studies with increased attention to securing manuscripts from researchers, evaluators, policy makers, and practitioners working in settings that improve health through population-based interventions and policies. The panel felt the journal had been in existence long enough to revise and expand its key areas to focus on 4 main topics:

- Behavioral, psychological, genetic, environmental, biological, and social factors that influence health
- Development, implementation, and evaluation of population-based interventions to prevent chronic diseases and control their effect on quality of life, illness, and death
- Interventions that reduce the disproportionate incidence of chronic diseases among populations at high risk of developing these diseases
- Development, implementation, and evaluation of public health law and health policy–driven interventions

Expanding the journal's focus beyond articles on behavioral, psychological, genetic, environmental, biological, and social factors required securing volunteers with expertise in areas such as identifying and tracking disease prevalence; cultural identity; community engagement; health behaviors; health disparities; minority health; sexual orientation; lesbian, gay, bisexual, transgender, or queer (LGBTQ) health; health equity research and practice; implementation science; multilevel interventions and data analyses; structural and environmental supports; policy changes; geospatial epidemiology; health system changes; and others. We have taken deliberate and timely steps to secure individuals at different career stages with diverse racial and ethnic backgrounds, gender identities, geographic locations, training, and experiences to serve as associate editors and on our editorial board and our Statistics Review Committee. Please visit the journal's website to learn more about these individuals who volunteer their time and expertise to advance the journal's mission and vision (https://www.cdc.gov/pcd/about_the_journal/index.htm).

PCD will build on past efforts to advance DEI by securing and maintaining scientific leadership that consists of skilled, trained, respected, and courageous volunteers who are not afraid to voice their opinions to ensure that the journal is relevant and responsive to advances in the science and practice of public health. We look forward to learning from our volunteers how public health research and evaluation can examine less-explored ways of conducting health disparities research, by taking a fresh look at traditional determinants of health and advancing health equity to better define constructs around race and the impact of racism — broadly defined — given that this determinant is a serious threat to the public's health (22,23).

By December 2021, we will finalize our strategic plan to advance DEI activities through continued expansion of 4 key areas:

- Scientific leadership
- The peer-review process, including enlarging the pool of authors and peer reviewers
- Expanding research to identify potentially effective ways to improve health equity and shed light on the intersection of racism and health
- DEI-related training and continuing education opportunities among PCD staff members, volunteers, peer reviewers, and authors

We believe these activities, when undertaken collectively, will help the journal continue to serve as a critical resource of relevant and responsive peer-reviewed content focused on eliminating health disparities and advancing health equity (Figure).

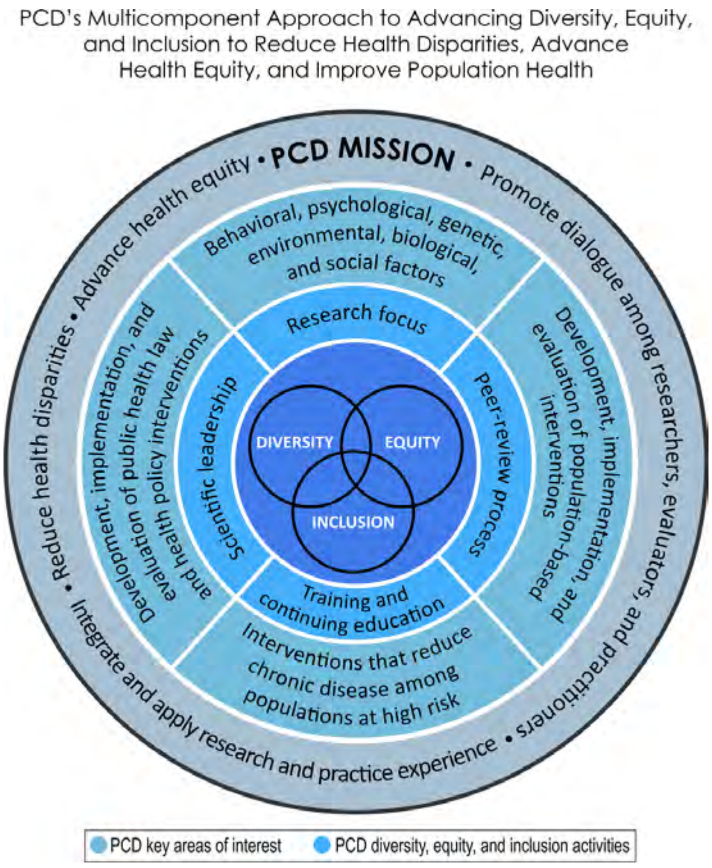

Figure. *Preventing Chronic Disease*'s multicomponent approach to advancing diversity, equity, and inclusion to reduce health disparities, advance health equity, and improve population health.

Continuing Efforts to Expand PCD Scientific Leadership

We will continue conversations with our associate editors, editorial board, Statistics Review Committee members, and other scholars and experts to identify ways to advance DEI in several key areas. Despite our previous success with securing diversity in expertise, racial and ethnic background, geographic location, institution, career status, and other areas, we will continue to assess our needs and proactively work to obtain additional volunteers in these key roles. We will continue discussions with our volunteers on ways to advance DEI at all levels of journal operations: in appointing board and committee members, in widening the scope of topic areas, in considering the impact of all forms of racism on health, and in increasing awareness through minority-serving institutions, organizations, and networks to encourage submissions from researchers from diverse races and ethnicities. We will continue to assess needs and make appointments annually to these groups that are vital to the journal's operations.

PCD is also committed to giving authors as many tools as possible to improve the quality of manuscripts submitted for consideration. The Author's Corner section of the PCD website provides detailed guidance on how to generate a manuscript for submission. In addition, we expanded our article types to increase the number of submissions that advance our understanding of how multiple, competing, and interconnected determinants shape health; how aspects of the environment (including setting and location) and diverse community partners must be considered to create viable solutions to improving conditions that influence health; and how the discovery of new and improved ways to capture data and report findings make it possible to learn what is working. PCD is also committed to identifying factors that influence dissemination and uptake of innovative and effective policy-level interventions. We will continue to update this guidance to encourage integrating, where possible and necessary, information on the impact of racism on a range of health outcomes and potential ways to advance health equity. Prospective authors can learn more about the simplified submission process at https://www.cdc.gov/pcd/for_authors/SimplifiedSubmissionProcess.htm and see criteria and descriptions of each PCD article type at https://www.cdc.gov/pcd/for_authors/types_of_articles.htm. This guidance has been a valuable resource to authors in generating the best manuscripts for submission, and it is used by peer reviewers to evaluate submissions and recommend their suitability for publication.

Peer-Review Process: Expanding Authorship and Peer Reviewers

PCD has done an exceptional job securing contributions from authors around the world. However, like other peer-reviewed journals, we have an opportunity to encourage less-represented individuals and groups — inclusive of gender identity, sexual orientation, race and ethnicity, age, disability status, socioeconomic status, geographic location, and institution — to submit manuscripts for consideration. We will continue our efforts to identify potential contributing authors to submit manuscripts related to the journal's 4 focus areas and any special topics through our many calls for papers. PCD will also continue to identify and recruit people from these groups to serve as guest editors and reviewers on manuscripts submitted in response to calls for papers and general submissions to the journal. PCD will also continue to provide feedback to authors, when necessary, on ways to strengthen their submissions. We will identify, with the assistance of our editorial board members and associate editors, ways to provide resources on the PCD website that further develop scientific writing skills among novice authors. For example, PCD's identification of best practices in scientific writing, along with those identified by other experts, were incorporated into an online scientific training course consisting of 8 modules that addressed topics ranging from basic writing principles to abstracts to components of a research report (introduction, methods, results, discussion), to supporting materials, and finally to submitting the manuscript for publication. This online training course will be available on the journal's website in English and Spanish in early 2022.

Research Focus: Expanding Research and Evaluation Topic Areas of Interest

PCD's topic areas during 17 years of publication have evolved and expanded to address multiple pressing public health issues (24), including the following:

- Understanding causes of health disparities and how such discoveries can be translated into evidence-based interventions to address them
- Using implementation science to understand the ways in which evidence-based interventions are adopted — including exposure, dose, quality of delivery, participant responsiveness, and program differentiation — in real-world settings
- Developing and applying spatial statistical methods and new geospatial tools to identify and intervene on drivers that affect health at multiple geographic levels
- Using maps and geospatial results to guide program and policy decision making
- Promoting health and wellness among diverse racial and ethnic groups, socioeconomic and educational levels, and geographic locations
- Implementing risk communication approaches through preparation, response, and recovery phases of major health threats
- Improving population health through collaboration between public health and pharmacy
- Reporting on public health responses to COVID-19 and chronic disease
- Collecting and using surveillance data to inform policy changes, guide new program interventions and public communications, and assess research investments
- Evolving population health approaches to address mental health
- Sustaining changes in how health care systems, public health, and other sectors address social determinants of health in partnership with community-based organizations
- Identifying better and best population health practices to improve population health across the lifespan
- Developing, implementing, and evaluating public health law and health policy–driven interventions

The articles published by PCD on these topics represent a collaborative effort. Although PCD is an editorially independent journal, we are continually engaged with peer reviewers, associate editors, editorial board members, Statistics Review Committee members, external panels, and other experts who provide critical input and feedback on important issues facing public health from their position of expertise. We value engagement as part of the dialogue that needs to happen to better understand the complexity of the landscape of chronic disease prevention. And as an integral part of this dialogue over the years, we recognize a simple truth: no single area of focus can or will provide the solution to ameliorating long-standing public health challenges in chronic disease prevention and control. Instead, a combination of these approaches, inclusive partnerships, patience, commitment, and sustainability, along with rigorous research and evaluation, are needed to monitor and document progress. While acknowledging the contributions of previously published articles, we will continue to engage with partners as this dialogue evolves, as new evidence becomes available, and as new areas of research emerge. With that in mind, and based on feedback from our editorial board, associate editors, and Statistics Review Committee members, and in consultation with experts in the field, PCD's focus of interest will expand this year to include 2 urgent and pressing issues in public health: identifying potentially effective ways to improve health equity and exploring the intersection between racism and health.

Where, when, and how to effectively intervene to improve health equity

Advancing health equity and eliminating health disparities have been and continue to be critical areas of great interest to us. Healthy People 2020 defines health equity as the attainment of the highest level of health for all people: "Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities" (25). Healthy People 2020 defines health disparities as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage" (25). We want to understand where, when, and how health equity–related interventions should be implemented. Furthermore, we want to learn from the field about the effectiveness of innovative interventions that address the root causes of health inequities. We plan to release a call for papers seeking submissions on the creation of health equity constructs, theories, frameworks, and outcomes to advance the field's understanding of how to design, implement, and evaluate such interventions. Given that contributing causes of health inequities result from complex underlying and sustained structures, we will be interested in manuscripts that document how collaborations across diverse partnerships are used. We anticipate releasing this call for papers and naming guest editors no later than August 27, 2021.

The intersection of racism and health

A growing body of peer-reviewed literature provides evidence of the generational effects of various forms of racism on educational systems, housing practices, mental health services, and other areas (23). The impact of racism on health status can be examined collectively to better understand causes of downstream health disparities, particularly among racial and ethnic groups who have experienced decades of disproportionately poor health outcomes. Although this downstream effect has at times been acknowledged, it has not been rigorously explored to identify the mechanisms and pathways through which it operates. Clearly, this represents an important emerging area of research, evaluation, and implementation science in chronic disease prevention and control. We will expand our interest in receiving manuscripts that examine forms of racism and their deleterious effects on other social determinants of health, chronic conditions, and overall physical, mental, and emotional health. Specifically, PCD will make widely known our interest in receiving papers that explore the intersectionality of structural racism and other social determinants of health (socioeconomic position, social support, culture, access to health care, residential environment, and access to environments that support active living and healthy eating). A universal way of measuring structural racism does not exist. Hence, PCD will play an important role in increasing knowledge and identifying best methodologic approaches to quantify structural racism's association with, or driver of, physical and mental health inequities (23). We will also promote these topics of interest widely to our authors and peer reviewers. By November 30, 2021, we will engage our editorial board and consult with leading experts in the field to develop and release a call for papers that examine the negative impact of all forms of racism on aspects of chronic disease prevention, management, and control.

In May 2017, the National Institute on Minority Health and Health Disparities and the US Department of Health and Human Services Office of Minority Health conducted a workshop to identify and determine ways to incorporate constructs of structural racism and discrimination into health and health disparities research (26). We will use findings from this workshop along with input from our associate editors, editorial board, and Statistics Review Committee members; results from emerging peer-reviewed literature; and consultations with leading experts to identify a range of topics of interest to the journal. These future topic areas will be shared on the journal's homepage, integrated into author checklists for all article types, and incorporated, where appropriate, in calls for papers. In February 2021, PCD released "COVID-19 and Chronic Diseases: Burden, Access to Care, Community Engagement, and Partnerships," a call for papers that recognizes that persistent social determinants compound the negative effects of COVID-19 on people with a chronic condition. We are interested in all article types (eg, essays, original research, program evaluation, systematic reviews, tools for public health practice, implementation evaluation) to help further elucidate factors (eg, unstable housing, racism, limited access to nutritious food, inadequate transportation, low socioeconomic status) that affect health outcomes. This call for papers represents the journal's commitment to increasing rigorous scholarship with an intentional focus on the impact of various forms of racism on health and health disparities. Papers must be submitted to the journal by December 3, 2021. Please visit https://www.cdc.gov/pcd/announcements.htm for more details.

Offering DEI Training and Continuing Education

We have identified opportunities to advance our understanding of best DEI practices in scientific publishing, and we will maintain our commitment to seek the participation of contributors regardless of race, ethnicity, gender identity, sexual orientation, disability, religion, age, or geographic location. The journal is better positioned to publish rigorous content that can lead to reducing health disparities and advancing health equity when authors of manuscripts undergoing rigorous peer review reflect the population of those most affected. We will continue to maintain an environment among our staff members, volunteers, authors, and peer reviewers that supports increasing knowledge about DEI best practices. For example, several timely resources, such as Toolkits for Equity, published by the Coalition for Diversity and Inclusion in Scholarly Communications, offer PCD staff members access to training and continuing education opportunities not previously available. PCD's editorial staff has updated our internal house style to reflect the revised inclusive language section of the *AMA Manual of Style: A Guide for Authors and Editors* (27), and the reporting of race and ethnicity in medical science journals.

In 2016, we began conducting orientations for newly appointed associate editors, editorial board members, and Statistics Review Committee members. This time was used to familiarize appointees about their roles, discuss the journal's peer-review process and research and evaluation standards, review author submission checklists, learn how to effectively assess feedback from peer reviewers, review the journal's expectations on scientific integrity, and receive guidance on providing concrete and respectful feedback to authors. All volunteers are required to participate in an orientation designed to position them to achieve optimal success in their roles during their appointment term. We will incorporate PCD's commitment to advancing DEI best practices in all aspects of our operations. We recognize that advancing DEI best practices will require all involved to share in this responsibility so as not to place greater demands intentionally or unintentionally on any individual or subset of individuals.

This year, PCD celebrates the 10-year anniversary of efforts to build scientific publishing skills and abilities among diverse students. We play an important role in enhancing diversity in the student pipeline as a way of helping to create generational diversity across the field of public health. To date, we have received more than 500 student papers submitted in response to our student paper research contest in the following 5 categories: high school, undergraduate, master's, doctoral, and postdoctoral (28–30). Specifically, we aim to provide applicants with an opportunity to

- Become familiar with a journal's manuscript submission requirements and peer-review process
- Connect their knowledge and training on conducting quality research with a journal's publication expectations
- Develop their research and scientific writing skills to become producers of knowledge in addition to consumers of knowledge
- Be first author on a peer-reviewed article
- Engage in supportive, respectful, and mutually beneficial author–mentor relationships that result in strengthening applicants' ability to generate and submit future scholarly manuscripts

In June 2021, PCD released a new call for papers for our Student Paper Contest. Students from high school to the postdoctoral level are encouraged to submit manuscripts relevant to the prevention, screening, and surveillance of chronic diseases; population-based interventions for chronic diseases; and social determinants of health as they relate to chronic disease prevention, which will now include the intersection of racism, health, and health disparities. Chronic diseases and public health concerns of greatest interest to the journal include but are not limited to cancer, diabetes, cardiovascular disease, obesity, Alzheimer's disease, epilepsy, arthritis, oral health, asthma, reproductive health, and the bidirectional relationship between COVID-19 and chronic conditions. Students and their faculty mentors interested in submitting research manuscripts to the journal for consideration must do so no later than March 28, 2022. Please visit https://www.cdc.gov/pcd/announcements.htm for more details on the journal's Student Paper Contest.

Since April 2013, PCD has offered readers opportunities to earn continuing education credit via Medscape, LLC, a leading organization in professional education and continuing medical education (CME) for health care professionals. Medscape, LLC, is jointly accredited by the Accreditation Council for Continuing Medical Education, the Accreditation Council for Pharmacy Education, and the American Nurses Credentialing Center to provide continuing education for the health care team. In collaboration with Medscape, PCD provides opportunities for health care professionals to earn continuing education credit by reviewing original research articles. We anticipate publishing timely articles exploring the impact of all forms of racism on health and possible evidence-driven interventions to improve health equity. Our readers and registered users of Medscape can take the test and earn credit in a variety of topic areas to include these expanded areas, as well as numerous other timely research topic areas. It is an advantage for readers of the journal because it offers another resource for earning CME credits, and it is an advantage for authors because it gives them the recognition that their article was not only selected for publication in PCD but also considered relevant as an educational resource for researchers, clinicians, and physicians. Our intention to publish articles on racism and health aligns with recently published position statements by major medical associations encouraging their professions and associated health care providers to understand more deeply the less-explored and less-acknowledged causes of health disparities (31–33).

Conclusion

The call to advance DEI best practices across many levels of a journal's operations has received increasing attention. PCD is well positioned to put into practice the input from our diverse and inclusive groups of volunteers on advancing these imperatives. This, our journal's position statement, sets forth our continued commitment to advancing DEI through continued expansion of 4 key areas: 1) the journal's scientific leadership, 2) the peer-review process, 3) research focus (including the intersection of racism and health and developing, implementing, and evaluating interventions to address health inequities), and 4) DEI training and continuing education. We will finalize our strategic plan to implement these DEI activities by the December 2021.

In February 2017, PCD published its first Editor in Chief's Column — a column published 2 to 3 times annually to provide updates on the journal's progress, public health topics, announcements and acknowledgments, and issues of interest to the field of public health and the journal's readership. We will continue to use our Editor in Chief's Column to provide updates on the journal's progress in advancing the 4 DEI activities. The next update on progress is scheduled to be published in an Editor in Chief's Column in mid-November 2021. As always, PCD is open to receiving feedback through the Contact Us page (https://www.cdc.gov/pcd/contactus.htm), and we look forward to updating you on our progress over the coming months.

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Appendix. *Preventing Chronic Disease* 2017 External Review Panel

Hector Balcazar, PhD, MS (Chair)

Hector Balcazar is dean of the College of Science and Health at Charles R. Drew University of Medicine and Science. Dr Balcazar specializes in the study of public health problems of Latinos/Mexican Americans. He has conducted numerous studies of Latino birth outcomes, acculturation and health-related behaviors, cardiovascular disease prevention programs in Latinos, and border health issues. He served as an editorial board member for several journals and served as chair of the editorial board of the *American Journal of Public Health*.

Ana F. Abraido-Lanza, PhD (Co-Chair)

Ana Abraido-Lanza is professor of sociomedicine and director of the doctor of public health program at the Mailman School of Public Health at Columbia University. In addition, Dr Abraido-Lanza serves as the director of the Initiative for Minority Student Development. Her research focuses on cultural, psychological, and socioeconomic processes that affect psychological well-being, adjustment to chronic illness, and mortality among Latinos. Dr Abraido-Lanza is an associate editor at the journal *Health Education & Behavior* and a member of the editorial board at the *Annals of Behavioral Medicine*.

Collins O. Airhihenbuwa, PhD, MPH

Collins Airhihenbuwa is former professor and dean of the College for Public Health and Social Justice at Saint Louis University (SLU). He was also the director of the Global Health Institute at SLU. Dr Airhihenbuwa is an internationally recognized expert on behavioral health and a pioneer in centralizing culture in health behaviors. He has served on editorial boards for several peer-reviewed journals: the *American Journal of Health Behavior*, *AIDS Education and Prevention*, *Health Education & Behavior*, the *Journal of Health Communication*, and the *Journal of Medical Anthropology*.

Melissa Grim, PhD

Melissa Grim serves as chair and professor at Radford University in the Department of Health and Human Performance. Dr Grim's expertise and interests include planning and evaluating public health interventions to increase physical activity and investigating differences in health behavior in urban, rural, and suburban settings. She currently serves as the deputy editor for *Health Promotion Practice*, a journal dedicated to linking research and practice.

Shiriki Kumanyika, PhD, MPH

Shiriki Kumanyika is a research professor in the Dornsife School of Public Health at Drexel University. Dr Kumanyika retains an appointment as an emeritus professor of epidemiology at the University of Pennsylvania. She was vice-chair of the US Department of Health and Human Services' Secretary's Advisory Committee on Healthy People 2020 objectives, is a past president of the American Public Health Association and is a member of the National Academy of Medicine (formerly known as the Institute of Medicine). She is currently a member of the CDC Task Force on Community Preventive Services, co-chair of the Policy and Prevention Section of the World Obesity Federation, and a member of *The Lancet* Commission on Obesity.

William L. Lanier Jr, MD

William L. Lanier is professor of anesthesiology at the Mayo Clinic. His research interests involve neurosurgical anesthesiology and ischemic brain disease, and he has been engaged in both laboratory and clinical research. He was a founding section editor of the *Journal of Neurosurgical Anesthesiology* and founding editorial board member for *Disaster Medicine and Public Health Preparedness*. Dr Lanier served as a faculty member for the Council of Science Editors (CSE) for its 2-day Short Course for Editors and director of the CSE's Short Course. He served as editor in chief of *Mayo Clinic Proceedings*, the world's third-largest circulation scholarly medical journal. He is emeritus editor in chief of *Mayo Clinic Proceedings*.

Sarah Patrick, PhD, MPH

Sarah Patrick is director of the Jackson County (Illinois) Department of Health. She directs and manages 3 major divisions of the Department of Public Health: Communicable Disease Control, Health Promotion and Public Health Research, and Environmental Health. Dr Patrick has extensive experience developing and supporting collaborative public health practice partnerships between local health departments, academic institutions, and hospital systems. In 2015, she served on a project led by the Council of State and Territorial Epidemiologists to identify scientific writing needs among applied epidemiologists.

All positions reflect those at the time of appointment to the panel.

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COMMENTARY

Engaging With Communities — Lessons (Re)Learned From COVID-19

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PEER REVIEWED

Summary

What is already known on this topic?

Responding to pandemics requires engagement with marginalized communities.

What is added by this report?

Responding to coronavirus disease 2019 (COVID-19) has demonstrated that effective responses involve partnerships that use a health equity lens, build on community strengths, and use data and community engagement to respond, build trust, and advocate for health for all. Specific steps for effective partnerships are outlined, based on previous recommendations and refined by current examples.

What are the implications for public health practice?

Community partnerships are critical elements of public health, and can be built through intentional, stepwise engagement with marginalized communities and wider partners.

Abstract

Coronavirus disease 2019 (COVID-19) has underscored longstanding societal differences in the drivers of health and demonstrated the value of applying a health equity lens to engage at-risk communities, communicate with them effectively, share data, and partner with them for program implementation, dissemination, and evaluation. Examples of engagement — across diverse communities and with community organizations; tribes; state and local health departments; hospitals; and universities — highlight the opportunity to apply lessons from COVID-19 for sustained changes in how public health and its partners work collectively to prevent disease and promote health, especially with our most vulnerable communities.

Introduction

Long before the coronavirus disease 2019 (COVID-19) pandemic began, there was widespread recognition of persistent disparities in health outcomes in the United States by race, ethnicity, gender identity, and sexual orientation, as well as awareness that such disparities are symptoms of deeper inequities and racial discrimination across multiple systems and structures. COVID-19 exacerbated these disparities, with Black, Latino, American Indian, and Pacific Islander individuals and their communities having age-adjusted mortality rates 2 or 3 times greater than that of White residents (1). Concerningly, COVID-19's impact on the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community is largely unknown (2).

Although analysis continues to be hampered by inconsistent collection and reporting of data on race, ethnicity, gender identity, and sexual orientation, possible explanations of COVID-19 disparities include the impracticality or even impossibility of following advice such as physical distancing and self-isolation among those who live in crowded conditions, work in service jobs, cannot telework, or have no sick leave (3). Additional factors affecting some racial/ethnic groups include limited testing availability and mistrust of accessing testing in some racial/ethnic communities once testing is offered (4); the need for communications in languages other than English; failure to provide protective equipment to essential workers, who are often from specific racial/ethnic groups; and closures of work places that disproportionally impact some racial/ethnic communities, leaving increasingly large numbers without employer-sponsored health insurance (1,5,6). LGBTQ Americans report difficulty accessing needed treatments, and most are concerned about the combined risks of COVID-19 and HIV (7). These factors are compounded among the homeless or those who are incarcerated (8). Social stigma and racism are factors as well. Black men are reportedly less likely than White men to wear face coverings out of fear of police harassment and violence (9). In addition, Black men who violate stay-at-home orders in 3 of the most populous jurisdictions in Ohio (Toledo, Columbus, and Cincinnati) are 4 times more likely than White men to be charged for violating the orders (10). Finally, a long-term mistrust of government, research, and health care institutions, built on decades to centuries of neglect and abuse, including but far from restricted to the Tuskegee syphilis study (11), make it less likely that some racial/ethnic communities and historically marginalized communities will trust public health messaging by these bodies, or will believe that they will receive equal access to testing, treatment, and vaccines (12).

Despite and often because of these realities, communities, local health departments, and partners across the country with histories of collaboration were able to rapidly react to the challenges of COVID-19. By using community-engaged/participatory research and programmatic coalitions to showcase and bolster the resiliencies within communities and across partnerships, they were able to respond to immediate and critical needs. Here are a few early examples:

- In Chicago, the Homelessness and Health Response Group for Equity coalesced multiple working groups into a coalition of more than 100 members, including hospitals, federally qualified health centers (FQHCs), city officials, shelter operators, housing advocates, and others. Meeting every morning, they established dedicated quarantine and isolation sites for people with unsafe home environments in which to self-isolate; acquired and distributed tens of thousands of pieces of donated personal protective equipment to group settings across the city; crafted evidence-based guidance for varied settings; administered tests to thousands of individuals; created housing for those who were healthy yet at high risk so as to shield them from ongoing outbreaks; and established clinical linkages for shelters and with FQHCs to provide outreach and health checks for high-risk groups (13).
- The University of California, San Francisco (UCSF), leveraged expanded test processing at UCSF and partnered with community organizations to test all residents of a densely populated portion of San Francisco's Mission District as well as the small, rural town of Bolinas. This community-wide testing effort began as a grassroots initiative in Bolinas, driven by residents who partnered with UCSF scientists, state and county public health departments, and the local Coastal Health Alliance, to ensure community engagement and support (14).
- The Navajo Nation, among other tribes, is facing some of the worst rates of COVID-19 in the United States. The tribe has long-standing health inequities attributable to persistent federal neglect, a high prevalence of chronic disease, and geographically dispersed multigenerational homesteads, often with no running water or internet access. As COVID-19 struck, Navajo Nation President Jonathan Nez immediately created a Health Command Center, working with state and local governments, the Indian Health Service, and hospitals to begin testing and contact tracing. With the delay of release of federal funds to tribes, Navajo launched its own COVID-19 Relief Fund (15), and local nonprofits and GoFundMe efforts stepped up, distributing food and medical and household supplies, with volunteers dropping off boxes to families with someone positive for COVID-19 and in self-quarantine. The Gallup-based Community Outreach and Patient Empowerment organization (16), a partnership with the Navajo Nation, Brigham and Women's Hospital, and Partners in Health, and the nonprofit United Natives (17) coordinated medical supplies for clinicians and home-based resources for community members; the Na'nizhoozhi Treatment Center and the City of Gallup provided needed housing; and Auntie Project, Native women from Oklahoma, sent peer-to-peer financial support. Long-term academic partners contributed: for example, the Johns Hopkins Center for American Indian Health organized 140 Native American and other health professionals for surveillance, education, and critical supplies; the University of California, San Francisco, and Doctors Without Borders sent volunteer clinicians; and the University of New Mexico's Transdisciplinary Research, Equity and Engagement Center for Advancing Behavioral Health (TREE Center) health equity center worked with the Diné Centered Research and Evaluation Group and provided material and emotional support (18).
- A partnership across the University of New Mexico, city of Albuquerque, state and city emergency operations centers, nonprofits, primary health care clinics, the city department of health, and the Medical Reserve Corps used the community-based participatory research (CBPR) model as a planning and evaluation tool (19). The partnership first identified a short-term goal of encouraging homeless people, especially older adults, not to leave shelters. To strengthen engagement of seniors unused to sheltering in place, the partnership created a rapid-cycle CBPR process of surveying seniors on their perceived barriers to staying at the shelter, returning the results through town hall dialogues, then providing COVID-19 testing within 2 days, and responding to recommendations, such as increased meal variety, more activities, toiletries and snacks, and improved access to medical providers and case managers. After the first 3 weeks, the proportion of seniors who stayed in the shelter after sleeping there grew from 20% to 75%, with no one testing positive for COVID-19. As the crisis continued, new goals were established each week, with responses including hotel rooms paid for by the city and state for people with COVID-19, and contact tracing for this difficult-to-reach population (20).
- LGBTQ communities have organized information networks and support funds as well as advocated for the needs of LGBTQ communities (21). In semirural Solano County, California, the Solano Pride Center is conducting virtual emotional support and practical information sessions for LGBTQ youth and older adults and has opened a chat service and other safe spaces in response to the social isolation and limited emotional support accentuated by the COVID-19 crisis (22).
- In rural Eagle County, Colorado, the response built on the Mobile Intercultural Resource Alliance, which serves as a clearinghouse for local services in health education and screenings, application support for public assistance

programs, food resources, workforce development, early childhood education coordination, and physical activity programming. Funded by Vail Health, Eagle Valley Community Foundation, and Eagle County government, and housed in a recreational vehicle that travels from community to community, it brings needed services to low-income and often isolated communities in the region. As schools closed, they shifted to providing information, free COVID-19 tests, and school lunches to anyone who needs one (23).

- In New Brunswick, New Jersey, the response has been channeled through peer-to-peer interaction and networks of partnerships with a history of practicing collective impact. Community health ambassadors, New Brunswick residents who decided to do their part to better their community, serve as the cultural bridge between community-based organizations, health care agencies, and their respective communities. They have provided valuable community insight during the pandemic. They, along with the New Brunswick Heathy Housing Collaborative partners (New Brunswick Tomorrow, Robert Wood Johnson University and Saint Peter's University hospitals, and the Middlesex County Office of Health Services) are part of a multisector network (Healthier New Brunswick) that has continued to work together to mitigate the effects of COVID-19 (24). Saint Peter's University Hospital conducted an informal geo-mapping of infected New Brunswick residents and found that close to 100% of New Brunswick residents infected with COVID-19 lived in 2 predominately Latino neighborhoods whose census tracts have the most substantial health and social disparities in the city. In response, the hospitals put together care kits that included masks, soap, and public service announcements (in English and Spanish) on proper prevention methods, which the hospitals and community partners disseminated in these neighborhoods. Other announcements addressing COVID-19 health concerns and underlying structural inequities (inability to isolate in home settings) are promoted by using community outreach and New Brunswick Tomorrow's health communications initiative (Live Well Vivir Bien New Brunswick) that uses a website, mobile app, and social media outlets.
- The state of North Carolina, recognizing the impact of COVID-19 on its racial/ethnic communities and the substantial challenge of contact tracing efforts by its local public health departments, partnered with its state primary care Medicaid program, Community Care of North Carolina (CCNC), and the North Carolina Area Health Education Centers to hire and train staff to augment local health department–led efforts in tracking transmission (25). CCNC has worked with and within local health departments for more than decade, supporting and improving data standardization for the statewide care management services provided for children and pregnant women. The need for food and housing security has been amplified in poor, rural areas of the state during the isolation and quarantine efforts of the pandemic response, so the state also accelerated the rollout of NCCARE360, an electronic coordinated care network to connect those with identified needs to community resources and allow for a feedback loop via electronic health record or web-based notifications on the outcome of those connections (26). The personal care management provided to individuals locally, in concert with the new technologically advanced data system, aims to facilitate the connection of individuals to badly needed services and resources.
- In the coastal plain town of Raeford, North Carolina, Dr Karen Smith, a solo family practitioner, was called by her local health department director about a potential outbreak at a 24-bed youth treatment center, where 2 staff members had tested positive. A quick call to First Health, the local hospital, yielded testing kits; testing was quickly accomplished, and the local emergency medical services drove the tests to Raleigh. Fourteen were positive, and the facility then was able to separate, isolate, trace, treat, and monitor both positive and negative cases (27).

Academic groups have stepped up as well:

- Historically Black colleges and universities (HBCUs) are at the epicenter of large-scale outbreaks. Howard University partnered with Wells Fargo to offer free testing in Ward 7 of Washington, District of Columbia (which had among the highest rates in the Maryland, District of Columbia, and Virginia region) (28). North Carolina Central University (NCCU), with Duke University and University of North Carolina at Chapel Hill, are partnering with Granville Vance Public Health to offer free mobile testing in rural communities in northeastern North Carolina, with a special focus on Black and Latino neighborhoods and churches. And NCCU, along with 5 other HBCUs, was just awarded state funds to study the public health and economic impact of COVID-19 in the state's underserved communities (29).
- Schools of public health have taken lead roles in analysis and advice responses locally and nationally (30).
- Multiple medical schools and health centers have responded, especially those with histories of community engagement. The Center for Reducing Health Disparities at the University of California, Davis, quickly became a local resource and coordination point for community-engaged efforts, especially in Latino communities and for those with behavioral health challenges (31). The HealthStreet Community Engagement Program at University of Florida, which has been working to build community trust, pivoted from being a face-to-face community health worker model to a telephone-based program to continue to assess the needs of their 12,000 members and link them to needed services (32). In Minnesota, a community-engaged research partnership worked with community leaders to refine messages, leverage resources, and advise policy makers on a community-based risk communication framework, which was used to deliver messages in 6 languages across 9 electronic platforms to almost 10,000 individuals over 14 days (33).
- Nursing schools have engaged, including offering resources for health equity (34).
- Hundreds of public health, medical, nursing, and other students have participated in local public health activities, including serving as contact tracers (35).

Lessons From the Past

Partnering with the community and collaborating with its members have long been recognized as cornerstones of efforts to improve public health and its core value of social justice. Community engagement was a critical driver of success during the AIDS epidemic, when activists raised awareness, educated individuals about strategies to reduce their risk, and advocated for timely governmental response. Community-based organizations in racial, ethnic, and sexual communities played critical roles in HIV prevention efforts, as the Centers for Disease Control and Prevention (CDC) recognized that such efforts "must be appropriate for and responsive to the lifestyle, language, and environment of members of that population" (p. 704) (36).

These lessons were reinforced in 1995, when CDC, recognizing the importance of involving the community, established the Committee for Community Engagement, which was composed of representatives from across CDC and the Agency for Toxic Substances and Disease Registry (ATSDR). That committee developed the booklet Principles of Community Engagement, which was published by CDC and ATSDR. A second, enlarged edition of the Principles of Community Engagement was published in 2011 by the National Institutes of Health (NIH), with CDC and ATSDR (37). The same year, CDC released its social vulnerability index, facilitating the ability of local officials to identify communities that may need support in responding to hazards (38).

The response to the next major outbreak, severe acute respiratory syndrome (SARS) in 2003, again noted the need to identify high-risk groups; provide close, targeted communication and coordination across community partners; and ensure access to needed supplies by those in isolation or quarantine (39).

The Institute of Medicine (IOM) report The Future of the Public's Health in the 21st Century reinforced the idea that public health's broad mission of ensuring healthy communities required interactions among numerous health-influencing actors, such as communities, businesses, the media, governmental public health, and the health care delivery system (40).

These reports were accompanied by a broader movement of agencies in partnering with communities in improving health. In 2006, NIH established the Clinical and Translational Science Awards to spur clinical and translational research, with community engagement as one of its core functions. The IOM reinforced this effort in a 2013 review of the program, calling for ensuring community engagement in all phases of research (41). Similar efforts followed in the National Institute on Minority Health and Health Disparities (42) and National Institute on Drug Abuse (43).

A parallel IOM initiative in 2012 assessed the opportunity to link primary care and public health around the needs of communities, noting that "Improving population health will require activities in 3 domains: 1) efforts to address social and environmental conditions that are the primary determinants of health, 2) health care services directed to individuals, and 3) public health activities operating at the population level to address health behaviors and exposures" (p. 19) (44). In turn, this led to the establishment of a collaboration between the deBeaumont Foundation, CDC, the Health Resources and Services Administration, and Duke University to provide practical tools for partnerships for health, to connect interested individuals and organizations, and to support training and capacity building for partnerships for health (45).

Common across all these examples and activities are several principles, which have been consistent themes for how public health and its partners can effectively engage to ensure improved health in diverse communities (37):

- "All aspects of community engagement must recognize and respect the diversity of the community. Awareness of the various cultures of a community and other factors affecting diversity must be paramount in planning, designing, and implementing approaches to engaging a community" (p. 51).
- "Partnering with the community is necessary to create change and improve health" (p. 50).
- "Organizations that wish to engage a community as well as individuals seeking to effect change must be prepared to release control of actions or interventions to the community and be flexible enough to meet its changing needs" (p. 52).

Public Health Implications

Pandemics and epidemics are most dangerous to those already at risk: people with underlying health conditions (caused, in part, by deeper racial, structural, and systemic inequities), and those who are members of marginalized communities without access to preventive care or health care services at their time of greatest need. As was seen in AIDS, SARS, and now COVID-19, responding to an evolving pandemic requires identification of and collaboration with those groups at greatest risk, who often lie outside the mainstream. Engagement with communities early on and throughout is critical, especially communities of color and other marginalized groups that require a public health response that is not channeled through discriminatory systems and structures and does not perpetuate inequities in the midst of crisis. Effective public health roles include gathering data on those affected; building from community strengths and priorities to shape the actions of collecting, sharing, and interpreting data with the communities; developing plans with community leaders; co-creating and communicating risk and harm reduction strategies through existing communication methods; and rapidly tracking and adjusting plans as the epidemic progresses. Although public health holds a leadership role during the epidemic response, it needs the engagement, partnerships, and trust of communities in shaping, communicating, implementing, and disseminating recommended strategies. Trust can only be built when government and academic collaborators are themselves trustworthy and engage communities as partners in addressing what matters to them, including inequities in testing, treatment, and potentially future access to vaccines. Community engagement and partnerships are at the heart and core of public health, are essential for achieving health equity, and are most dramatically needed during pandemics such as we now face.

The Box outlines practical steps that public health can take to successfully engage with its communities and partners for sustained equitable changes in how we live, learn, work, and play. What is not known, but which COVID-19 is helping us learn, is what additional steps public health and its partners can take to effectively work together so that trust is established and maintained, resilience is strengthened, and communication plans are refined. We must also learn how to effectively communicate the need for long-term investment in the infrastructure required for healthy, productive communities, including public health, health care from primary care through hospitals, and community partners. COVID-19 is not our last disaster, and the lessons (re)learned can both prepare us for the next challenge and help reduce and eliminate our longstanding underlying inequities in health.

Box. Steps That Public Health Can Take to Engage With Communities and Partners for Sustained Changes in How We Live, Learn, Work, and Play

Learn

- Train staff in health equity, using local resources or national training such as the National Association of County and City Health Officials' online course Roots of Health Inequity (46)
- Learn about effective multisector partnerships through sources such as The Practical Playbook (45)
- Reframe the COVID-19 pandemic as a "community" problem in which social determinants of health play leading roles, not just a "public health" problem

Partner

- Gather, share, and interpret data with affected communities, working with community members and leaders, and with analysis by race, ethnicity, language, location (zip code or census tract), and social factors
- Identify the unique risks and protective factors with affected communities
- Ensure equitable access to testing, protective equipment, clinical trials, and treatment
- Incorporate community oversight as a quality assurance tool

Work collectively (47)

- Design and implement with a priority placed on equity
- Co-create with cross-sector partners — community-based organizations, clinicians, universities, medical centers, schools of public health (especially those located in or partnered with racial/ethnic communities), housing and transportation sectors, and community development, among others. Students, including in public health, medicine, and nursing, have much to contribute and learn
- Collectively define the problem and create a shared vision to solve it
- Focus on outcomes — not just on activities or processes
- Use data to continuously learn, adapt, and improve
- Develop and deliver health risk messaging that is culturally and linguistically appropriate, relevant to vulnerable communities, and delivered through trusted sources (48)
- Move beyond information delivery to community conversations that encompass knowledge, beliefs, attitudes, and behavior
- Build a culture that intentionally fosters relationships, trust, and respect across participants

Share

- Gather and distribute stories and data both of initial failures and of solutions found
- Participate in a learning collaborative, such as Community Campus Partnerships in Health's Communities in Partnership: Ensuring Equity in the Time of COVID-19 (49), and the Big Cities Health Coalition (50)

Advocate

- Engage with partners in coordinated efforts to advocate for immediate support for communities that are most affected, for removal of barriers, for support of programs that address the root causes of health inequity, and for a diverse public health and health care workforce that works together in partnership with its communities
- Pursue health in all policies as a fundamental tool for ensuring health for all (51)

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We would like to note that we have capitalized names of races (Black, White) to mirror how groups name themselves and to match the practice of capitalizing names of ethnic groups. We also chose single names for groups, despite variation in usage, and so used the label “Latino” rather than the alternatives of “LatinX” or “Hispanic.” We recognize that these labels may suggest that groups are distinct, rather than overlapping and evolving. Most of all, we have tried to put our communities first, and for them to tell their stories, and apologize if we have erred in the process of summarizing and editing.

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COMMENTARY

Culture Matters in Communicating the Global Response to COVID-19

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PEER REVIEWED

Summary

What is already known on this topic?

The World Health Organization developed risk communication and community engagement (RCCE) to facilitate global response to COVID-19. RCCE communicates about individual risks but communicates little about community risks.

What is added by this report?

Community engagement requires knowledge of culture in framing COVID-19 communication and messaging. The PEN-3 cultural model was used to frame community engagement for collective actions.

What are the implications for public health practice?

COVID-19 reveals existing structural inequity in black and brown communities nationally and globally. PEN-3 offers a cultural framework for community-engaged communication and messaging for COVID-19.

Abstract

Current communication messages in the COVID-19 pandemic tend to focus more on individual risks than community risks resulting from existing inequities. Culture is central to an effective community-engaged public health communication to reduce collective risks. In this commentary, we discuss the importance of culture in unpacking messages that may be the same globally (physical/social distancing) yet different across cultures and communities (individualist versus collectivist). Structural inequity continues to fuel the disproportionate impact of COVID-19 on black and brown communities nationally and globally. PEN-3 offers a cultural framework for a community-engaged global communication response to COVID-19.

Introduction

Our primary aim in this commentary is to offer a community-engaged communication strategy that focuses on coronavirus disease 2019 (COVID-19) messages in cultural context. COVID-19, the disease caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was declared a global pandemic on March 11, 2020. Since that time, messages of prevention have focused primarily on preventing individual risks, particularly for those with preexisting chronic conditions, including hypertension, diabetes, stroke, and asthma. As infection and death rates grow, communication about response to the pandemic has increasingly focused on individual behavior choices, which assumes that prevention is largely in an individual's control. In efforts to promote uniform messaging for COVID-19, the World Health Organization developed a multilevel risk communication and community engagement (RCCE) response strategy for health care workers, the wider public, and national governments (1,2).

Well intentioned as RCCE may be, the strategy ends up focusing more on individual risk and less on community engagement. By community engagement, we mean creating spaces and opportunities for those who live in the community to have their voices heard in naming the problem and offering solutions to the problems they face (3). The process of such engagement also includes identifying community resilience and ways to build on values that are important to the community. Communication about individual risk is important, but prevention and control messaging is more likely to be achieved when we engage the voices of those who live in the communities, particularly communities that bear the heaviest burden of the pandemic.

Vulnerability to the COVID-19 pandemic cannot be fully explained by individual risks alone but rather by broader social and structural determinants of health that result in inequities in communities where vulnerable populations live, work, play, pray, and learn (4–6). Moreover, a disproportionate burden of COVID-19 mortality is among racial and ethnic populations in communities that have had historical inequities in health (7–9). With increasing global mortality, a deep concern remains about the alarming levels of general spread, disease severity, and inaction for these communities (10). Research on health disparities, particularly on antiracism (11), demands a focus on risk environment and risk situation rather than the conventional epidemiologic focus on risk factor, which tends to place the burden of behavior change on individuals rather than the context and structure that define and confine their vulnerability (12–14). Thus, community-engaged communication is crucial for acknowledging the voices of those in the community with culturally relevant solutions that are more likely to be sustained beyond the pandemic. Communities that are the most affected experience historical, structural inequities that create not only their preexisting chronic health conditions but also their preexisting vulnerable living and working conditions (15). To understand these communities, the role of culture matters if any communication strategy is to be adopted or sustained.

Culture and Communication for Health

Culture is central to effective COVID-19 messaging for community engagement. We define culture as a collective sense of consciousness that influences and conditions perception, behaviors, and power and how these are shared and communicated (3). Culture may appear neutral, but its power to define identity and communities as a collective is based on values expressed through institutions such as health care, education, and families (3). Culture shapes language, which in turn shapes communication both in message delivery and reception. In response to COVID-19 in Europe, for example, cultural sensitivity to racial and ethnic minority group experiences is believed to be critical if messages for mitigation are to have broader impact (16).

Framing communication messaging that engages the most affected communities can draw some lessons from the multilevel strategies employed in HIV communication, which identify relevant structural factors of institutional policy, economic status, gender, and spirituality while grounded in the force of culture (17,18). For example, as part of HIV communication strategy, the concept of “zero grazing” was introduced in Uganda as a prevention message for multipartner marriages by encouraging that sexual activities be kept within the circle of those in the marriage only. This message was a community collective response to the conventional individualist message of one-to-one sexual relations.

For COVID-19, some black and brown communities have initiated collective communication for mitigation so that messages have cultural meanings for those with whom they share common cultural values. For example, although heavily affected by COVID-19, some indigenous communities in the United States have sought their own solutions to this pandemic by using traditional knowledge and language to promote voluntary isolation at the individual level and sealing off their territories at the community level (19) while still being able to continue aspects of their spiritual well-being (20). Thus, to rapidly improve our communication messages in response to COVID-19, we need an effective global response that invites community-engaged solutions with culture as a connecting space.

Culture is key to the global response to community engagement. COVID-19 unveils a pattern of cultural insensitivity that has also been evident in communication about Ebola. In the early stages of the Ebola outbreak in 2014–2015, conventional messages did more harm than good because they did not value the cultural roles associated with death. Two examples of these messages were, “When you get Ebola, you will die” or “If someone is sick, don’t touch him.” In Liberia, the high death rate from malaria and other diseases among the poor blunted messages for urgency to heed prevention and treatment of Ebola (21). In the West Point slum of Monrovia, Liberia, for example, adhering to physical distancing for Ebola and now COVID-19 is made difficult by sea erosion from the past 10 years, which reduced the land mass by 50%, even though the same number of people remain. Structural inequities often reveal the limit of individual choices in the absence of corrective actions to address contextual constraints over which the community has no control. These constraints are the preexisting contexts of inequities in many black and brown communities globally (5,22).

We believe that COVID-19 mitigation efforts that focus on individual behavior such as handwashing and physical distancing must be balanced with structural mitigation efforts such as clean water, access to housing, unemployment, and for those with jobs, ability (type of job) and tools (access to computer and internet) to work from home. These are the daily realities of racial/ethnic and economically disadvantaged populations that bear the heaviest burden of the pandemic (22). Yet as has been learned from HIV (23) and Ebola (21), culture offers communication messaging that ranges from positive aspects of lived experience that should be promoted to negative practices that should be overcome within the context of communities. To frame approaches to communications and community engagement for COVID-19, we use the PEN-3 cultural model (Figure). We believe that this model offers a roadmap for engaging communities in communication about COVID-19 mitigation efforts.

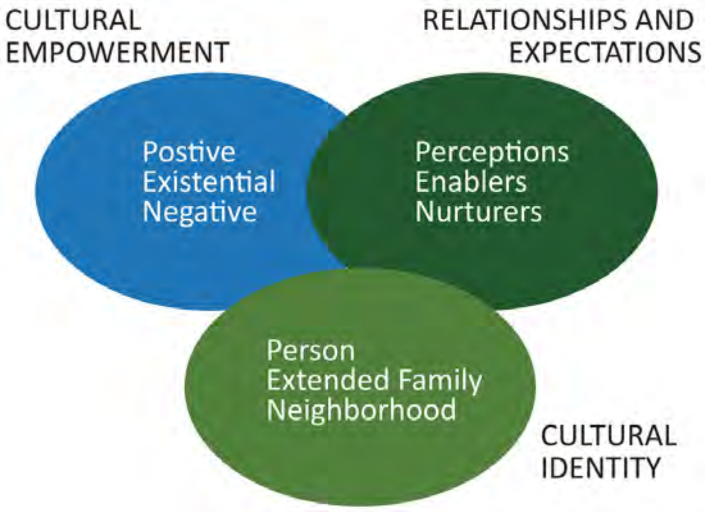

Figure. The PEN-3 Model. The model has 3 primary components: cultural identity, cultural empowerment, and relationships and expectations, and each of the 3 components has 3 domains.

PEN-3 Model and Communication Response to COVID-19

PEN-3 is a cultural model that was developed and first published in 1989 (24). The PEN-3 cultural model consists of 3 primary domains: 1) cultural identity, 2) relationships and expectations, and 3) cultural empowerment. Each domain includes 3 factors that form the acronym PEN; person, extended family, neighborhood (cultural identity domain); perceptions, enablers, and nurturers (relationship and expectation domain); positive, existential and negative (cultural empowerment domain). The domains are described in detail elsewhere (3). A key outcome of using PEN-3 is learning to first identity the positive aspects of behavior and culture such that negative behavior is not the only focus of intervention, as shown in a systematic review (25). At the height of the global HIV stigma and racism against the cultures of black and brown identities, PEN-3 was developed to offer a space for voices to be heard that are otherwise silenced. The model was designed to guide researchers and practitioners to listen to those voices, and in so doing, to ask for not only what these communities were doing wrong but to begin with what they are doing correctly. Culture exists where we live, work, play, pray, and learn. In PEN-3, the focus on cultural logic of decision making about a pandemic is less about who is right or wrong than about what societal reasoning and rationale are at the foundation of the message. Even more important is which populations and communities are the intended audience for messages meant to be solutions. Thus, the importance of the positive aspects of a community and people, their collective resilience, and their cultural logic must not be overshadowed by the presence of diseases, as we have learned from the work on HIV and Ebola and now COVID-19. Therefore, reframing COVID-19 communication messages globally must respond not only to individuals but to the community as a collective. Individuals must not be privileged over the collective or community.

Science also has culture. The application of the PEN-3 model to COVID-19 communication also applies to the scientific community whose task it is to solve the disparities unveiled by COVID-19. To acknowledge that the scientific community exists within 1 or more cultures is to remove it from the pedestal on which it has rested for so long in ways that are well beyond any reproach and critique of the notion that science is inherently value-free (26). Indeed, questions about the effectiveness of social distancing have contrasting beliefs between a country like Sweden (which does not believe in social distancing) and the United States (which does); yet both are based on scientific claims, confirming that science is itself a production of culture and politics. In focusing on the PEN-3 domain of cultural empowerment, for example, the positive and existential dimensions of scientific culture are eagerly and frequently promoted by the scientific community. However, the negative dimensions evident in contrasting recommendations must also be examined, because they create communication challenges. To remedy the challenges requires messaging that promotes cultural inclusivity in the responses to the COVID-19 pandemic.

For years, science ignored the role of structural racism in explaining and predicting disease burdens. Yet it is structural racism that created and maintains communities in which preexisting chronic health conditions such as hypertension and diabetes exist. Therefore our communication should address actions we take at the individual level, risks we face at the collective and community level, and the role science plays in promoting or hindering mitigation efforts. Thus, for COVID-19, PEN-3 offers the importance of cultural empowerment anchored in community-engaged mitigation efforts. We need to focus on both individual risks and community engagement and in so doing address 3 binarisms that must be coalesced to advance global communication for COVID-19. To illuminate the power of culture in community engagement, each of the PEN-3 domains is paired with a binary that needs to be understood and coupled in communication about COVID-19.

Preexisting Chronic Conditions and Preexisting Structural Contexts: Cultural Empowerment

Whereas the language of risk factors focuses on individual preexisting chronic conditions such as diabetes, hypertension, and asthma, the language of health disparities and risk environments focuses on preexisting community contexts. These include unhealthy food structures, unemployment environments, poor housing (eg, intergenerational cohabitation), and job types that define and confine vulnerability to COVID-19. The language of individual risk has been used to frame the prevention message of social distancing and wearing a mask. Yet, a recent commentary concluded that physical distancing is a privilege for populations with preexisting contexts that reinforce not only vulnerability to conditions like diabetes but also living conditions that make it impossible to adhere to physical distancing (27). Several recent publications have emerged in which scholars have lamented the heavy racial burden of COVID-19 on African American, Latino, and Native American populations in the United States (8,9,28). Similar alarm has been raised in Europe, particularly among immigrant populations (16) and in Brazil, which has one of the highest number of cases in the world. In Brazil, nearly 6% of the population, which is mostly black, live in favelas (slums or shantytowns located within or on the outskirts of the country's large cities) and are exposed to social and environmental vulnerability with poor access to water and employment, among other needs (29). Sociospatial inequality determines the patterns of Brazilian cities and the disposition of housing conditions, which limit adherence to the health policy of social isolation. This accumulation of disadvantages represents structural risks for any health condition, which has resulted in high prevalence of many neglected diseases in these vulnerable areas in Brazil. In South Africa, particularly in the absence of official data based on race/ethnicity, the government downplayed racial/ethnic vulnerability until the premier of the Province of Gauteng, which includes Johannesburg, revealed that the hotspots of COVID-19 in his province were shifting from the suburbs, where most whites live, to townships, where most blacks and people of mixed race (known as coloreds) live (30). In many Nigerian cultures, certain cosmological viewpoints suggest that fate determines diseases and ill health and that these are independent of science and human actions (31). The cultural empowerment domain of the PEN-3 model allows COVID-19 interventionists to look at the total context, including how people construct their lived experience within their resilience and the hurdles in their communities. COVID-19 communication should begin with positive factors, such as persistence and resilience, to achieve solutions that nurture and revive the community. To better understand the role of culture in a pandemic we can draw lessons from 2 pandemics that remain with us today, HIV and Ebola (Table).

Individualist Versus Collectivist: Cultural Identity

Every society has a social contract that frames the ways we act and prioritize decisions and choices: as individuals, such as in the United States, as the collective as in China, or some mix of those forms as in Canada and France. One of the key lessons for a global response to a pandemic is that the cultural logic of different societies shapes and influences their prevention strategies. In the United States, individual vulnerability to risk is culturally privileged over community risk, when both should be addressed equally. Such coalescing of dual logics is embodied in the cultural messages from the yin and yang (coexistence and balancing of opposite forces) that may inform messaging in China; Ubuntu (I am because we are) in South Africa; and the expression "Nit nittay garabam" (The person is the remedy of the person) in Wolof in Senegal (32). These cultural expressions are different, neither better nor worse than individualist cultural logic that typically informs messaging in the United States. In China, for example, quarantine was implemented in Wuhan as a collective action to varying degrees and scopes. At the individual level, everyone was mandated to stay at home, and a permit to leave home could be obtained only from a community committee made up of volunteers. At the city level, all city entries and exits were screened; all public transport was discontinued including public bus, subway, ferry, and taxi. This response reflected the collectivist social and cultural contract of Chinese society (33). Thus, when a message of response in one country is communicated in another as draconian, for example, we need to unpack the different rather than competing cultural logics that inform these messages, particularly in a pandemic. Given the virulence of COVID-19, communication messages must be inclusive of multiple cultural logics whereby the word "and" is preferred over the word "or". In the book entitled *Built to Last* (34), the authors debunked the competing binarism of and/or in their study of the characteristics of successful and enduring visionary companies. In advancing the phrases, the "tyranny of the or" and the "genius of the and," the authors made the case for why duality is a strength and not a competition in which one side has to win. COVID-19 messaging globally should embrace cultures and communities with the genius of the "and" by not privileging any one culture over another. The late Chinua Achebe, a Nigerian novelist, once noted that for collective cultures, wherever one idea stands, it is absolutely necessary to expect another idea to stand next to it (35). Thus, instead of thinking in single cultural logic, we have to embrace multicentric logics – individual, collective, and everything in between.

Noncommunicable Diseases and COVID-19: Relationship and Expectation

As the world is consumed with the COVID-19 pandemic, there remains a silent pandemic of noncommunicable diseases (NCDs) that now coexist in the same communities most affected by COVID-19. The response to NCDs in the context of COVID-19 should remain a top priority as part of structural solutions to inequities. To promote equity, we must address the structural determinants of health by first addressing structural racism, which is inscribed in institutional policies and practices that have created and sustain the disproportionate burden of hypertension, diabetes, and other NCDs in the black and brown communities (5). Thus, structural racism is a key determinant of such NCDs as hypertension, diabetes, stroke, and asthma (6). NCDs are the leading cause of death worldwide, with the most significant burden placed on low-income and middle-income populations in terms of premature deaths. In the United States, racial minorities, specifically black, Latino, and Native American populations, are the most burdened by NCDs (36). Indeed, the leading causes of death in these populations are heart disease, cancer, unintentional injuries, chronic lower respiratory disease, stroke, and cerebrovascular diseases, which together account for approximately 65% of total deaths (37). Thus, the NCD burden exists in the same population where COVID-19 exists. Our communication messaging, therefore, should erase a binarism of competition that leads to a pandemic *or* NCDs rather than COVID-19 *and* NCDs. The behaviors and context that favor one condition are likely to favor the others. Indeed, where NCD stands, infectious diseases like COVID-19 are likely to stand next to it. The messages of COVID-19 prevention in social and physical distancing and wearing masks are important solutions, but their sustainability depends on adequate response to disparities in the burden of diabetes, asthma, and other NCDs that are preexisting chronic conditions. Structurally, social distancing is problematic in South African townships, Brazilian favelas, and Nigerian slums where people share with one another basic essentials, such as sugar or salt when they run out of stock. The situation is further exacerbated by the lack of access to potable water in many of these communities including the *quartiers* of Senegal, the town of Khayelitsha in South Africa, favelas in Brazil, slums of Nigeria, and Flint, Michigan, in the United States. Communication and messaging for COVID-19 should also focus on us as health scientists and professionals by looking to ourselves for the same needed cultural transformation that we expect from communities responding to NCD pandemics as we do for infectious pandemics. Similar to Ebola (38) and HIV, COVID-19 revealed the falsehood in the separation of disease burdens by how they come to inhabit our bodies. This is the time for communication and messaging to focus not only outward to the community but also inward toward public health experts who frame the messages. How we respond now to COVID-19 is how we must respond to NCDs like hypertension, diabetes, obesity, cholesterol management, and asthma, because these disorders are constant reminders of persistent inequities in our communities.

Implications for Public Health

COVID-19 communication and messaging should address community risks at least as much as individual risks. PEN-3 offers a communication framework that engages the community by promoting positive factors, acknowledging unique factors, and preventing negative factors. There is a limit to the culture(s) of science, and scientists should reexamine the negative dimensions of scientific cultural solutions to the pandemic. Research and evaluation are also needed to embrace alternative perspectives and the culture of policy and politics that influence the choice of architecture for communication and messaging strategies. Such research and evaluation, for example, on communicating risk mitigation, should democratize scientific research and empower communities to advance solutions to the root causes of health inequities and strategies to improve their own well-being (39). By offering a model for effectively engaging communities, PEN-3 also focuses on mutual community-centered strategies, highlighting not only the perceptions that matter but also the enablers or resources and nurturers or collective roles that foster community agency and voice in mitigating the COVID-19 pandemic. Moreover, to the extent these strategies center equity, they enable culturally grounded approaches to scientific inquiry and challenge the field from within itself to honor community agency and resilience. These alternative perspectives can accelerate efforts in health equity by identifying and addressing the underlying structural determinants of inequities, such as structural racism, that lead to the disproportionate burden of COVID-19 cases and deaths among racial/ethnic minority groups. Ultimately, the goal of COVID-19 communication and messaging within culture is to mitigate increase in new cases and deaths, address preexisting structural contexts, and ultimately advance global communication messaging that promotes health and social justice for this pandemic now and others in the future.

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Table

Table. Application of the PEN-3 Cultural Model to COVID-19, Ebola, and HIV

PEN-3	COVID-19	Ebola	HIV
Perceptions	++Knowledge about 80% exposure with little or no illness ==Pandemic affected all countries, rich and poor –Awareness did not translate into action for prevention, therefore the need to modify messages	++Knowledge of virulence of the disease ==Pandemic affected mostly West and Central Africans –Awareness did not translate into behavior change, therefore messages had to be modified to fit cultural context	++Knowledge of behaviors that lead to vulnerability ==Different contexts and factors of vulnerabilities –Awareness did not translate into behavior change
Enablers	++Availability and use of protective personal equipment, such as masks and gloves ==Traditions like burial were partly affected –Health care providers do not have all the support they need to care for those infected	++Availability and use of protective personal equipment, such as masks and gloves ==Traditions like burial were fully and directly affected –Health care providers do not have all the support they need to care for those infected	++Availability of male and female condoms and needle exchange programs ==Traditions like marriages were directly affected –Health care providers do not have all the support they need to care for those infected
Nurturers	++Family members caring for loved ones even when there is risk ==Cultural identity–based messaging about community inequities as response to COVID-19 and noncommunicable diseases –Family members losing their jobs and not being able to provide basic needs for loved ones	++Family members caring for loved ones even when there is risk ==Culture-based solution such as traditional leaders (eg, chiefs overseeing burial rites) –Family members losing their jobs and not being able to provide basic needs for loved ones	++Family members caring for loved ones even when there is risk ==Culture-based messages such as monogamy for individualists and “zero grazing” for collectivist contexts –Job discrimination against those infected

Key: ++ positive to be promoted; == existential to be recognized; – negative to change.

PREVENTING CHRONIC DISEASE
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COMMENTARY

Reaching the Hispanic Community About COVID-19 Through Existing Chronic Disease Prevention Programs

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PEER REVIEWED

Summary

What is already known on this topic?

Emerging data suggest that the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) has disproportionately affected Hispanic communities in the United States.

What is added by this report?

We summarize how available infrastructure from Better Together REACH, a community–academic coalition promoting chronic disease prevention, and Penn State Project ECHO, a telementoring program, was adapted to support coronavirus disease 2019 (COVID-19) pandemic efforts for the Hispanic community.

What are the implications for public health practice?

Leveraging resources, including community health workers, from an existing chronic disease prevention program is a promising strategy to reach Hispanic populations during these unprecedented times.

Abstract

Publicly available data on racial and ethnic disparities related to coronavirus disease 2019 (COVID-19) are now surfacing, and these data suggest that the novel virus has disproportionately sickened Hispanic communities in the United States. We discuss why Hispanic communities are highly vulnerable to COVID-19 and how adaptations were made to existing infrastructure for Penn State Project ECHO (Extension for Community Healthcare Outcomes) and Better Together REACH (a community–academic coalition using grant funds from Racial and Ethnic Approaches to Community Health) to address these needs. We also describe programming to support COVID-19 efforts for Hispanic communities by using chronic disease prevention programs and opportunities for replication across the country.

Introduction

Pennsylvania is home to over 970,000 Hispanic people (1). Vibrant Hispanic-majority communities can be found across the state in cities such as Lebanon (total population, 25,902; 44.0% Hispanic) and Reading (total population, 88,495; 66.5% Hispanic) (1). Compared with state and national averages, incidence for Hispanic people in these 2 communities are higher for poverty, lack of health insurance, and poor health outcomes as a result of inadequate fruit and vegetable consumption, obesity, and a higher incidence of chronic diseases (2). In 2018, Better Together, a community–academic coalition led by Penn State College of Medicine, received a Racial and Ethnic Approaches to Community Health (REACH) award from the Centers for Disease Control and Prevention (CDC) to reduce the high incidence of chronic diseases among Hispanic people in both Lebanon and Reading (3). The coronavirus disease 2019 (COVID-19) pandemic has substantially affected our coalition's ability to deliver REACH program activities because many were planned as in-person events or large community gatherings.

The pandemic has also created great fear and anxiety in Hispanic families as many face language barriers and limited access to health care and health information. The Pew Research Center recently found that about two-thirds (65%) of Hispanic adults say the novel coronavirus is a major threat to the health of the US population as a whole, compared with less than half (47%) of the general public (4). In the same national survey, more Hispanic adults than American adults overall also said that COVID-19 is a major threat to their personal health (39% vs 27%, respectively) (4). Recognizing these challenges, our REACH coalition has strategically shifted resources to actively support the demands of local and state COVID-19 response efforts while still attending to our main goal to reduce disparities related to chronic disease prevention. The objective of this commentary is to discuss why Hispanic communities seem to be highly vulnerable to COVID-19, summarize the Better Together REACH initiatives, discuss how Better Together REACH has adapted program offerings to support COVID-19 pandemic efforts for the Hispanic community, and consider steps that might be taken to replicate these efforts across the country.

Hispanic Communities Are Especially Vulnerable to COVID-19

Publicly available data on racial and ethnic disparities related to COVID-19 (ie, people who have been tested for, who were infected by, or who have died from the virus) are now surfacing, and these data suggest that the novel virus has disproportionately sickened Hispanic communities (5–7). For example, in Pennsylvania's neighboring state New Jersey, 19% of the total population is Hispanic but Hispanic people make up 30% of COVID-19 cases (6). Similar COVID-19 case rate disparities for Hispanic people are reported in many states across the United States such as Utah (14% of total population vs 38% of COVID-19 cases) and Washington (13% of total population vs 34% of COVID-19 cases) (6). Partial COVID-19 death data disaggregated by Hispanic ethnicity also show that Hispanic people are dying at a rate above what population data would suggest (7). For example, CDC's weighted population data show that over 26% of US COVID-19 deaths were among Hispanic people, who represent only 18% of the total US population (7). In Pennsylvania, where Hispanic people are 7.6% of total state population, 11% of COVID-19 deaths were among Hispanic people, when applying weighted population distributions (7).

The vulnerability of Hispanic communities to COVID-19 can arise from many factors, including differential exposure, susceptibility, and access to health care (8). First, many Hispanic people work in frontline jobs in grocery stores, waste management, cleaning and sanitation services, and food delivery (9), putting them at constant exposure to people or materials that may be infected with COVID-19 (10). In addition to work circumstances, living conditions may also increase exposure to COVID-19 among Hispanic families (11). Twenty-five percent of Hispanic people live in multigenerational households (compared with only 15% of non-Hispanic white people) (12), which may make it challenging to take precautions to protect older family members or to isolate those who are sick if space in the household is limited (11). Although having a chronic disease does not increase the risk of contracting the new coronavirus, the presence of chronic disease can worsen the outcome of COVID-19 (13). Emerging data from the state of New York show that among those who died of COVID-19 (23,083 people as of May 20, 2020), the leading underlying illnesses were hypertension (54% of deaths) and diabetes (36% of deaths) (5). This is alarming for Hispanic people because they have higher rates of both hypertension and diabetes as compared with non-Hispanic white people (14). Also, the lack of reliable information in Spanish has impeded efforts to combat the spread of the virus in Hispanic communities (15). This is especially true among those with language barriers, making them more likely to be unaware of best practices. Lastly, Hispanic people are the largest population segment without health insurance coverage in the United States (14), leaving those with presumptive symptoms or with a positive COVID-19 test with limited access to needed health care.

Better Together REACH Initiatives

Established in 1999, REACH is CDC's cornerstone program aimed at reducing racial and ethnic health disparities. In 2018, CDC funded a new 5-year cycle of 31 grant recipients to reduce health disparities among racial and ethnic populations (ie, Hispanics, African Americans, American Indians, Asian Americans, Alaska Natives, and Pacific Islanders) with the highest level of chronic disease such as hypertension, heart disease, type 2 diabetes, and obesity (3). Through REACH, recipients plan and carry out local, culturally appropriate programs to address preventable risk behaviors leading to chronic diseases, such as poor nutrition and physical inactivity. Given the overwhelming socioeconomic and health disparities that Hispanic people face in both Lebanon and Reading, our coalition focused on improving chronic disease prevention outcomes in these 2 communities. Since 2018, Better Together REACH has leveraged strong community collaborations to implement locally tailored practice-based and evidence-based strategies aimed at increasing healthy nutrition programming, physical activity opportunities, and diabetes prevention programs. This initiative brings together over 60 local organizations that are now working together to break down silos, to share a common agenda to address health disparities, and to improve community wellness and the quality of life for all their residents (16).

Two of our signature initiatives related to healthy nutrition include expanding access to affordable and nutritious food (eg, Farmers Market Nutrition Program; Veggie Rx, a fruit and vegetable prescription program to alleviate food insecurity among patients with diabetes) and creating bilingual hospital-based breastfeeding programming and support with local Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) offices. To improve physical activity opportunities, we are actively promoting use of existing walking and bike routes that connect everyday destinations (eg, parks, schools, businesses, community facilities) and supporting the planning and designation of new routes (eg, Walk Works). To address critical community–clinical linkages, we are expanding access to diabetes prevention program offerings by training local, bilingual community health workers (CHWs) to connect at-risk people with existing programs and supporting the CHWs to become certified lifestyle coaches. Our initiatives are promoted throughout our community networks with culturally relevant marketing campaigns. Many of these initiatives have been paused following CDC's social distancing recommendations and Pennsylvania's stay-at-home orders. What has not paused in the face of the pandemic is the commitment of our coalition to serve the Hispanic communities in Lebanon and Reading in these uncertain times. Our local and state partners are now facing an increased demand for health and social services, without receipt of additional resources and while simultaneously experiencing a loss of revenues and staff. The Better Together REACH team has been quick to recognize these challenges and the changing needs of the Hispanic communities over the past few months.

Local Response to Help Hispanic Communities

Since Pennsylvania's Department of Health confirmed the first cases of COVID-19 in early March, the Better Together REACH team has been working to assist the Lebanon and Reading communities in their fight against this novel disease. As the rapidly evolving pandemic unfolds across our communities, families are faced with unprecedented challenges including loss of income, which has a trickledown effect in their ability to support basic needs. National survey data show that Hispanic adults (44%) were more likely than non-Hispanic white adults (26%) to report that they "cannot pay some bills or can only make partial payments on some of them" as a result of the economic challenges caused by the pandemic (17). Sixty-one percent of Hispanic adults also reported that they or someone in their household had lost a job or wages because of the coronavirus pandemic, compared with 38% of non-Hispanic white adults (17). Many members of our community are unpaid if their employers cannot open for business, and those who are immigrants are less likely to qualify for most government-sponsored assistance programs. Acknowledging these major issues, our team developed and disseminated a 1-page resource in Spanish to address questions about emergency lodging, food access, unemployment benefits, utility payments, and other nonmedical basic needs in Lebanon and Reading during local COVID-19 response events. This resource has been distributed to families picking up meals from local school district distribution sites.

Our team also identified, and has helped to address, the need for Hispanic families to stay informed about best practices to avoid the spread of COVID-19 as well as how and where to seek testing and health care if they develop symptoms. To better understand this need, our bilingual CHW convened virtual meetings with Hispanic community leaders and organizations serving Hispanic people (Figure). Through these conversations, we learned that Hispanic people were struggling to access reliable information in Spanish. We also learned that many had access to smartphones and internet (major carriers are now providing free internet access during the pandemic), and they were willing to join remote learning activities if offered in Spanish. With this information in hand, we reached out to Penn State Project ECHO (Extension for Community Healthcare Outcomes) to facilitate a series of community-facing webinars in Spanish to disseminate information about COVID-19.

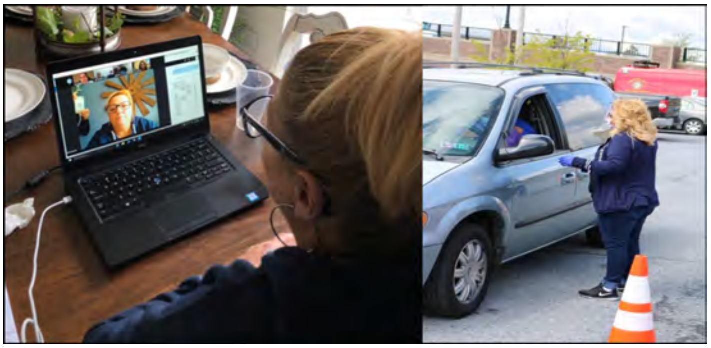

Figure. Community health worker leading a video conference call with community leaders in Lebanon County, Pennsylvania, to discuss the needs of Hispanic residents regarding coronavirus disease 2019 (COVID-19) (left) and distributing masks, bottles of hand sanitizer, and Spanish-language public service announcements at a local drive-through COVID-19 response site (right).

We partnered with Penn State Project ECHO at the right time, as they had launched a COVID-19 ECHO series on March 20 to inform health care providers and administrators of the latest best practices in emergency preparedness and patient treatment of COVID-19. Through this series of 1-hour webinars, participants presented patient and clinic or hospital system cases to academic expert teams who mentor them on patient care and systems quality improvement. These case-based discussions were supplemented with brief didactic presentations to improve content knowledge and share evidence-based best practices for dealing with COVID-19. Project ECHO is not telemedicine where expert specialists assume the care of the patient, but instead is "telementoring." Registered participants received the sessions via real-time, interactive videoconferencing by using Zoom (https://zoom.us; Zoom Video Communications, Inc), a user-friendly, Health Insurance Portability and Accountability Act (HIPAA)–compliant, cloud-based software application offered at no cost to them. Zoom has numerous benefits, including the ability to run on lower-speed internet connections. Participants easily connected to sessions by using a PC or Mac computer, laptop computer, tablet, or smartphone with or without a camera.

By using this existing infrastructure, we conducted the first Spanish-language community-facing COVID-19 ECHO series for the Hispanic community on April 2. This first session was "Preparing your household for COVID-19" and it was well attended through Zoom with concurrent transmission via Facebook Live (Table). While our bilingual CHW continued communicating with Hispanic community leaders daily, she assessed the evolving needs of Hispanic people in Lebanon and Reading with regard to COVID-19. Knowing our community needs, we planned and delivered Spanish-language sessions on diabetes management, mental health resources for families, and how to keep children physically active and eating healthily during COVID-19 times. We partnered with bilingual health care providers and public health scientists with expertise on these topics to deliver the sessions in Spanish. Additional sessions are being scheduled for upcoming weeks (eg, the role of CHWs in COVID-19 responses).

A key feature of our community-facing COVID-19 ECHO series was the opportunity for community members to actively participate in discussions about situations or challenges they have faced. Before each session, our CHW assessed questions or concerns from the community, so speakers used that information to craft their presentations and discuss those real-world scenarios as deidentified cases. These local cases served to reinforce the didactic portion of the webinar. Because we used an "all teach, all learn" approach, community members were free to ask questions and participate in discussions at any time during the session. Participants had the option to write questions in the chat box or use the raise hand feature to indicate that they had a question or comment to share with all participants. We also instructed the presenters to set aside the last 10 to15 minutes of the session to allow questions from the public. Because these community-facing sessions were delivered in Spanish, all questions were raised and responded to in the same language. Most of the participants' comments were requests for educational materials in Spanish to be distributed in their communities.

After each session, we made available to the general public the video recordings through the Penn State Project ECHO's YouTube channel (https://bit.ly/COVID_Spanish; YouTube, LLC). Presentation slides and other resources (eg, information sheets from CDC, public service announcements [PSAs] developed by Better Together REACH [18]) discussed in the sessions were also sent to participants via email or shared through access to a dedicated online shared folder. The success of our community-facing COVID-19 ECHO series motivated other collaborators to launch a Nepali-language series to reach the growing Nepali Bhutanese community that has found refuge in Pennsylvania. Our Better Together REACH team also supported the COVID-19 ECHO series for health care providers and administrators by organizing and presenting sessions about maternity health and breastfeeding and how to reach minority populations during the pandemic.

We have also been very active supporting local organizations and state agencies in their communication efforts. The Pennsylvania Commission on Latino Affairs and the state's Office of Health Equity have noted a lack of reliable messaging in Spanish about COVID-19 as a barrier for information dissemination in the state. To address this issue, we have translated health communication materials for local nonprofit organizations needing assistance in serving Spanish-speaking Hispanic people, and we have created educational resources in Spanish to help families stay informed during the pandemic. For example, we developed a collection of Spanish and English PSAs, which have been published through regional media outlets and distributed at local events to reinforce the importance of following CDC guidelines for preventing the spread of COVID-19. We developed these PSAs with an understanding that not all community members have access to a computer or internet in their homes. These PSAs are available for any community organization to use and can be freely accessed online (18), already having been shared with the National REACH Coalition.

Opportunities for Next Steps

As we did with the existing infrastructure of Better Together REACH, other chronic disease prevention programs can employ similar promising strategies to reach vulnerable populations across the country during these unprecedented times. Using the infrastructure of Penn State Project ECHO to deliver Spanish language, community-facing webinars was an invaluable asset to connect hard-to-reach populations with best-practice communication about COVID-19. Equally important, supporting our COVID-19 responses with CHWs was effective for both public health and community well-being.

We need to continue leveraging available infrastructure and technology to amplify the unique community connections CHWs have. On the basis of our own experience in Pennsylvania, we can offer several suggestions, although we acknowledge that every community faces unique challenges and every organization has unique strengths and limitations. We found that CHWs can easily use low-key and freely available technology like Zoom or social media to get real-time data from local leaders and organizations and share it with decision makers so that they can disseminate health and social service resources to vulnerable populations. CHWs can likewise deliver evidence-based information about COVID-19 prevention, testing, and health services to community members. At a time when misinformation is widespread and culturally appropriate information is limited, CHWs' communication skills are more important than ever. Also, as many health care organizations and government health agencies are turning to CHWs to fill gaps in community-based pandemic response efforts, including contact tracing, we have to protect their well-being (19).

Implications for Public Health

Despite the observed health disparities, the pandemic presents a window of opportunity for achieving greater equity in preventing disease and providing health care for vulnerable populations (20). To achieve this goal, we require improved data collection to monitor and track disparities among racial and ethnic groups in the number of COVID-19 cases, complications, and deaths (20). These data would serve to quickly inform decisions on how to effectively address disparities and allocate resources at different levels of action. We also need consistent and credible culturally appropriate information to share with the general public (11,15). CHWs are proven to be effective messengers (19). Increasing the CHW workforce, especially in underserved communities, can meet the urgent demand to educate and connect people to health care services (19). Efforts should continue working across sectors beyond health to identify critical resources, such as temporary housing, because many families are now facing serious financial struggles (11). Our experience suggests that by working together, we all help to make our communities stronger, more stable, and healthier.

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Table

Table. Participation Metrics of the Spanish-Language Community-Facing COVID-19 Project ECHO Series, Lebanon and Reading, Pennsylvania, 2020

Session Topic	Zoom[a]	YouTube[b]	Facebook		
			Reach[c]	Engagement[d]	Views[e]
Preparing your household for COVID-19[f]	62	250	746	15	122
Diabetes management[g]	36	122	1,595	209	509
Mental health resources for families[h]	31	90	415	92	165
Healthy eating and physical activity[i]	24	54	258	30	140

Abbreviation: COVID-19 Project ECHO, Coronavirus disease 2019 Project ECHO (Extension for Community Healthcare Outcomes).

[a] Number of unique people who joined the session via Zoom (https://zoom.us; Zoom Video Communications, Inc).

[b] Number of recording views in YouTube as of May 27, 2020 (https://www.youtube.com; YouTube, LLC).

[c] Number of unique people (estimated metric) who saw any session content in Facebook (https://www.facebook.com; Facebook, Inc).

[d] Total number of actions (eg, likes, comments, shares) that people took involving the session.

[e] Number of times the session content was viewed by people.

[f] Spanish title shown in YouTube “COVID-19: Estrategias para preparar su hogar y cuidar a su familia” (April 2, 2020).

[g] Spanish title shown in Youtube “COVID-19: Manejo de la Diabetes” (April 14, 2020).

[h] Spanish title shown in YouTube “COVID-19: Recursos de salud mental para familias durante la pandemia” (April 22, 2020).

[i] Spanish title shown in YouTube “COVID-19: Como Mantener Niños Activos y con Habitos Alimentarios Saludables en tiempos de COVID-19” (May 6, 2020).

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COMMENTARY

Community Engagement of African Americans in the Era of COVID-19: Considerations, Challenges, Implications, and Recommendations for Public Health

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PEER REVIEWED

Summary

What is already known on this topic?

African Americans are more likely to contract coronavirus disease 2019 (COVID-19), be hospitalized for it, and die of the disease when compared with other racial/ethnic groups. Psychosocial, sociocultural, and environmental vulnerabilities, compounded by preexisting health conditions, exacerbate this health disparity.

What is added by this report?

This report adds to an understanding of the interconnected historical, policy, clinical, and community factors associated with pandemic risk, which underpin community-based participatory research approaches to advance the art and science of community engagement among African Americans in the COVID-19 era.

What are the implications for public health practice?

When considered together, the factors detailed in this commentary create opportunities for new approaches to intentionally engage socially vulnerable African Americans. The proposed response strategies will proactively prepare public health leaders for the next pandemic and advance community leadership toward health equity.

Abstract

African Americans, compared with all other racial/ethnic groups, are more likely to contract coronavirus disease 2019 (COVID-19), be hospitalized for it, and die of the disease. Psychosocial, sociocultural, and environmental vulnerabilities, compounded by preexisting health conditions, exacerbate this health disparity. Interconnected historical, policy, clinical, and community factors explain and underpin community-based participatory research approaches to advance the art and science of community engagement among African Americans in the COVID-19 era. In this commentary, we detail the pandemic response strategies of the Morehouse School of Medicine Prevention Research Center. We discuss the implications of these complex factors and propose recommendations for addressing them that, adopted together, will result in community and data-informed mitigation strategies. These approaches will proactively prepare for the next pandemic and advance community leadership toward health equity.

Introduction

Racial/ethnic minority populations have historically borne a disproportionate burden of illness, hospitalization, and death during public health emergencies, including the 2009 H1N1 influenza pandemic and the Zika virus epidemic (1–4). This disproportionate burden is due to a higher level of social vulnerability — "individual and community characteristics that affect capacities to anticipate, confront, repair, and recover from the effects of a disaster" — among racial/ethnic minority populations than among non-Hispanic White populations (5). These characteristics include, but are not limited to, low socioeconomic status and power, predisposing racial/ethnic minority populations in general and African Americans in particular to less-than-optimal living conditions. Some racial/ethnic minority populations are more likely than non-Hispanic White populations to live in densely populated areas, overcrowded housing, and/or multigenerational homes; lack adequate plumbing and access to clean water; and/or have jobs that do not offer paid leave or the opportunity to work from home (6,7). These factors contribute to a person's ability to comply with the mitigation mandates of the coronavirus disease 2019 (COVID-19) pandemic established to reduce risk for infection, such as physical distancing and sheltering in place (8).

The COVID-19 pandemic presents new challenges for public health evaluators, policy makers, and practitioners, yet it mirrors historical trends in health disparities and poor health outcomes among African Americans. African Americans are more likely to contract, be hospitalized, and die of COVID-19–related complications (9–12). Social vulnerability is often compounded by preexisting health conditions, exacerbated during times of crisis (13–17).

Public health leaders are now at a critical juncture to advance health equity among vulnerable African Americans. To advance this health equity, we must first have a comprehensive understanding of the factors that create health disparities and the factors that can contribute to an effective, multilevel response. With this understanding, we can then deploy effective mitigation strategies based on a community-based participatory research framework that fosters and sustains community leadership in the assessment and implementation of culturally appropriate and evidence-based interventions that enhance translation of research findings for community and policy change (18,19). The objective of this commentary is to 1) detail the interconnected historical, policy, clinical, community, and research challenges and considerations central to comprehensively advancing the art and science of community engagement among African Americans in the COVID-19 era; 2) describe The Morehouse School of Medicine Prevention Research Center (MSM PRC) pandemic response strategies, driven by community-based participatory research (CBPR); and 3) discuss community-centered implications and next steps for public health action.

Challenges and Considerations

Historical context

Racial/ethnic health disparities have always existed in the United States. Differential health outcomes between African Americans and non-Hispanic White Americans have been part of the American landscape for more than 400 years (20). Many measures of health status have been used to assess differences among racial/ethnic groups; more recently, health researchers have advanced concepts and constructs of health equity and social determinants of health (21). Reaching back to the mid-20th century, the US government documented that African Americans were far more likely than non-Hispanic White Americans to have a wide range of potentially fatal illnesses, including noncommunicable diseases such as type 2 diabetes, asthma, end-stage renal disease, and cardiovascular disease (21). In 1985, the US Department of Health and Human Services published the landmark *Report of the Secretary's Task Force on Black and Minority Health*, better known as the Heckler report (21). The report documented an annual excess 60,000 deaths among African American and other racial/ethnic minority populations. These underlying determinants can only result in disproportionately adverse health outcomes for racial/ethnic minority populations during the COVID-19 pandemic.

The COVID-19 pandemic is intensified by the long-standing income inequality between non-Hispanic White people and racial/ethnic minority populations. Economists use the Gini coefficient to measure income inequality. Values for this measure range from 0 to 1, with higher values representing greater income inequality. From 1990 to 2018, the Gini coefficient in the United States rose from 0.43 to 0.49 — an increase in income inequality. When income disparities exist along with other disparities (eg, health insurance, employment, education, social justice, access to quality health care), public health pandemics marginalize racial/ethnic minority groups, and this marginalization requires a strong and strategic response (22).

Policy landscape

Racial/ethnic minority populations are disproportionately affected by COVID-19 (23), as they are by many diseases. In the United States, African Americans, Hispanics/Latinos, Native Americans, Native Hawaiians, and Pacific Islanders are more likely than other racial/ethnic groups to die of COVID-19 (24). The pandemic has not affected all populations equally for several reasons, including social, behavioral, and environmental determinants of health. In addition, economic and social policies have not benefitted all populations equally. Obesity, asthma, depression, diabetes, heart disease, cancer, HIV/AIDS, and many other disorders that put vulnerable populations at greater risk of dying of COVID-19 can often be linked to a policy determinant (25). Air pollution; climate change; toxic waste sites; unclean water; lack of fresh fruits and vegetables; unsafe, unsecure, and unstable housing; poor-quality education; inaccessible transportation; lack of parks and other recreational areas; and other factors play a large role in overall health and well-being (26). These factors increase a person's stress and limit opportunities for optimal health (27). Too often, public health researchers and practitioners stop at the social determinants of inequities. These social determinants do, indeed, play an outsized role in these human-made inequities, but underlying each one is a policy determinant that should be addressed to improve health equity.

Consider, for example, the problem of asthma among many racial/ethnic minority populations. One community, in East Harlem, one of Manhattan's poorest neighborhoods, found that a bus depot caused the high rates of asthma among children who lived near it

(28). Six of 7 bus depots in Manhattan are located in East Harlem, and East Harlem has the highest rate of asthma hospitalizations in the country (29–31). In another community, the exhaust and dust from the vehicles traveling a major highway that cut through the middle of the community was found to contribute to the high rates of asthma among residents who lived near it (32). In both of these examples, an underlying policy determined the placement of the bus depots and the highway, which led to the eventual health inequities.

Examples of how legislative and policy change can immediately affect the social determinants of health are demonstrated in government and public responses during the first 3 months of the COVID-19 pandemic in the United States. Federal, state, and local policies were implemented to stimulate local economies and infuse communities with free food and direct revenue, including increases in SNAP (Supplemental Nutrition Assistance Program) benefits and expanded unemployment benefits. These initiatives have helped communities and individuals during the crisis. Despite these programs, however, some marginalized African American communities have not benefitted. As the nation adjusts to the "new normal," it is imperative that the social, economic, and health gaps in these communities also conform to a "new normal" that is driven by new or expanded *and* sustained policies.

Clinical mechanisms, chronic conditions, and increased risk of COVID-19

African Americans are twice as likely as non-Hispanic White Americans to die of heart disease and 50% more likely to have hypertension and/or diabetes (33,34). This elevated risk increases the likelihood of other complications and death from COVID-19 (35,36). Let us consider, for example, people living with diabetes. Their immune system is depressed overall, because their blood glucose is not well controlled (hyperglycemia) (37). It is hypothesized that hyperglycemia causes an increase in the number of a particular receptor in the lungs, pancreas, liver, and kidneys; this increase impairs the function of white blood cells, which are designed to fight off infections (37). This impairment predisposes the person living with diabetes to an increased risk of bacterial and viral infections. When severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) enters the lungs by way of this particular receptor, it overwhelms the alveoli (air sacs) in the lungs and disables the exchange of oxygen and carbon dioxide (38). As a result, some people with diabetes may need supplemental oxygen, intubation, and/or admission to an intensive care unit (37). Hyperglycemia in combination with a disease such as COVID-19 makes recovery difficult (37). People with diabetes who are in good mental health, know the names and dosages of their medications, and know their blood pressure, blood glucose, and other laboratory values, such as hemoglobin A_{1c}, tend to have better control of their disease and have lower levels of illness and death (16,37). Emphasizing the importance of good blood glucose control to prevent diabetes complications and associated COVID-19 risk is more important now than ever (36–38). Mental health plays a major role in a person's ability to maintain good physical health and optimally manage their chronic conditions, and mental illnesses may affect the ability to participate in health-promoting behaviors (39).

Mental and behavioral health

The constellation of stressors triggered by the COVID-19 pandemic undermines the nation's mental health (40–42). Various disruptions in daily life, coupled with the threat of contracting the deadly virus, is leading some people to experience anxiety and depression, sometimes to the extreme. Reports of family violence and use of suicide prevention hotlines have increased (43,44). Physical distancing, shelter-in-place orders, business and school closures, and widespread unemployment have radically changed ways of life and contributed to a sense of hopelessness, isolation, loneliness, helplessness, and loss (45,46). Pandemic-related factors, including quarantine, have led to posttraumatic stress disorder, confusion, and anger (47). One study indicated that a constant consumption of media reports had detrimental psychological effects on some people (48). If interrelated mental, behavioral, and emotional issues are not adequately addressed, disorders among racial/ethnic minority populations and other vulnerable populations (eg, the medically underserved, homeless, and disabled; inmates in the criminal justice system) will surge and exacerbate disparities (49).

Interrelated COVID-19–related stressors include childcare and safety, elder care, food insecurity, and interpersonal relationships (50). These stressors may trigger aspects of unresolved trauma. Poor coping mechanisms (eg, use of illicit drugs, excessive alcohol consumption, overeating, inadequate sleep) may develop or worsen. In addition to facing chronic stressors, communities of racial/ethnic minority populations often deal with the stigma associated with seeking mental and behavioral health care. A Surgeon General's report, *Mental Health: Culture, Race, and Ethnicity*, concluded that racial/ethnic minority populations, compared with the non-Hispanic White population, have less access to mental health care, are less likely to receive treatment, and when treated, often receive poorer quality of care (51). As a result, racial/ethnic minority populations often have a greater burden of behavioral disorder–related disability (51). Addressing the multifaceted mental and behavioral health needs of racial/ethnic minority populations in the United States is a complex issue that warrants attention from clinicians, researchers, scientists, public health professionals, and policy makers. It is imperative to recognize the significant role of community leaders in exploring solutions to COVID-19–related mental and behavioral health problems among racial/ethnic minority communities. Their lived experiences are central to the co-creation of pandemic response strategies for these populations.

Perspectives of community leaders

The realities of research, evaluation, and clinically focused community engagement after the COVID-19 pandemic may change for the foreseeable future. Efforts to initiate and sustain culturally competent engagement of racial/ethnic minority groups previously relied on face-to-face interactions in homes, churches, and other community settings. Social or physical distancing has nearly stopped communities and their collaborators from real-time gathering. These changes challenge the human need for connection and in-person exchange. Although the adjustment has been difficult, the pandemic has resulted in new modes of engagement. Webinar and digital technology are now accessible for most people at low or no cost. Many community residents have newfound capacities to use technology for social and professional interactions as part of daily life.

Current health communication and messaging require community-informed improvements. The use of terms like *sheltering in place, social distancing*, and *flattening the curve* do not naturally resonate with many people. For some, these terms foster anxiety and distrust of systems perceived to separate communities rather than promote COVID-19 mitigation strategies. Community leaders, as well as business and faith leaders, have found themselves in a space of terminology and descriptions that are understood mostly by public health practitioners. Therefore, health literacy and the interpretation of current health conditions are vital.

The pandemic has intensified the economic strains among low-income and moderate-income people and families (52). Low-wage workers, many on the frontlines of the pandemic since it began, have had little to no increase in income (53). African American families who struggled to make ends meet before COVID-19 are now facing dire economic circumstances in making the best decisions for their families. Stressors include, but are not limited to, deciding how to pay rent or a mortgage, paying for food, assisting children with virtual learning, and protecting themselves with minimal or no health care benefits. The mental and behavioral health implications of these problems, along with the economic and practical challenges, have made a fragile ecosystem even more unstable. Low-wage workers in hospitality, food service, and retail industries cannot work from home. Workers who depend on employer-provided health insurance now have the additional burden of how to maintain health insurance coverage (54). Ultimately, lack of adequate access to health care, along with the complex realities of the COVID-19 pandemic, will increase health disparities for socially vulnerable African American employees and their families.

Local examples of COVID-19 response strategies driven by community-based participatory research

The MSM PRC relies on a deeply rooted, community partnership model that responds to the health priorities of vulnerable African American residents before, during, and after public health emergencies such as the COVID-19 pandemic. For more than 20 years, the MSM PRC has applied dynamic CBPR approaches that focus on prevention, establish partnerships between communities and research entities, and are culturally tailored (6,55–57).

The MSM PRC capitalizes on community wisdom through a community coalition board (CCB) that has governed the center since its inception. The CCB is composed of 3 types of members: neighborhood residents (always in the majority), academic institutions, and social service providers (58). Neighborhood residents hold the preponderance of power, and all leadership seats and are at the forefront of all implemented approaches. Neighborhood resident members are intentionally recruited from census tracts with a high incidence and prevalence of chronic and infectious diseases. The communities served by the MSM PRC are majority (87%) African American, have an average household income of $23,616, and rank lowest among other local communities in other socioeconomic conditions and community neighborhood health factors (55).

The MSM PRC has strategically partnered with the CCB and the community to facilitate health research and related interventions based on a comprehensive understanding of historical, political, clinical, and community considerations. The community governance model was developed to address CBPR challenges that exist when academics are not guided by neighborhood leaders in understanding a community's ecology, when community members do not lead discussions about their health priorities, and when academics and neighborhood leaders do not work together as a single body with established rules to guide roles and operations (59,60).

The MSM PRC conducts a recurring (every 4 years) community health needs and assets assessment (CHNA^2) process through the CCB, empowering community members to take on roles as citizen scientists who develop locally relevant research questions and identify priority health strategies (60). The recently completed CHNA^2 (February 2018) was co-led by neighborhood residents to advance a community health agenda. Survey development, data analyses, and response strategies are reviewed, monitored, and evaluated by the CCB and its Data Monitoring and Evaluation

Committee (55). This 7-member committee, established in 2011, is designed to extend the CBPR engagement of CCB members in the work of the MSM PRC. It exists through academic–community co-leadership (a CCB neighborhood resident member and the MSM PRC assistant director of evaluation) of a group of CCB members tasked with leading assessments. For CHNA^2, members met bimonthly (every other month, when the CCB did not meet) to discuss and inform evaluation and data collection activities and prepare for reporting of evaluation findings and interim results to the broader CCB to determine corresponding respond strategies. CHNA^2 primary data included surveys administered to 607 community residents. The most frequently cited community health concerns were diabetes, nutrition, high blood pressure, overweight/obesity, and mental health. County-level, top-ranking causes of illness and death, including cardiovascular disease, diabetes, and mental health disorders, align with these community perspectives (61).

CHNA^2 is relevant, despite being administered before the outbreak of COVID-19. The chronic conditions and health problems identified are those exacerbated by COVID-19 (diabetes, cardiovascular disease, and mental health), thereby making their focus even more relevant to the community.

The mental and behavioral health components of CHNA^2 were amplified to address the stress and anxiety caused by the pandemic. First, during National Mental Health Awareness Month (May 2020), the MSM PRC convened a virtual forum, *Our Mental and Behavioral Health Matter*s. It was strategically designed to address the culturally bound mental health stigma in racial/ethnic minority communities that is due, in part, to the schism between religion and therapy. The forum also addressed challenges related to social isolation. Concerns centered on how to navigate a virtual mental health checkup and support for parents seeking to help their children process the realities of the pandemic and minimize childhood trauma. Featuring psychologists, researchers, and community- and faith-based pioneers, the forum engaged more than 230 local and national participants. Second, a CCB member representing Fulton County's Department of Behavioral Health and Developmental Disabilities helped the MSM PRC to develop and disseminate an infographic on mental and behavioral health services for insured and uninsured residents. Third, the MSM PRC will offer annual Mental Health First Aid (62) trainings to community residents and professionals over the next 4 years.

The MSM PRC leads the Georgia Clinical and Translational Science Alliance's Community Engagement Program, which is designed to advance community-engaged clinical and translational research (63,64). The Program is led by a community steering board adapted from the CCB model and includes co-leaders (faculty and staff, including a community health worker) from Emory University, the Georgia Institute of Technology, and the University of Georgia. The program conducted a webinar, *Community Engagement in the Era of COVID — Opportunities, Challenges and Lessons Being Learned*, in May 2020. The webinar addressed the challenges and opportunities associated with initiating or sustaining community-engaged research during physical-distancing and shelter-in-place mandates. Clinicians, scientists, and community leaders from Atlanta, Athens, and Albany, Georgia, discussed uniquely nuanced issues for urban and rural community engagement and the basic need for social connectedness through virtual navigation of community engagement strategies (eg, via Zoom) and newly expanded access to telehealth medical visits (65). The webinar emphasized the importance of being a credible source of COVID-19 information and linkage across social and economic services, given heightened community anxiety and preexisting mistrust of medical research.

The MSM PRC is a central collaborator in a national initiative led by the National Center for Primary Care at Morehouse School of Medicine and the Satcher Health Leadership Institute, also at Morehouse School of Medicine. The National COVID-19 Resiliency Network is designed to mitigate COVID-19 in racial/ethnic minority, rural, and socially vulnerable communities. The initiative will work with community organizations to deliver education and information on resources to help fight the pandemic. The information network will strengthen efforts to link communities to COVID-19 testing, health care services, and social services through the institution's leadership in policy, community engagement, and primary care. The MSM PRC's CCB model will be scaled to collaborate with community organizations in highly affected geographic areas to assess and inventory community assets for COVID-19 testing, vaccination, and other health care and social services through a national community coalition board. The MSM PRC CHNA^2 model will also be scaled to inform mitigation approaches implemented by community-based organizations through establishment of a centralized inventory of culturally appropriate COVID-19 response strategies, by geography and population vulnerability. Approaches will engage community health workers, who are mission-critical stakeholders, nationally galvanized, and locally deployed.

These MSM PRC activities are founded on long-standing, community-partnered, and informed relationships in response to preexisting health priorities that are simply heightened by the COVID-19 pandemic. Ideally, this CBPR framework is established before a public health crisis. This framework and the practice of identifying community needs and mobilizing strengths are now poised, adapted, and scaled up in response to the COVID-19 pandemic. The continued evolution of the pandemic means that these approaches and solutions must be flexible in response to changing needs and new data.

Implications for Public Health

Public health practitioners, evaluators, policy makers, researchers, and clinicians with a community-engaged mindset have long understood, grappled with, and proclaimed the complexities of health disparities in the context of historic and current social determinants (66). When considered together, the challenges and realities detailed in this commentary create opportunities for new approaches to intentionally engage socially vulnerable African Americans. The response strategies proposed below reflect the complex web of historical and current policy and clinical, mental and behavioral, and community factors. Use of a CBPR framework undergirds all response strategies proposed.

Promote local community leadership to proactively inform mitigation strategies. The importance of CBPR and related needs assessments and response strategies are heightened during the COVID-19 era. Health promotion for chronic conditions such as diabetes, obesity, and cardiovascular diseases may have previously been structured to result in poor health or premature death for racial/ethnic minority populations through reduced or nonexistent access to health care; these conditions now require more immediate attention because they increase vulnerabilities and risks that can lead to poor health outcomes or death. Community knowledge, perceptions, and approaches to culturally responsive mitigation strategies must be prioritized. Carefully constructed local community governance boards that include multidisciplinary leadership (clinical, policy and social service, and research, among others), should be formed to lead assessments toward community and data-informed COVID-19 mitigation strategies for vulnerable populations in highly affected geographic areas.

Strategically engage public health and community-attuned policy leaders and prioritize community stimulus strategies. The political landscape calls for public health leadership by mitigation response teams (25). These teams are key informants from the beginning of public health initiatives designed to mitigate the pandemic, and their engagement is essential. They will provide another lens through which to examine the structures and processes that enable inequities to systematically develop and flourish or be eradicated through community co-created responses.

The essential areas of policy for optimal community health are in prioritized economic development, food security, and access to health care protection for vulnerable African American communities. Collectively, these areas present opportunities for intervention in response to chronic disease self-management (clinical), economic strains (community), and health care protections (policy) associated with the COVID-19 vulnerabilities of many African American communities. These essential policy areas represent a proposed foundation that rests on 4 “Es” hypothesized to narrow disparity gaps and offer opportunities for self-sufficiency and community resiliency.

- **E**mploy trained/certified, compensated community health workers, coaches, and ambassadors who are charged with cultural messaging and education, contact tracing, and surveillance toward increased adherence to policies on physical distancing and sheltering in place.
- **E**xpand SNAP programs with vouchers to include the purchase of household and personal care items rather than encouraging recipients to barter for basic care products.
- **E**nhance school lunch programs so that all children receive high-quality, balanced meals throughout the year, regardless of the ability to pay.
- **E**nsure universal broadband internet access to reduce education, health care, and information barriers.

Cultivate community-informed public health disaster health literacy. Health literacy concepts, modes, and education must be reframed. The media have newly exposed the lay public to the realities of unequal treatment and unequal pandemic risk. The public is, thereby, witnessing the more rapid connection between who they are, where they live, and who is more likely to suffer from and die of COVID-19. Marketing frameworks for community-based prevention can be used to position community leaders to inform and lead health communication strategies. These marketing frameworks will ensure that messages resonate, engage, and foster action with objectivity and community/cultural sensitivity.

Foster culturally tailored behavioral and mental health dialogue and response. Multidimensional prevention education strategies that encourage resilience (positive adaptation to adversity) must be promoted in African American communities. This promotion should involve advocating for proactive self-care, reducing stigma, and encouraging integrated health care. These strategies should be promoted and proactively integrated as cross-cutting components of *any* research and health initiative.

Prioritize patient-centered medical homes and neighborhood models. Patient-centered medical home infrastructures that include models of integrated care (mental and behavioral health care services in primary health care settings) can help overcome barriers to comprehensive health care and overall wellness. This model engages comprehensive resources to care for a patient, regardless of race/ethnicity, sex/gender, sexual orientation, language, socioeconomic status, or health insurance coverage. Primary care providers are encouraged to incorporate this model into their practices to decrease illness and death among African Americans at heightened risk of COVID-19 (67,68).

Redefine essential workers. Although the accomplishments of first responders — physicians, nurses, scientists, and other people fighting to preserve life — are laudable and undeniable, many African American nonclinical frontline workers, such as maintenance, janitorial, or food processing workers, are excluded from the definition of essential workers. The social vulnerability of nonclinical frontline workers, who often have chronic health conditions that place them at particular risk for contracting COVID-19, should be acknowledged and considered in planning.

Community and public health leaders in health care, behavioral health, and policy must consider the implications of health inequities among racial/ethnic minority populations, seriously tackle their root causes, and develop culturally responsive COVID-19 strategies for socially vulnerable African Americans. CBPR-driven approaches that elevate marginalized communities as senior partners in planning, implementing, and evaluating strategies will promote community leadership and increase adherence to health communication messages as the COVID-19 pandemic evolves. Efforts should be characterized by strong data (research or evaluation), contextually relevant community engagement strategies, and action (policy, systems, and environmental change approaches). The COVID-19 pandemic has presented an optimal opportunity to reprioritize and sustain approaches toward advancing community engagement of vulnerable African Americans. These new approaches will prepare us for the next pandemic. More importantly, they will foster CBPR leadership in advancing health equity.

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PREVENTING CHRONIC DISEASE

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TOOLS FOR PUBLIC HEALTH PRACTICE

Addressing Racial and Ethnic Disparities in COVID-19 Among School-Aged Children: Are We Doing Enough?

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PEER REVIEWED

Summary

What is already known on this topic?

The disproportionate impact of COVID-19 and associated disparities among some racial and ethnic minority populations has been documented across age groups, including children and teens.

What is added by this report?

We provide a summary of potential community-based strategies that can be used to address health disparities and educational inequities among minority children and teens that have been exacerbated during the pandemic.

What are the implications for public health practice?

Evidence-based community health promotion models that center partnerships in a strategic and comprehensive approach may reduce racial and ethnic health disparities and educational inequities due to COVID-19 and advance health equity.

Abstract

The disproportionate impact of COVID-19 and associated disparities among Hispanic, non-Hispanic Black, and non-Hispanic American Indian/Alaska Native children and teenagers has been documented. Reducing these disparities along with overcoming unintended negative consequences of the pandemic, such as the disruption of in-person schooling, calls for broad community-based collaborations and nuanced approaches. Based on national survey data, children from some racial and ethnic minority groups have a higher prevalence of obesity, asthma, type 2 diabetes, and hypertension; were diagnosed more frequently with COVID-19; and had more severe outcomes compared with their non-Hispanic White (NHW) counterparts. Furthermore, a higher proportion of children from some racial and ethnic minority groups lived in families with incomes less than 200% of the federal poverty level or in households lacking secure employment compared with NHW children. Children from some racial and ethnic minority groups were also more likely to attend school via online learning compared with NHW counterparts. Because the root causes of these disparities are complex and multifactorial, an organized community-based approach is needed to achieve greater proactive and sustained collaborations between local health departments, local school systems, and other public and private organizations to pursue health equity. This article provides a summary of potential community-based health promotion strategies to address racial and ethnic disparities in COVID-19 outcomes and educational inequities among children and teens, specifically in the implementation of strategic partnerships, including initial collective work, outcomes-based activities, and communication. These collaborations can facilitate policy, systems, and environmental changes in school systems that support emergency preparedness, recovery, and resilience when faced with public health crises.

Introduction

The population health impact of COVID-19 has exposed decades, if not centuries, of inequities that have systematically undermined the physical, social, material, and emotional health of racial and ethnic minority groups (1,2). The disproportionate impact of COVID-19 and associated disparities in outcomes among some racial and ethnic minority populations is documented across age groups, including among children (3–5). Reducing these disparities along with the inequitable economic and social impact of the pandemic on families from racial and ethnic minority groups requires broad community-based and underused collaborations, as well as innovative approaches.

In this article, we highlight health disparities and inequities among children and teenagers from racial and ethnic minority groups. We discuss education as a major social determinant of health and the impact of restricted access to in-person school, and we describe disparities in underlying chronic medical conditions and social inequities associated with poverty and systemic disadvantage. In combination, these factors exacerbate poor health outcomes in populations disproportionately affected by social conditions beyond their control, including infection with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19. In light of documented disparities and the potential collateral damage inflicted by the COVID-19 pandemic, such as delays in health care, increases in social isolation, and decreases in vaccination rates (6), we invoke a renewed sense of urgency in attending to the population health status of children and teens from racial and ethnic minority groups.

We argue for community-based approaches that are organized to achieve greater proactive and sustained collaborations between local health departments, local school systems, and other public and private organizations. Although these approaches are not new, the impact of the COVID-19 pandemic on school-aged children experiencing systemic disadvantage reintroduces and amplifies the need for community-based collaborations and strategic partnerships. Since the causes of health disparities are complex and multifactorial, eliminating these health disparities cannot be accomplished by a single sector or entity (7). As trusted members of their communities, partners from the public and private sectors can play a key role in improving population health (8). Revitalizing old partnerships and establishing new collaborations may reduce COVID-19 disparities; improve and protect the physical and mental health of children and teens from racial and ethnic minority groups experiencing systemic disadvantage; and advance health equity, which is the opportunity for everyone to be as healthy as possible (2). We posit that these partnerships and collaborations can facilitate policy, systems, and environmental changes within school systems that support emergency preparedness and recovery and resilience when faced with public health crises.

Education is a Major Social Determinant of Health

Education is a major social determinant of health and is essential to achieving health equity (9). Educational attainment and disparities in health are closely linked (10). Moreover, education is highly correlated with income and occupation, and “less education predicts earlier death” (11). Furthermore, through occupational attainment, education most often determines access to health care and health-related benefits, including paid time off and paid sick leave (12). Adults with less education report worse general health, more chronic conditions, and more functional limitations than those with higher levels of education (13,14).

School closures (during the spring of 2020) in response to the COVID-19 pandemic, including in-person kindergarten through grade 12 (K-12) schools, and the safe reopening of schools and institutions of higher education have been at the center of public health decision making to ensure guidelines protect students, teachers, faculty, and staff. According to Fay et al, along with the economy and the health care system, schools are “a third pillar of a pandemic-resilient society” (15). Besides education, schools provide facility-based services on which many students and families rely, including academic intervention supports, food and nutrition programs, childcare, after-school support, and social, physical, and mental health services. Schools can also serve as an extension of the home environment and offer a protective social environment for some students (16). As enduring community institutions, services provided by schools to “communities made vulnerable by systemic racism, inadequate insurance, family instability, environmental toxicity, and poorly paid jobs” (17) are essential to the overall well-being and psychosocial health of students experiencing poverty and systemic disadvantage (12). In this article, students experiencing systemic disadvantage include those who are disproportionately from racial and ethnic minority groups, with disabilities, experiencing homelessness, in foster care, and for whom English is a second language (18).

Children who experience poverty and systemic disadvantage, who are more likely to be from racial or ethnic minority groups, may be at higher risk of infection, severe illness, and death from COVID-19 (4). Because of school closures, children already experiencing disadvantage may have limited access to the facility-based services, academic supports (eg, private instructors, learning pods), virtual learning options, and digital technologies needed to successfully complete their grade-level academic requirements (18). Parents’ lives are also impacted by school closures. Some parents may not be able to return to work or may not have paid leave, flexible schedules, or options to work remotely and may have to balance how they provide supervision to several children at home with different academic schedules (17,18). Parents’ comfort with their own educational attainment and confidence to help their children academically is also a factor in how well students perform (19,20). These challenges may widen the gap in academic performance for students experiencing disadvantage compared with their more privileged counterparts. Conversely, in-person learning during the pandemic may pose challenges for these children and their families. Schools that serve communities with a disproportionate number of people experiencing poverty are often under-resourced, overcrowded, and understaffed, which increases risk for COVID-19 transmission in schools and adds to the challenges associated with safe reopening (17). Furthermore, some students may live with others who, for various reasons, are at increased risk for COVID-19 infection or live in intergenerational or crowded housing, which may influence their parent's or guardian's decision to send them to in-person school. Under-resourced schools may also have reduced capacity to offer high-quality virtual learning or be able to provide the supports needed for students with disabilities or other special needs. To mitigate the impacts of COVID-19 on the scope and quality of educational resources available to these students, decision makers, programs, and interventions must consider health disparities and social inequities and act on the unique conditions that could increase students' risk of infection and severe illness from COVID-19.

Disparities in Underlying Medical Conditions and Social Determinants of Health

As of May 2021, the US continues to experience substantial levels of SARS-CoV-2 transmission. Although less common than in adults, children and teens are still at risk of developing severe illness and complications from COVID-19; approximately 1 in 3 children hospitalized with COVID-19 were admitted to the intensive care unit, similar to the rate among adults (4). Although evidence on which medical conditions in children are associated with increased risk is limited, children with the following conditions might be at increased risk for severe COVID-19: obesity, diabetes, asthma, other chronic lung disease, congenital heart disease, medical complexity, severe genetic disorders, sickle cell disease, chronic kidney disease, severe neurologic disorders, inherited metabolic disorders, and immunosuppression due to malignancy or immune-weakening medications (21).

Serious racial and ethnic health and health care inequities persist for children with chronic health conditions (22). National estimates indicate significant disparities in the prevalence of chronic disease conditions that may place some children and teens at increased risk for severe illness from COVID-19 (Table 1). Nearly 1 in 5 children aged 2–19 years (19.3%) in the United States have obesity (24). The prevalence of obesity among Mexican American (26.9%), Hispanic (25.6%), and non-Hispanic Black (NHB; 24.2%) children was higher than among non-Hispanic White (NHW; 16.1%) and non-Hispanic Asian (8.7%) children during 2017-2018. Children who have obesity are more likely to have risk factors for adult cardiovascular disease (27), including high blood pressure and high cholesterol, increased risk of impaired glucose tolerance, insulin resistance, and type 2 diabetes, as well as asthma (28) and sleep apnea (29). Racial and ethnic disparities also are evident in asthma, diabetes, and cardiovascular disease. In 2018, the prevalence of current asthma among NHB (14.2%), Hispanic overall (8.0%), and Mexican American (7.0%) children was higher than among NHW (5.6%) children younger than 18 years (Table 1).

The SEARCH for Diabetes in Youth Study has reported disparities in the incidence of type 2 diabetes per 100,00 among children aged 10–19 years. During 2014–2015, NHB (37.8), American Indian (32.8), Hispanic (20.9), and Asian/Pacific Islander (11.9) children had higher incidence rates of type 2 diabetes than NHW (4.5) children (Table 1) (25). Additionally, using 2013–2016 data from the National Health and Nutrition Examination Survey (NHANES), Jackson et al reported that among children aged 12–19 years, the estimated prevalence of hypertension (≥130/80 mm Hg) was 4.2%. However, the prevalence for NHB (6.3%) and Mexican American (4.9%) children was higher than among NHW children (3.0%) (26). According to Lopez et al, mortality rates resulting from congenital heart disease significantly declined during 1999–2017 among all races/ethnicities, although disparities in mortality rates persisted among NHB children in comparison with NHW children; the highest mortality rate was in infants (<1 year) of all races/ethnicities (30). Improvements in cardiovascular health have not been equally shared by US children aged 12–19 years of varying socioeconomic status. A study using NHANES data reported increases in the prevalence of obesity among only adolescents from low-income (18.1%–21.7%) and middle-income (17.1%–26.0%) households from 1999 to 2014. During 2011–2014, significant disparities in prevalence of obesity were observed between adolescents from low-income and high-income households (21.7% vs 14.6%). Although no significant disparities were observed in children aged 12–19 years in the prevalence of prediabetes, diabetes, hypertension, or hypercholesterolemia, the prevalence of prediabetes and diabetes increased (21.4%–28.0%) among adolescents from low-income households during 1999–2014 (31).

Approximately 42% of children hospitalized with COVID-19 during March 1 through July 25, 2020, had 1 or more underlying medical conditions (4). The most prevalent conditions among these children were obesity (37.8%) and chronic lung disease, including asthma (18.0%). For hospitalized children aged 5–17 years, Hispanic (42.3%) and NHB (32.4%) children had a higher prevalence of underlying conditions compared with NHW children (14.1%); Hispanic (47.2%) and NHB (31.8%) children also had higher hospitalization rates than NHW children (12.6%) (4).

The families of children experiencing systemic disadvantage likely share similar COVID-associated health risks and, therefore, may be more likely to be hospitalized or die if they contract COVID-19 (2,32). As of November 30, 2020, compared with NHW individuals, hospitalization rate ratios were 4 times higher among non-Hispanic American Indian or Alaska Native people and Hispanic or Latino people, and 3.7 times higher among NHB or African American people (32). Likewise, deaths were 2.8 times higher for NHB or African American people and Hispanic or Latino people, and 2.6 times higher for non-Hispanic American Indian or Alaska Native people compared with NHW people (32). Family and household members may be at increased risk of exposure to COVID-19 through their occupation (33). Parents then play an important role in ensuring strict adherence to established mitigation measures by everyone in the household (34).

Inequities in Social Determinants of Health

Racial or ethnic minority populations are more likely to experience lower socioeconomic status, live in crowded housing, and possibly be employed in occupations that require in-person work (2). Furthermore, access to health care may be limited, including obtaining testing and care for COVID-19 (2). Compared with NHW (26%) and Asian/Pacific Islander children (25%), a larger proportion of NHB (58%), American Indian (56%), and Hispanic (53%) children younger than 18 years lived in families with incomes less than 200% of the federal poverty level in 2019 (35). Compared with NHW (21%) and Asian/Pacific Islander children (21%), a larger proportion of NHB (41%), American Indian (44%), and Hispanic (31%) children's parents lack secure employment (35). In addition, Hispanic and NHB children, regardless of their families' income, are more likely than NHW or Asian children to attend schools with a high proportion of students from families with incomes below the federal poverty level (36).

School districts that serve a high proportion of students who are from racial and ethnic minority populations and students who are from families with lower incomes receive less state and local funding than schools that serve a lower proportion of these groups (37). School funding determines the availability of student supports, classroom sizes, and a myriad of other factors that can affect student learning (37). Under-resourced schools may be unable to sufficiently address students' academic, social, emotional, and mental health needs that were exacerbated by the COVID-19 pandemic without support from community institutions and resources, including public health. However, in light of new federal funding through the American Rescue Plan (38), these school districts have a new opportunity to invest in meaningful and productive partnerships.

In addition to the potential for overcoming educational inequities, promotion of resilience may prevent or ameliorate the impacts of social adversity on children. Evidence suggests that specific individual (eg, cognitive skills, emotion regulation, self-esteem), relational (eg, relationships with caregivers), and school factors (eg, academic engagement) are associated with resilience (39). Factors that promote resilience can be considered at multiple levels (eg, individual, family, environmental) and are complimentary to public health efforts (40).

Community-Based Approaches to Reducing COVID-19 Disparities

Understanding the social context of populations with high rates of COVID-19 infection and severe illness is critical to the development, implementation, and evaluation of public health prevention strategies. Although structural long-term solutions to eliminating racial and ethnic health disparities are optimal and preferred (41), evidence suggests that immediate relief and support during the COVID-19 pandemic can be achieved when local public health departments, school leaders, and community partners join forces. For example, the Coordinated Approach to Child Health: Curriculum & Training (CATCH) program consists of comprehensive and coordinated programs, policies, and services that involve partnerships between families, schools, and the community (42). This school health program focuses on coordinating the efforts of teachers, school staff, and the community to promote healthy behaviors to prevent childhood obesity. Through this approach, programs had greater impact in reducing overweight and obesity when schools worked with community-based partners (42). Using a coordinated approach can impact the way communities conceptualize and address problems and can enhance implementation of strategies (8). This approach may help address the unique challenges some children face throughout the pandemic and support transitions into early pandemic recovery and beyond.

Another way to inform focused prevention strategies is for school districts to develop plans that can be tailored at the individual school level to address gaps in learning and well-being for the students. According to a study by researchers at Johns Hopkins University, most state and territorial boards of education (89%, 48 of 54) have individual plans with provisions to narrow gaps in learning and well-being that may have been exacerbated by school closures for children experiencing poverty and systemic disadvantage (43). Some of these provisions include providing access to digital technologies and corresponding training and support for students and parents; special virtual instructional support (eg, tutoring); prioritization of children experiencing disadvantage for in-class instruction; and accommodation of schedule-related or childcare needs of parents with lower income, people of color, or essential workers. Because states and school districts may have implemented their reopening plans differently, partnerships and collaboration with public health departments and community-based organizations could help with monitoring the execution and reach of those plans as well as assessing critical needs to ensure that equity considerations are implemented. Examining these provisions can inform models and standards to use during the COVID-19 pandemic and for emergency preparedness planning.

Plans should be comprehensive and consider disparities in conditions that could affect educational achievement, including mental health and emotional well-being, within the context of the COVID-19 pandemic. For example, compared with 2019, the proportion of mental health–related visits for children aged 5–11 and 12–17 years increased approximately 24% and 31%, respectively; these increases began in April 2020, corresponding to the time in which many schools were required to close (44). Younger adults (aged 18–24 y), Hispanic people, NHB people, essential workers, and unpaid caregivers for adults reported having experienced disproportionately more adverse mental health outcomes (45).

Zimmerman et al found what they describe as "nuanced contextual covariables in our society that provide a fuller back story" to the complex association between educational attainment and health outcomes (46). Namely, they identified social skills, emotional dysregulation, trauma, abuse, and neglect, among other variables that should be addressed when the goal is to increase educational attainment. Moreover, Hahn and Truman argue that another essential element in the pathway from educational attainment to health outcomes is the "psychosocial environment," which includes sense of control (eg, work-related factors, health-related behaviors, stress), social standing (social and economic resources, stress), and social support (social and economic resources, health behaviors, family stability, stress) (10). If these variables require attention absent a global pandemic, then they cannot be ignored during this public health crisis. Partnerships can facilitate obtaining resources to promote coping and resilience, reduce health and mental health disparities, and expand access to services to support children's and teens' mental health. For example, schools could help link children and their families to community health centers for affordable mental health support services.

Implementing Strategies to Advance Health Equity Through Partnerships

Community-based public and private sector partnerships are a cornerstone of community health promotion, chronic disease prevention, and a range of health equity initiatives. In addressing COVID-19 disparities and consequent social and health inequities, we borrow from the evidence base and experience of other public health interventions. Dicent Taillepierre and colleagues identified several elements in program design that enhance health equity, including consideration of sociodemographic characteristics, understanding the evidence base for reducing health disparities, leveraging multisectoral collaboration, using clustered interventions, engaging communities, and conducting rigorous planning and evaluation (47). Considering these elements and other experiences that support the benefit of community-based partnerships, we propose immediate actions that can be taken to respond to the pandemic, as well as to establish and track outcomes (34,47).

We propose 4 evidence-based approaches to form community-based partnerships, including initial collective work, outcome-based activities, and communication efforts, that collaborators can use to improve health equity among students from racial and ethnic minority groups (Table 2). First, education departments should identify organizations with the mission and expertise to support tailored efforts to ameliorate education inequities among children and teens who are experiencing systemic disadvantage and falling behind academically. Multiple sectors and community actors such as clergy and faith-based organizations, YMCA, YWCA, Boys & Girls Clubs of America, Head Start programs, federally qualified community health centers, and parent–teacher associations can be effective community-based partners to protect students and support access to equitable education (Table 2).

Relevant community partners can supplement available resources and sponsor critical activities to meet students' unique needs (48). Participating community-based organizations should be aware of the characteristics of a community, including language, race, ethnicity, countries of origin, and other factors that could affect health status, access to health care, and the provision of culturally and linguistically responsive prevention messages (52).

Second, to facilitate successful collaborations, initial collective work by partners is needed to define the problem and create a shared vision to achieve specific outcomes. Assessments to inform policy, systems, and environmental change are needed. These assessments can include public health data describing the impact of COVID-19 in the community of interest, particularly among children and teens enrolled in school; school system equity plans to mitigate exposure and transmission of COVID-19; and reviews of the school system's digital learning capacities. Place-based approaches can align community members, businesses, institutions, and others in a collaborative and participatory process to address health and contextual factors influencing the social well-being of children within a defined community (49). For example, these efforts planned with community members offer an opportunity to strategically assess and monitor trends in population health status and the needs and assets of a community.

Third, it is important for partners to take the lead or facilitate activities that focus on outcomes they have the capacity to achieve. For example, the Boys & Girls Club of America can provide tutoring services and other extra-curricular activities to minimize academic delays and poor performance on standardized tests. Later, rigorous program evaluations can document the effectiveness of these strategies post-pandemic (50).

Finally, communication is one of the core components for promoting and improving public health (51). Ongoing communication between schools, parents, and community-based organizations is essential. Particularly, a commitment to transparency is needed so that parents and the larger community are kept apprised of partnership efforts and informed when outcomes are on track. Partners can leverage various media outlets, including social media, to disseminate tailored prevention messages as well as connect students and parents to health care services. For example, existing digital platforms can be used for tutoring small groups or individual students. Telemedicine, including telehealth technologies, can be used to provide counseling to families about coping with stress. Although these evidence-based approaches are not new to public health, there are new opportunities to scale these approaches for greater reach and impact in communities disproportionately impacted by COVID-19.

Because of their critical role for all children and the disproportionate impact that school closures can have on those students experiencing systemic disadvantage, it is crucial that K-12 schools open safely and remain open for in-person learning (53). Community engagement and partnerships are foundational to public health and its core value of social justice (54). Partnerships can help facilitate delivery of quality virtual learning, policies, and systems changes that keep classrooms safe for in-person learning, and they can facilitate communication strategies that ensure the dissemination of scientifically sound public health prevention strategies that build community confidence in the safe reopening of schools. In addition to facilitating and sustaining in-person learning, partnerships can help prevent further exacerbation of educational inequities, support parents' full return to work and more everyday activities in different settings, and fuel economic recovery. Because the needs, risk factors, assets, and resources vary across communities, local public health departments and school boards of education should work with local organizations that can help provide tailored support. Moreover, local organizations are more likely to be perceived as trustworthy and credible by communities (52). Recent federal funding opportunities can help facilitate and sustain these partnerships. The American Rescue Plan Elementary and Secondary School Emergency Relief Fund, with funds totaling $122 billion, supports efforts by states, Puerto Rico, and the District of Columbia to reopen K-12 schools safely and to equitably expand opportunity for students experiencing disadvantage (38). These funds can be used to implement strategies, including evidence-based interventions, to meet the social, emotional, mental health, and academic needs of students. Furthermore, the Centers for Disease Control and Prevention (CDC) is providing $10 billion to states to support COVID-19 screening and testing for K-12 teachers, staff, and students (38). Partnerships can leverage these funding opportunities and aid the implementation of rapid response efforts needed to facilitate learning.

The COVID-19 pandemic has not only exposed longstanding health and social inequities in the US but also revitalized efforts to achieve authentic community engagement in promoting mitigation efforts to end the pandemic. Partnerships between local health departments, local school systems, and other public and private organizations can offer immediate support to these children and teens during the COVID-19 pandemic and over the long term as we move into the recovery phase.

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Tables

Table 1. Estimates of Selected Chronic Conditions Among Children and Teenagers, by Race/Ethnicity, United States

Chronic Condition (Age, y)	Estimate
Current asthma (<18)[a]	**Age-Adjusted Prevalence, % (SE)**
White, non-Hispanic	5.6 (0.40)
Black, non-Hispanic	14.2 (1.52)
Hispanic	8.0 (0.85)
Mexican American	7.0 (1.01)
Obesity (2-19)[b]	**Prevalence, % (SE)**
White, non-Hispanic	16.1 (1.5)
Black, non-Hispanic	24.2 (2.0)
Hispanic	25.6 (1.9)
Mexican American	26.9 (2.5)
Asian, non-Hispanic	8.7 (1.1)
Type 2 diabetes (10–19)[c]	**Incidence Rate Per 100,000**
White, non-Hispanic	4.5
Black, non-Hispanic	37.8
Hispanic	20.9
American Indian	32.8
Asian/Pacific Islander	11.9
Hypertension (12–19)[d]	**Prevalence, % (95% CI)**
White, non-Hispanic	2.97 (1.73–4.74)
Black, non-Hispanic	6.27 (3.84–9.59)
Mexican American	4.94 (3.01–7.59)
Other	5.22 (3.65–7.20)

[a] 2018 data from the National Health Interview Survey (23).
[b] 2017–2018 data from the National Health and Nutrition Examination Survey (24).
[c] 2014–2015 data from the SEARCH for Diabetes in Youth Study (25).
[d] 2013–2016 data from the National Health and Nutrition Examination Survey (26).

Table 2. Summary of Potential Community-Based Strategies to Address Racial and Ethnic Disparities in COVID-19 Outcomes Among Children and Teens

Partnerships: public health and boards of education work together with cross-sector partners[a]
• Identify and engage community partners with interest in or established relations working with K-12 schools serving minority populations • Engage women's, parents', and adolescent and youth groups to ensure there is effective peer outreach • Leverage trusted community resources, influencers, and other community leaders (eg, faith-based organizations) and businesses (eg, Adopt a School Program) • Facilitate innovative partnerships to include auxiliary services (eg, Head Start programs, YMCA, YWCA, Boys and Girls Club of America, cooperative extension services) • Include other governmental (eg, local parks and recreations departments) and nongovernmental organizations (eg, Food Bank programs) • Develop partnerships with a priority based on equity and removing systemic barriers of students experiencing disadvantage • Incorporate community oversight of activities to ensure their voice is represented and to build trust in the community • Gather, share, and use data (race, ethnicity, language, location, social factors) to focus efforts
Initial collective work: partnerships collectively define the problem and create a shared vision to solve it[b]
• Plan community-based support for learning, families, and whole child development • Conduct rapid assessment of the digital literacy capacity for students and teachers • Conduct rapid assessment of barriers to virtual learning • Identify resources needed by students to receive optimal virtual learning • Conduct rapid assessment of barriers to safe (return to) in-person learning • Collaborate to identify and fill the gaps in mitigation efforts in schools • Support under-resourced schools in planning to mitigate exposure and transmission of COVID-19, as well as testing and contact tracing • Identify other health-related needs
Outcomes-based activities: partnership leads and/or facilitates activities with a focus on outcomes[c]
• Address barriers to optimal virtual learning (eg, limited access to technology and eLearning materials, experience, instructor issues) • Quantify tutoring and mentoring needs and invest in rapid, remote support (eg, local volunteers tutor remotely) • Address barriers to in-person learning (eg, implementation of mitigation strategies in K-12 schools, safe transportation) • Pilot test and evaluate mitigation strategies among K-12 schools that serve a high proportion of students from racial and ethnic minority populations or from families with low incomes or limited resources • Support the capacity to identify and respond to signs of stress, isolation, or poor mental health in students • Protect students from abuse/violence • Improve adolescents' health literacy related to the COVID-19 pandemic and general health • Identify and facilitate afterschool and expanded learning opportunities
Communications: leverage existing and innovative approaches using focused messages[d]
• Use existing digital platforms for small group or individual tele-tutoring (eg, 2 times per week) to strengthen learning, social engagement, and cultural affirmation • Schools identify and address inclusive delivery mechanisms for students with disabilities who are learning remotely • Develop and deliver accurate and culturally responsive information about COVID-19 and how students can protect themselves (eg, ensure language access, broad distribution through trusted sources, and relevance to students from racial or ethnic minorities) • Provide teleconsultations/telecounseling and educational sessions (webinars) to families about coping with stress and providing information on positive parenting • Provide resources and links to psychosocial and mental health support services (eg, community health centers and other health-related social needs) • Implement messages to increase awareness and resources for children and teens experiencing abuse/violence • Provide outreach activities and culturally tailored prevention messages/campaigns focused on COVID-19 • Provide outreach activities and culturally tailored prevention messages focused on preventing chronic diseases (eg, healthy eating, exercise)

[a] Hann NE (48).
[b] Dankwa-Mullan I and Perez-Stable EJ (49).
[c] Porterfield DS et al (50).
[d] Bernhardt JM (51).

PREVENTING CHRONIC DISEASE
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TOOLS FOR PUBLIC HEALTH PRACTICE

A Framework for Mobilizing Health Care to Respond to the Community Within the COVID-19 Pandemic

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PEER REVIEWED

Summary

What is already known on this topic?

The COVID-19 pandemic is a pressing public health challenge. Interventions to reduce disparities in disease such as COVID-19 between racial and ethnic populations are most effective when they are multifactorial and community-based.

What is added by this report?

We hypothesize that a framework of delivering health information through trusted community leaders may partially mitigate the deleterious effects of government mistrust and could increase COVID-19 testing.

What are the implications for public health practice?

Although specifically directed toward the COVID-19 crisis, this particular framework could be useful in addressing the disproportionate share of chronic and other diseases among racial or ethnic minority populations and other disproportionately affected populations.

Abstract

Cultural mistrust of government with regard to health issues has pressed the need to engage trusted community leaders with influence and reach in disproportionately affected communities to ensure that essential public health activities related to COVID-19 occur among populations experiencing disproportionate impact from the pandemic. In April of 2020, a Georgia-based integrated academic health care system created a Community Outreach and Health Disparities Collaborative to unite trusted community leaders from faith-based, civic, and health-sector organizations to work with the health system and Emory University to develop tailored approaches and mobilize support within the context of the communities' cultural and individual needs to reduce the burden of COVID-19. We describe the framework used to join health care and academic collaborators with community partners to mobilize efforts to address the disproportionate impact of COVID-19 on racial, ethnic, and socioeconomic minority groups. The framework outlines a series of steps taken that led to a community-driven collaboration designed to engage local influential community leaders as partners in improving access to care for disproportionately affected communities, collaborations that could be replicated by other large health care systems. This framework can also be applied to other chronic diseases or future public health emergencies to improve communication, education, and health care access for communities experiencing disproportionate impact.

Problem

The COVID-19 pandemic has amplified health care disparities, differences in social determinants of health, and cultural mistrust that have historically and negatively affected racial and ethnic minority communities and their access to equitable health care (1). With the spread of COVID-19 in our communities, we are acutely aware that Black, Hispanic/Latino, and rural communities are disproportionately affected by the virus. Our proposed work is based in Georgia, one of the early COVID-19 epicenters in the United States that has high rates of racial and ethnic inequality in income, housing, and disease burden (2–4), yet was also the first state to "re-open" despite public health advice to the contrary. One study found that although only 32% of residents in metropolitan Atlanta are Black, 79% of COVID-19 patients hospitalized at 6 metropolitan Atlanta hospitals from March to April 2020 were Black, and diabetes, hypertension, chronic kidney disease, obesity, and smoking were all more prevalent among hospitalized patients than among nonhospitalized patients (5). The COVID-19 Health Equity Interactive Dashboard, sponsored by our academic collaborators at

Emory University, also highlighted the substantial health care disparities among COVID-19 patients in Georgia with corresponding effects on racial and ethnic minority populations (6).

Structural racism refers to manners in which societies foster racial discrimination in areas such as housing, employment, and health care. Examples of how social determinants of health affect racial minority communities during this pandemic include the inability for many to effectively socially distance in multigenerational households, the inability for frontline employees to work from home, the lack of health care insurance, and the lack of access to COVID-19 testing sites (7). Evidence of a positive association of stay-at-home orders with lower state-level COVID-19 case rates exists, and states with larger Black populations have higher rates of COVID-19 than states with smaller Black populations, which highlights the importance of these stay-at-home orders in addressing racial disparities in COVID-19 rates of infection (8).

There is a deep-rooted history of cultural mistrust in the United States that stems from numerous atrocities to racial minority communities, such as the well-known US Public Health Service syphilis study performed at Tuskegee and not so well-known incidents, including gynecologic procedures on enslaved Black women and grave-robbing in slave quarters with resultant unauthorized autopsies (9,10). Fear of deportation by the US Immigration and Customs Enforcement is also a consideration in Hispanic/Latino communities (1). This mistrust not only serves as a barrier for accessing health care but also in the consideration of enrollment in clinical trials.

Disparities in health care access and patient outcomes are associated with factors such as race, gender identity, sexual orientation, primary language, and socioeconomic status. The structural and cultural divide between the academic health care systems and underrepresented minority communities must be bridged by trusted sources that, in many cases, are community organizations. Community organizations that are faith-based, nonprofit, civic, social support–related, or education-focused serve as the foundation of community engagement. Because many Black people and people in other underrepresented minority groups are often not included in health decision making and policy development, we developed an integrated academic health care system and community coalition to address complex health challenges and stretch and test the capacity of traditional health systems to reduce the burden of COVID-19. This article describes the development of this coalition.

Call to Action

Coalition recruitment

The chair of the Emory Healthcare board of trustees charged 2 health care board members to lead a group of clinicians, researchers, educators, and health advocates to mitigate disparities and determine how the health care system could play a role in reducing the disproportionate burden of COVID-19. This charge led to the development of the Community Outreach and Health Disparities Collaborative (Table 1). This team comprised health care professionals and leaders from the disciplines of pharmacy, public health, nursing, medicine, and health care operations. A major initiative of the team was to unite trusted community leaders from faith-based, nonprofit, education, civic, and health sector organizations to work with the health care system and university to develop tailored approaches and mobilize support within the context of the communities' cultural and individual needs to reduce the burden of COVID-19. A steering committee was established and created 4 work groups to achieve the goals of the team: 1) messaging — aimed at developing targeted message content and engaging community representatives, such as social influencers and academic experts, to provide education and promote best practices for COVID-19 prevention and intervention; 2) research — focused on advancing new knowledge and scholarship in health disparities specific to COVID-19; 3) data — integrates data sources to analyze and identify populations experiencing disproportionate impact in order to direct resources and target interventions; and 4) community partnerships — connecting with trusted community leaders (faith-based, civic and other organizations, businesses, and others) for bidirectional learning, feedback, and collaborative interventions.

The president of the health system was tapped as the executive sponsor of the collaborative to ensure connection to the health system's COVID-19 response efforts and accountability to the directive of the board of trustees. Weekly reports were made to the collaborative's COVID-19 Incident Command Center, and quarterly reports were made to the board. The established steering committee comprised the board of trustees' cochairs, senior university and health system leaders, innovation and data experts, public health department representatives, and a leader of a local medical association for Black physicians. They met weekly to develop the strategic work plan, engage participants, and evaluate sources of funding to support intervention efforts. After 3 months, the steering committee added a health system director of community engagement and began to field requests for COVID-19 program support partnerships. The steering committee provided the key benefit of centralized leadership, decision making, triage of requests for community partnerships, and a vector of escalation of barriers to the Incident Command Center for mitigation.

The messaging work group comprised university and health care educators with marketing and communication system resources. This group developed segmented marketing strategies to leverage messengers representative of the community as a trusted voice to educate and inform communities of focus and community leaders on COVID-19 and prevention strategies. A speaker's bureau was established to harness and promote these voices to the community. Personal and organizational print and social media platforms were leveraged to produce informative ads and videos. Virtual educational webinars were designed and conducted in partnership with community organizations for further outreach. A targeted messaging campaign leveraging a text messaging opt-in/out platform directed recipients to symptom evaluation tools for COVID-19 and to testing sites and provided additional preventive health reminders. Outputs of this work group are measured by number of community-representative messengers, impact of each media platform, and the attendance of educational sessions.

The data group comprised innovation, health system operations, and research experts working with state and local departments of health to analyze data to establish a strategy to identify hot spots and blind spots of COVID-19 disparities. Partnerships and data agreements to coalesce data streams to produce results are key outputs for the work group to design a dashboard for ongoing monitoring and analysis. This information can be leveraged to design a tailored intervention based on the needs of the identified population of focus, and it was used to develop the text messaging campaign for targeted recipients. Dashboards continue to raise awareness regarding COVID-19 disparities and can be monitored for the closure of the identified disparity gap.

Shared learning of the experiences of mobilizing health care to respond to the community during the pandemic and health disparities research was important and required its own goals to ensure accountability to the academic mission. Research outputs can be measured by the number of publications and grant-supported projects addressing these specific topics.

The final component of the framework required engaging trusted community partners to ensure wider usage of COVID-19 programs, testing, treatment, vaccination, and interventions among economically or socially marginalized populations experiencing disadvantage. We leveraged a parallel effort to establish a community partners advisory board for the work of the collaborative and aid community-based intervention research. A customized email account was created to manage communication to potential community partners. The members of each work group reached out to their personal and professional networks, which represent a diverse group associated with communities experiencing disadvantage (Figure). Colleagues from academic, health care, and community settings were contacted and given a call to action memorandum informing them of the need to support communities most disproportionately affected by COVID-19 and requesting their immediate support. The memorandum outlined the context of the problem and potential solutions. Memo excerpt:

> Emory Healthcare has formed a COVID-19 task force to address the health disparities that exist in vulnerable and underserved communities. As part of this task force, the research collaborative is pursuing grant opportunities. We are proposing to rapidly identify hot spots in vulnerable communities in the state of Georgia, to facilitate the connection of these communities to local prevention and treatment resources. We will do this through deployment of our existing community partnerships, our COVID-19 Symptom Check tool, and by delivery of a multi-level intervention targeted at leaders and individual community members. Our approach will be iterative and use community-based participatory implementation research methods. We envision this effort evolving into a national program for rapid identification of COVID-19 hot spots. Currently, we are seeking community partners and advisory board members that are interested in supporting our proposed efforts.

Figure. Outreach collaborative key representatives in a framework for mobilizing health care to respond to the community within the COVID-19 pandemic. Abbreviation: CEO, chief executive officer.

Coalition response

Within 5 days of the call to action memorandum being sent, we received commitments from 36 individuals statewide. Support was received from individuals recovered from COVID-19 (n = 4) and representatives from academic centers (n = 6), health care organizations (n = 6), business and community groups (n = 15), and civic and education agencies (n = 5). These supporters became our community partners. All community partners were asked informally to commit to a 2-year period of involvement. A multiprong virtual communication strategy was used to engage community partners, given social distancing guidelines, including 1) advisory meetings; 2) developing an organizational structure that gives community partners equal decision-making abilities and virtual attendance at research meetings; and 3) fostering bidirectional learning opportunities through virtual chat platforms. Surveys were then administered to help identify themes of community concerns and barriers, which were used to inform discussion and set common goals.

Individuals who recovered from COVID-19 were asked to provide details of their journey to inform the work and direction of the group. An engagement survey was distributed to partners for feedback on strategies and interventions that require support to mitigate disparities in COVID-19 communities of focus (Box 1). We also surveyed key informants and community partners (Box 2). We were interested in learning their concerns, ideas, and perspective as the team worked toward designing and implementing methods to effectively reach communities disproportionately affected by COVID-19 and other chronic illnesses. Engagement and time commitment preference were also assessed to inform the best way to communicate with the community partners advisory board.

Box 1. Inteview Questions for Key Informants

What was your personal experience with COVID-19?

How did this affect your interactions with family and friends?

Where did you have your COVID-19 testing performed? Was there information within your community to help guide you through the process?

Did you have personal experiences during your COVID-19 illness that you felt were different because you are from a minority racial group?

Do you know where/how you contracted COVID-19?

What resources, if any, did you use in your community to obtain more information about COVID-19?

What do you think can be done differently to help underserved and minority populations in Georgia who have been hard hit by COVID-19?

What resources do you think would have been the most helpful for you (or anyone else) diagnosed with COVID-19?

What else would you like to share?

Box 2. Survey Questions for Community Partners

Description of the community you represent.

What are the top 3 concerns you have relative to the impact of COVID-19 in the communities you represent?

What do you consider to be the greatest barrier to COVID-19 testing in your community?

What do you consider to be the 3 greatest barriers to masking and other COVID-19 disease prevention efforts in your community?

What messages regarding the COVID-19 pandemic are most important for your community to hear?

Who are the most effective leaders/community partners to deliver trusted messages to the communities you represent?

Would your organization be interested in partnering with Emory to provide free consultations/educational seminars regarding COVID-19? If yes, what kind of consultation would be most helpful?

How would you like to be involved in the Emory Collaborative effort?

Would you be interested in having a meeting (videoconference) with the collaborative and other community partners to further discuss initiatives?

Twenty-six community partners responded to the survey (response rate, 72%). More than half (65%, n = 17) of the partners were interested in partnering with us to provide free consultations or educational seminars regarding COVID-19. Community partners shared a desire to have access to health care consultants for education on COVID-19–related topics. In response, we formed a speaker's bureau that could be shared with community partners where they could select speaker packages for sponsored events. We also plan to host several education forums that will allow community partners to network. Topics for future forums include risks and benefits of returning children to school in the state of COVID-19 spread, how to engage with others who will not follow the COVID-19 spread prevention recommendations, the impact of physical distancing on social isolation experienced during COVID-19, COVID-19 "Truth and Lies" addressing misconceptions of who is affected by COVID-19, and promotion of our new normal in COVID-19 times — what can we do safely.

Additionally, 58% (n = 15) of the community partners expressed that COVID-19 testing and access to health care were major concerns for their communities, with testing availability being the greatest barrier to testing. A few partners (12%, n = 3) expressed fear of government documentation as a barrier to testing. After the team reviewed the survey results, 2 discussion sessions were held with community partners to further discuss mobilization and next steps. The following themes emerged from these discussions: aging community, connecting the community, access to health care, patient/family experience, staying connected to health care providers during the pandemic, and COVID-19 vaccine trials. These emerging themes will inform the future directions of community outreach efforts.

Interested community, academic, and health care partners will be added on a rolling basis. To maintain the level of engagement, routine meetings (in-person or virtual) are being held to identify problems and strategize solutions to improve outcomes for communities disproportionately affected by chronic disease. The community partner advisory board also has direct access to medical experts through the established speaker's bureau. We are frequently communicating with the group through quarterly newsletters to share updates and emails for time-sensitive information.

Strengths and Weaknesses

The key strength of our framework for mobilizing health care through community engagement lies within the unique nature of the multidisciplinary partnerships that have the capacity to reach disproportionally affected communities or those with longstanding issues of mistrust in the health care system (11–14). Leveraging key influencers and community partners is important in addressing many of the health disparities amplified by the COVID-19 pandemic. People with low literacy (and limited health care literacy) need culturally competent, relevant resources and the ability to give their feedback to a trusted community advisor who can help encourage changes to health behavior. Another strength associated with our community partnership model is that it is low in cost to implement, which makes this a feasible approach for low-resource or rural settings. Lastly, once developed, the partnerships can be leveraged to disseminate information about vaccine development and deployment or be a resource in the event of future public health emergencies.

The limitations associated with this framework are similar to those of other volunteer-based programs. Many community partnerships are created based on previously established relationships with individuals and organizations. Community partners could be lost because of a lack of participation in an ongoing collaboration without financial incentives or simply because of a lack of time because of other commitments. To address these weaknesses, partnerships should capitalize on momentum and develop strategies that will ensure community partners remain continually engaged through frequent meetings and directed action items. It would also be fruitful to have community partners serve in leadership roles within the collaborative to promote shared governance and foster trust with the community.

Implications

This framework for mobilizing health care for community engagement will remain in place beyond the COVID-19 pandemic. The unique nature of these partnerships should be valued and can assist organizations with removing barriers that can hinder community partner and member participation to improve the health status of many groups experiencing disadvantage. Surveys to community members, partners, and groups are critical for assessing their needs to create a purposeful and meaningful agenda to effect change. Connections to the local community will play an increasingly important role as the pandemic continues and can be a way to prevent the spread of misinformation and promote public health best practices. Empowering trusted community leaders is essential to the effective dissemination of a vaccine or information concerning COVID-19 vaccine trials where participation from racially diverse communities remains underrepresented (15). It is important to have appropriate messaging delivered by trusted voices who reflect the community being served.

Having support from the administration of the health care system facilitated the prompt execution of this framework. More specifically, the board of trustees held the collaborative accountable and expected routine reports to ensure that the population of focus received deliverables and resources. We also found that it was meaningful for us to have work groups focusing on messaging and education, data, research, and community partnerships because the output for each group contributed to the goals of another group. We recommend that interested health care organizations adapt this framework to their organizational culture and include these focus areas within their structure to meet their established goals. It is imperative for organizations that have existing collaboratives and efforts addressing health disparities to include key collaborators such as innovators and persons to serve on the front line to engage in the community. In a broader sense, this framework can be used to better prepare economically or socially marginalized communities for future public health emergencies as well as provide insight as the organization looks at the disproportionate share of chronic and other diseases among underrepresented minority and marginalized populations.

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Table

Table 1. Community Outreach and Health Disparities Collaborative Framework for Mobilizing Health Care to Respond to the Community During the COVID-19 Pandemic

Element	Governance	Messaging and Education	Data	Research	Community Partnerships
Goal	• Develop and implement a strategy for the collaborative to address the disproportionate impact of COVID-19 on the health system patient service areas	• Tailor public-facing education engagements and materials for disproportionately impacted communities • Establish a speaker's bureau of messengers that reflect the community served	• Identify COVID-19–impacted community hot spots and blind spots • Develop reporting strategy to guide current and future disparity awareness	• Develop and implement a research platform to publish findings and interventions of the collaborative	• Establish a community partner advisory board for bidirectional learning and feedback
Input	• Members: health system president, board of trustees, senior academic leader, senior health system leader, innovation leader, health system data analytics leader, community leader(s)	• Subject matter experts on health equity, health disparities, infectious diseases, chronic disease, public health, vaccination, community outreach, COVID-19 • Social influencers and marketing expertise for targeted communities	• Public health data, health system data, and research data collaborators • Data streams: symptom, race, ethnicity, age, language, comorbidity, social determinants of health	• Health disparities researchers	• Community partners and leaders
Output	• Steering committee with 4 work groups • Strategic plan • Health system resource support	• Virtual and in-person education events • Messaging campaigns on all platforms — print/radio/social media • Speaker's bureau	• Dashboard illustrating chronic disease, health disparity, and social determinants data • Continuous analysis and recommendation of hot spot and blind spot interventions	• Assess and promote health disparities research • Develop COVID-19 health disparities research questions and shared learning framework	• Advisory meetings • Education events
Metrics	• Steering committee engagement • Work group goals met • Amount of secured funding	• Number of messengers reflecting the community • Impact of messaging campaigns on platforms — print/radio/social media • Attendance of education events	• Improvement of identified health disparity gap	• Number of grant-supported health disparities and COVID-19 projects • Number of published health disparities and COVID-19 projects	• Survey participation • Meeting attendance

PREVENTING CHRONIC DISEASE
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ORIGINAL RESEARCH

Addressing Emotional Wellness During the COVID-19 Pandemic: the Role of *Promotores* in Delivering Integrated Mental Health Care and Social Services

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PEER REVIEWED

Summary

What is already known on the topic?

Mental health needs have been exacerbated by the COVID-19 pandemic. As a result, Latino communities experience disparate rates of stress, depression, and anxiety.

What is addressed by this report?

Few studies explore *promotor*-led mental health interventions as strategies to address service gaps in Latino communities. This article describes a community-based intervention that integrates social services and mental health services.

What are the implications for public health practice?

With ongoing COVID-19 surges and with vaccine distribution underway, a critical need remains to respond with equity. Latino Health Access's Emotional Wellness program emphasizes the importance of delivering mental health care integrated with social services and provides a model to reduce the effect of COVID-19 in socioeconomically disadvantaged communities.

Abstract

Introduction

The disproportionate impact of the COVID-19 pandemic on Latino communities has resulted in greater reports of depression, anxiety, and stress. We present a community-led intervention in Latino communities that integrated social services in mental health service delivery for an equity-based response.

Methods

We used tracking sheets to identify 1,436 unique participants (aged 5–86) enrolled in Latino Health Access's Emotional Wellness program, of whom 346 enrolled in the pre–COVID-19 period (March 2019–February 2020) and 1,090 in the COVID-19 period (March–June 2020). Demographic characteristics and types of services were aggregated to assess monthly trends using Pearson χ^2 tests. Regression models were developed to compare factors associated with referrals in the pre–COVID-19 and COVID-19 periods.

Results

During the pandemic, service volume ($P < .001$) and participant volume ($P < .001$) increased significantly compared with the prepandemic period. Participant characteristics were similar during both periods, the only differences being age distribution, expanded geographic range, and increased male participation during the pandemic. Nonreferred services, such as peer support, increased during the pandemic period. Type of referrals significantly changed from primarily mental health services and disease management in the prepandemic period to affordable housing support, food assistance, and supplemental income.

Conclusion

An effective mental health program in response to the pandemic must incorporate direct mental health services and address social needs that exacerbate mental health risk for Latino communities. This study presents a model of how to integrate both factors by leveraging *promotor*-led programs.

Introduction

Mental health needs of working-class Black and Latino communities have long been insufficiently met in the United States (1). The COVID-19 pandemic has exacerbated mental health needs through unpredictability and uncertainty, physical distancing, social isolation, loss of employment and income, mortality, and social suffering (2). Among US adults surveyed in June 2020, 52.1% of Hispanic adults reported at least 1 adverse mental or behavioral health condition, compared with 37.8% of non-Hispanic White adults. Hispanic adults reported higher prevalence of anxiety or depressive disorder, trauma-related and stressor-related disorder, substance use to cope with stress, and suicidal ideation (3). These disparities in mental health effects reflect the grief, bereavement, and stress related to financial insecurity resulting from the pandemic in Latino communities (4), which along with other racial and ethnic minority communities, have been disproportionately affected by COVID-19 as a result of structural racism (5).

Experts have called for local implementation (6) of community-level mental health interventions and prevention efforts that integrate financial relief and social services, promote social cohesion, and provide culturally and linguistically tailored education on COVID-19 and mental health (2,3). The American Psychological Association has also called for a “reimagining” of the behavioral health system as one that reaches people where they are, recognizes wisdom in each community to solve its own problems, and looks to innovative roles for new mental health practitioners who are firmly rooted in their communities (6,7). Responding to these calls to action, this study investigated the role of *promotores de salud* (community health workers) in providing community-led and integrated mental health care and social services in response to the COVID-19 pandemic in Latino communities of Orange County, California. Our findings may provide a model for integrating equity in mental health interventions during and after the pandemic.

Methods

Emotional Wellness program framework

Latino Health Access’s (LHA’s) *Bienestar Emocional* (Emotional Wellness) program draws on principles of narrative therapy and aligns with human-centered design, which prioritizes participant engagement throughout the lifecycle of the program (8,9). The program was developed by LHA *promotores* in partnership with a marriage and family therapist trained in narrative therapy. Narrative therapy recognizes participants as authors of their own stories, in which we are all participants in each other’s stories (10) and empowers people to write a new story as a process to overcome the inequities and oppressions of the dominant social narrative (11). In this way, narrative therapy can link people with similar stories, joining their voices together in shared purpose to improve their mental and emotional well-being (10). Narrative therapy has demonstrated success in overcoming stigma associated with therapy and social position because it centers the person rather than imposing a hierarchy, with the counselor as expert (11). A unique feature of LHA’s program is that it is facilitated by *promotores* with ongoing training and support provided by a marriage and family therapist.

The multipronged nature of the Emotional Wellness program addresses the spectrum of needs for the community, such that 1) narrative therapy and peer support achieve culturally appropriate mental health services, 2) services to overcome barriers to care address more immediate health and social needs, and 3) community advocacy and leadership are intended to address inequities by shifting the policy environment (Figure 1). Because of the its reach and grounding in human-centered design, along with the trusted relationships *promotores* have with participants as program facilitators and community members facing similar circumstances, the program was the appropriate vehicle for providing integrated care once COVID-19 hit communities in early March 2020. The Emotional Wellness program was enhanced to expand delivery of mental health services while addressing social needs of food and housing insecurity. Through these services, LHA ensured its mental health response was rooted in addressing the social inequities that created the conditions by which COVID-19 devastated working-class racial and ethnic minority communities and exacerbated mental health stressors (12). The Emotional Wellness program adopted a population health approach to address behavioral health needs along a continuum, regardless of whether participants had a mental or emotional health condition, providing a range of services (6). As COVID-19 policies took effect (Figure 1), the Emotional Wellness program was well-positioned to expand to help vulnerable groups meet their immediate mental health and social needs, while continuing to address the structural inequities exacerbated by the pandemic.

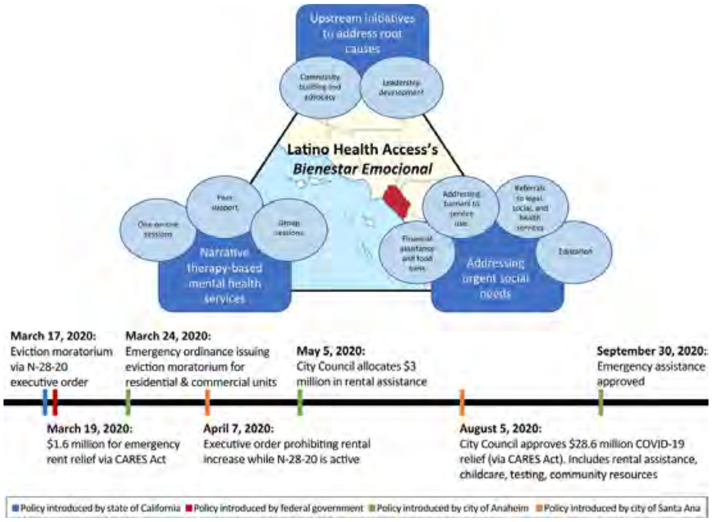

Figure 1. Framework for Latino Health Access's *Bienestar Emocional* (Emotional Wellness) program describing its 3 primary initiatives, their components, and the associated timeline of related events. The program is based in Orange County, California. Abbreviations: CARES, Coronavirus Aid, Relief, and Economic Security Act; N-20-28, executive order issued by Governor Newsom of California that allows local governments to impose temporary limitations on residential and commercial evictions under COVID-19-related financial distress.

Study design

Our observational study used de-identified tracking data collected by LHA over 2 years (March 2019–June 2020). No sampling was conducted, because the full universe of clients was needed to reflect changes in volume of services received (mental health and social services) and referrals provided during the prepandemic and pandemic periods. Because data were stripped of all identifiable information with no linkage to the participants from whom it was originally collected, the study did not constitute human subjects research and therefore did not require internal review board approval.

Study site and participants

LHA, a nonprofit public health organization in Santa Ana, California, partners with Latinx communities in Orange County to advance health equity through a combination of culturally and linguistically concordant direct services and upstream initiatives that address social determinants of health through community-led policy, systems, and environmental change. Programs are facilitated by *promotores*, who are members of the community and thus, have a wealth of local knowledge and expertise, understand the lived experiences of those in the community, and have specialized training in health promotion and community advocacy.

All participants in this study were drawn from LHA's Emotional Wellness program from March–June 2019 and January–June 2020, during which 1,436 unique participants were enrolled. All participants were recruited from Orange County, California, with participants representing 25 of the 34 cities and 50 of the 88 zip codes in the county. Historic data showed that LHA participants were predominantly female (72%), aged 18 or older (71%), Latino (98%), uninsured (46%), foreign born (95%), Santa Ana residents (78%), monolingual Spanish speakers (90%), and earned less than $30,000 annually (85%) (13).

Procedure

Promotores across all LHA programs referred participants to the *Bienestar Emocional* program whom they identified as having experienced or were currently experiencing trauma or domestic violence. Once enrolled, emotional wellness *promotores* conducted an exploratory session to uncover the priority issues for the participant and identify their most pressing social needs. Thereafter, participants engaged in group sessions and one-on-one sessions with a *promotor* by using a curriculum based on principles of narrative therapy. During each session, *promotores* provided a range of interventions, including education (navigating legal, medical, education, penal, or immigration systems), peer support (donations, goal setting, identifying strengths and barriers, moral support, system support), leadership development (advocacy and individual coaching), community building and engagement (group projects, activities, volunteering), addressing barriers to service use (application assistance, childcare, health care access, translation services, transportation arrangements), and referrals to legal, social, and health services. All *promotores* were trained by a marriage and family therapist to facilitate structured sessions through the program curriculum. In addition, *promotores* received training on mental health and community interventions from a bilingual and bicultural therapist.

Once COVID-19 struck, service delivery changed: group sessions convened via video conferencing, and one-on-one sessions were carried out over the telephone. In March 2020, LHA rapidly expanded its referrals to address social needs, with COVID-19 financial relief, nutrition assistance, and affordable housing support. As such, participant volume also increased substantially during the pandemic, because 1) social needs proliferated and 2) *promotores* organized an initial COVID-19 pandemic response by calling current and prior LHA participants to understand their experiences with the pandemic in real time. During these calls, *promotores* provided prevention information, education, and resources as well as presented civic engagement opportunities to address the rising housing crisis, the decennial census, and the 2020 Presidential election with nonpartisan voter engagement messaging.

Data collection and statistical analysis

During one-on-one sessions, data were captured by each *promotor* by using a 12-character unique identifier. Service providers removed all personal information and shared the de-identified data with Ohio State University researchers (K.J.M. and S.N.). Analyses were conducted to compare the effects of the pandemic on provision of services. First, demographic characteristics were compared for the sample of participants in the prepandemic (March 2019–February 2020) and the pandemic (March 2020–June 2020) periods. Demographics included age, ethnicity, sex, and geographic residence.

Second, analyses of services used were conducted at 2 levels, 1) by service volume and type, and 2) by participant. For analyses by participant, service use trends were controlled such that each participant received a maximum of 1 of each service during a particular month. For example, if Participant A had 3 service encounters for peer support and 1 service encounter for education during March, Participant A received 2 services during March: peer support and education. The denominator for participant-based analyses was the number of unique participants in each month. We used independent *t* tests to assess differences in service and participant volume from the prepandemic to pandemic period. The Pearson χ^2 test of independence was used to identify significant differences in demographic characteristics and service use by service type and referral category. Yates's continuity correction was applied when any cell in the contingency table had a frequency less than 10. Significance was established at $\alpha = .05$; 95% CIs were constructed for all proportions. To assess variation across the ten months, an overall *P* value was computed, and a second comparison was computed between prepandemic (March 2019–February 2020) and pandemic (March 2020–June 2020) periods. The third analysis involved the development of logistic regression models to compare predictors of participants receiving referrals in the prepandemic and pandemic periods. Participants with missing data for 1 or more demographic variable(s) were excluded from the regression models, as were participants enrolled during both prepandemic and pandemic periods. We included 722 unique participants in the analysis, of whom 210 were enrolled during the prepandemic period and the remaining 512 during the pandemic period. All analyses were performed by using R Statistical Software, version 3.6.2 (R Foundation for Statistical Computing).

Results

We enrolled 1,436 unique participants in LHA's Emotional Wellness program from March 2019 to June 2020. Of these, 660 participants (46.0%) were excluded from demographic analyses because of missing data, leaving 776 unique participants, 57 of whom were enrolled in the Emotional Wellness program during both the prepandemic and pandemic periods. The magnitude of missing data is largely due to the transition to virtual service delivery and the rapid expansion of the program in response to COVID-19. Of the 776 unique participants, most were Latino (n = 763, 98.3%), female (n = 594, 76.5%), aged 25–44 (n = 400, 51.5%), and from Santa Ana (n = 503, 64.8%) (Table 1). Group differences in sex (increased male participation during the pandemic period, $P < .001$), age (decreased participation among people aged 5–17 [12.8% vs 4.1%, $P < .001$] and increased participation among people aged 45–64 [30.1% vs 37.9%, $P = .03$] during the pandemic period), and geographic residence (decreased participation from Anaheim [20.3% vs 14.3%, $P = .03$] and increased participation from other cities [12.0% vs 22.2%, $P < .001$]) were significant. Groups did not differ by ethnicity (98.1% Latino prepandemic vs 98.6% pandemic, $P = .83$).

Trends in use of services

From prepandemic to pandemic periods, the volume of services ($P < .001$) and participants ($P < .001$) increased significantly (Figure 2). Although the volume of participants was driven, in part, by the *promotores*' COVID-19 outreach, the ratio of services to participants increased, though not significantly, from an average of 4.0 in the prepandemic period to 4.3 in the pandemic period ($P = .54$), meaning each participant received a greater number of services.

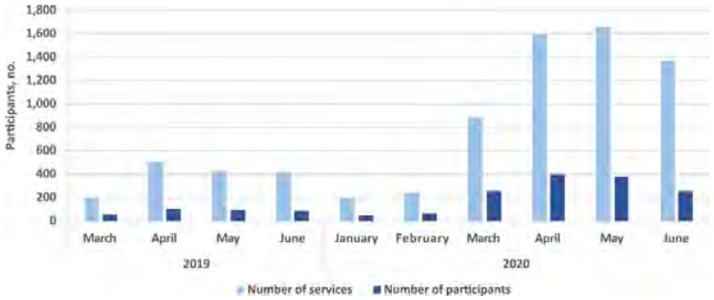

Figure 2. Service use among Latino Health Access's Emotional Wellness participants, showing trends in volume of services and participants during 10 months (March 2019–June 2020). The ratio of services to participants increased from an average of 4.0 in the pre-COVID-19 period to an average of 4.3 in the COVID-19 period ($P = .54$). Significance was assessed by using an independent *t* test.

Trends in referrals varied significantly in 8 of the 9 service categories in both periods (Table 2).When the COVID-19 pandemic struck in full force in March 2020, a significant uptick in referrals occurred for affordable housing ($P < .001$), financial assistance ($P < .001$), and food and nutrition assistance ($P < .001$). Paradoxically, referrals to mental health services declined steeply ($P < .001$) as did referrals for health education and disease management ($P < .001$) from the prepandemic to pandemic period.

Regression models

Results from logistic regression analysis identified factors associated with the receipt of referrals (Model 1), receipt of referrals for mental health services (Model 2), and receipt of referrals to address social needs (Model 3) (Table 3). During the prepandemic period, 179 (85.2%) received 1 or more referrals; 104 (58.1%) received a referral for mental health services. In March 2020, 475 (92.8%) received 1 or more referrals, of which 20 (4.2%) were for mental health services, and 416 (87.6%) to address social needs. Of those receiving a referral for mental health services, 13 (65.0%) received referrals to address both mental health and social needs.

During both prepandemic and pandemic periods, participants who resided outside of Santa Ana were significantly less likely to receive a referral (odds ratio [OR] = −1.06 during prepandemic, $P = .001$ vs −1.59 pandemic, $P = .004$). During the prepandemic period, participants receiving 1 to 3 services from LHA were significantly less likely than those not receiving services from LHA to receive a referral for mental health services (OR = −1.91, $P < .001$). Although still significant, the OR declined during the pandemic period (−1.17, $P = .02$), meaning the likelihood of participants not receiving mental health services decreased.

Discussion

Our study aimed to understand the ways in which *promotores* incorporated equity in a COVID-19 community mental health intervention in the Latino communities of Orange County, California. An equity response prioritizes the populations that are most affected by health disparities and engages them in developing strategies to address both the immediate needs and root causes of these disparities. Our intervention leveraged principles of narrative therapy, integrated social services that addressed needs created by structural inequities, and engaged participants in upstream initiatives to address not only gaps in services but the conditions that underlie these gaps. Although prior mental health initiatives sought to improve cultural competency of interventions (7,14), the intervention presented herein was unique in that it incorporated social services as a strategy to build equity in the delivery of community-driven emotional wellness services (15). This integration drew on human-centered design by addressing the community's social realities directly and centering the experiences of the communities it intended to affect.

Data from our study provide evidence of the association between social needs and mental health needs, because the pandemic period marked a rapid increase in the receipt of in-house mental health and social services. Increases in the volume of services and participants were likely the result of social and economic precarity: reduced work hours and unemployment (and thus, loss of income, food insecurity, and housing instability) during the shelter-in-place period and subsequent business closures. However, mental health and disease management referrals sharply declined as social service referrals increased. Before the pandemic, LHA provided programming in diabetes self-management, obesity prevention, and chronic pain management (16), all of which were *promotor*-led with group and individual meetings. Like mental health needs, disease management needs did not disappear during the pandemic, but because of the economic impact of COVID-19 on Latino communities, it became pressing to provide the referrals and additional services linked to the entrenched social determinants of health that resulted in greater social needs for vulnerable populations (12,17). Therefore, an equitable response to mental health during the pandemic had to, at a minimum, also account for the social needs and heightened stress that affected these communities. An approach that only focuses on adapting mental health interventions for Latino communities may fail without a more integrated approach to care that accounts for social needs. Furthermore, data from our study also suggests that housing, financial assistance, and food are among the most important social needs in the rise of the pandemic, and all 3 of these have been associated with mental health and stability (4,18). In many cases, financial strain — and the resulting poverty, increased exposure to violence, food insecurity, and reduced access to social safety nets — is the fundamental cause of mental health issues (18–20).

LHA Emotional Wellness participants were predominantly from immigrant backgrounds, and a high proportion were uninsured, which may have contributed directly to their reliance on community-based organizations such as LHA for critical mental health and social services for which they may have been ineligible through mainstream systems. At the same time, it may also have been these characteristics that drove a disproportionate need among these participants, in comparison to nonimmigrant Latino participants or those insured either through private insurance or Medicaid. Nonetheless, because the *promotor* model relies on a workforce with local knowledge and expertise, the model can be generalizable to other communities and has already been tested as a model for health education, health promotion, and programmatic interventions to address health outcomes in other ethnic communities in the United States and globally (21,22). Our study advances empirical knowledge on *promotor*-facilitated mental health programming by 1) providing understanding of community-based mental health interventions during the COVID-19 pandemic and 2) describing how leveraging a model built on strong community trust can be an effective vehicle in providing integrated care for mental health and social services. Because traditional health systems have proven less than effective in addressing the community spread of COVID-19 (23), our study showed how *promotor*-led interventions could rapidly address inequities arising from COVID-

19 and associated policies, meet social needs, and reduce social isolation, all while mobilizing the community to advocate against racist policies related to housing, employment, and access to social services. LHA's Emotional Wellness model illustrates how long-term engagement with a community is needed to effectively apply principles of human-centered design in health and social service delivery models to advance equity. As the role of social determinants of health in creating inequalities has become clear during the COVID-19 pandemic (24), many health systems have sought solutions, such as referral systems (25) or payment models (26), to screen patients and link them to services in the community. Though these have been effective in increasing referral rates, the acceptability of these services and their health effects has not been well documented. Because LHA is present in the community, it has helped shape programs proposed by health systems and public health and academic centers, establishing its unique value as part of the COVID-19 response.

Our study has several limitations. We relied on participant tracking data that were collected virtually during the pandemic period, resulting in missing data for demographic characteristics. A comparison of available data (services used, city, zip code) for participants with missing data versus those included in the study produced no significant differences, and we therefore believe our results are generalizable to all LHA participants. The outcome for our study was limited to use of services, and in the absence of a comparison group, we could not establish the effectiveness of the Emotional Wellness program on health outcomes. Previous *promotor*-led interventions in mental health services faced similar challenges, with favorable observations from ethnographic evaluation but no significant improvements in health outcomes (7), underscoring the need for further research to link interventions to mental health outcomes. Additionally, we had no tracking data to determine how many participants who received a referral accessed services at the referred agency. Given LHA's long-standing presence in Orange County, the organization has forged strong community partnerships for referrals. Where possible, *promotores* established an initial call to a service provider and helped program participants make the initial contact or appointment. *Promotores* also gave participants eligibility information for each service and all contact information for partner agencies. Future interventions are necessary to identify which social needs should be addressed to improve mental health (27). Given LHA's limited resources, the authors had to rely on existing data to assess program value and identify opportunities for improvement, adaptation, and expansion as the community's needs evolved. We, however, believe that the study's benefits outweigh its limitations as the US seeks effective models for addressing ongoing surges in the COVID-19 pandemic and ensuring equitable roll-out of vaccines to reach systematically disadvantaged populations (28,29). Effective communication strategies, with peer-to-peer vaccine education and outreach, may be an effective strategy to address vaccine mistrust and misinformation in Latino communities. Such efforts are likely to ease uncertainty and alleviate stress, and thus, may help address mental health conditions associated with COVID-19 (2,3).

Our study showed how a community-based organization with long-standing ties in the Latino community effectively expanded its Emotional Wellness program to provide integrated mental health care and social services to clients disproportionately affected by the COVID-19 pandemic. Despite some limitations, the study findings are informative for traditional health systems that have struggled to address the health inequities that have been exacerbated during the pandemic. Although social needs have taken precedence, evidence of the mental health toll of the pandemic are already well documented (3), and programs such as LHA's Emotional Wellness program are needed to reduce the pandemic's impact in systematically disadvantaged communities.

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Tables

Table 1. Demographic Characteristics of Participants (N = 722) in Latino Health Access's Emotional Wellness Program During the COVID-19 Pandemic, Orange County, California[a]

Characteristic	Pre-COVID-19 (March 2019-February 2020), n = 266[b]	COVID-19 (March 2020-June 2020), n = 567[b]	*P* Value[c]
Ethnicity			
Hispanic/Latino	261 (98.1) [96.5–99.8]	559 (98.6) [97.6–99.6]	.83
Other	261 (1.9) [0.2–3.5]	8 (1.4) [0.4–2.4]	
Sex			
Male	40 (15.0) [10.7–19.3]	146 (25.7) [22.2–29.3]	<.001
Female	226 (85.0) [80.7–89.3]	421 (74.3) [70.7–77.8]	
Age, y			
5–17	34 (12.8) [8.8–16.8]	23 (4.1) [2.4–5.7]	<.001
18–24	6 (2.3) [0.5–4.0]	9 (1.6) [0.6–2.6]	.69
25–44	133 (50.0) [44.0–56.0]	298 (52.6) [48.4–56.7]	.49
45–64	80 (30.1) [24.6–35.6]	214 (37.9) [33.9–41.9]	.03
≥65	13 (4.9) [2.3–7.5]	22 (3.9) [2.3–5.5]	.50
Location of residence			
Santa Ana	180 (67.7) [62.0–73.3]	360 (63.5) [59.5–67.5]	.24
Anaheim	54 (20.3) [15.5–25.1]	81 (14.3) [11.4–17.2]	.03
Other	32 (12.0) [8.1–15.9]	126 (22.2) [18.8–25.6]	<.001

[a] Fifty-seven participants were enrolled in both prepandemic and pandemic programs.
[b] Values are number (percentage) [95% CI] unless otherwise indicated.
[c] Pearson χ^2 test of independence was used to determine significance, with Yates' continuity correction applied when any cell had a frequency of <10. *P* value <.05 considered significant. *P* value assesses difference between prepandemic (March 2019-February 2020) and pandemic period (March 2020-June 2020).

Table 2. Trends in Referrals to Mental Health and Social Services Among Participants (N = 722) in Latino Health Access's Emotional Wellness Program During the COVID-19 Pandemic, Orange County, California[a]

Category	2019				2020						Overall *P* Value[b]	Pre-COVID-19 vs COVID-19 *P* Value
	Mar, n = 45	Apr, n = 69	May, n = 75	Jun, n = 66	Jan, n = 44	Feb, n = 67	Mar, n = 220	Apr, n = 307	May, n = 344	Jun, n = 224		
Affordable housing	0	4.3 (0–9.2)	0	3.0 (0–7.2)	2.3 (0–6.7)	1.5 (0–4.4)	13.6 (9.1–18.2)	13.0 (9.3–16.8)	10.5 (7.2–13.7)	12.1 (7.8–16.3)	<.001	<.001
Financial assistance	0	0	0	0	0	0	0.9 (0–2.2)	30.9 (25.8–36.1)	61.0 (55.9–66.2)	55.4 (48.8–61.9)	<.001	<.001
Food and nutrition assistance	0	1.4 (0–4.3)	0	1.5 (0–4.5)	0	0	74.1 (68.3–79.9)	61.6 (56.1–67.0)	45.9 (40.7–51.2)	49.6 (43.0–56.1)	<.001	<.001
Health education and disease management	62.2 (48.1–76.4)	34.8 (23.5–46.0)	36.0 (25.1–46.9)	7.6 (1.2–14.0)	15.9 (5.1–26.7)	4.5 (0–9.4)	0	2.0 (0.4–3.5)	4.4 (2.2–6.5)	7.1 (3.8–10.5)	<.001	<.001
Legal services and advocacy	4.4 (0–10.5)	5.8 (0.3–11.3)	9.3 (2.7–15.9)	12.1 (4.2–20.0)	9.1 (0.6–17.6)	9.0 (2.1–15.8)	2.3 (0.3–4.2)	3.9 (1.7–6.1)	3.5 (1.5–5.4)	6.3 (3.1–9.4)	.02	<.001
Medical care	6.7 (0–14.0)	1.4 (0–4.3)	2.7 (0–6.3)	4.5 (0–9.6)	11.4 (2.0–20.7)	4.5 (0–9.4)	2.3 (0.3–4.2)	4.2 (2.0–6.5)	9.0 (6.0–12.0)	25.9 (20.2–31.6)	<001	.002
Mental health services	4.4 (0–10.5)	33.3 (22.2–44.5)	28.0 (17.8–38.2)	45.5 (33.4–57.5)	72.7 (59.6–85.9)	83.6 (74.7–92.5)	12.3 (7.9–16.6)	6.8 (4.0–9.7)	2.3 (0.7–3.9)	6.7 (3.4–10.0)	<.001	<.001
Recreation	88.9 (79.7–98.1)	34.8 (23.5–46.0)	48.0 (36.7–59.3)	40.9 (29.0–52.8)	2.3 (0–6.7)	1.5 (0–4.4)	0.5 (0–1.3)	0.3 (0–1.0)	0	0	<.001	<.001
Other	2.2 (0–6.5)	7.2 (1.1–13.4)	2.7 (0–6.3)	4.5 (0–9.6)	0	3.0 (0–7.1)	0.9 (0–2.2)	2.9 (1.0–4.8)	5.5 (3.1–7.9)	3.1 (0.8–5.4)	.18	.93

[a] Values are percentage (95% CI) unless otherwise indicated.
[b] Pearson χ^2 test of independence was used to determine significance, with Yates' continuity correction applied when any cell had a frequency of <10. *P* value <.05 considered significant.

Table 3. Regression Analysis of Likelihood of Referral to Mental Health or Social Services Among Participants (N = 722) in Latino Health Access's Emotional Wellness Program During the COVID-19 Pandemic, Orange County, California[a]

Predictors	Model 1: ≥1 Referral		Model 2: Referred to Mental Health Services		Model 3: Referred to Social Services
	Pre-COVID-19	COVID-19	Pre-COVID-19	COVID-19	
Sex					
Female	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Male	−0.41 (−1.70 to 0.89)	0.06 (−0.67 to 0.85)	−0.23 (−0.92 to 0.60)	−0.64 (−1.76 to 0.27)	0.39 (−0.16 to 0.98)
Age, y					
<65	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
≥65	−0.98 (−3.18 to 1.02)	17.04 (NA)	−0.27 (−1.88 to 1.19)	−14.78 (−268.94 to 28.79)	−0.06 (−1.21 to 1.43)
Location of residence					
Santa Ana	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Outside Santa Ana	0.70 (−0.33 to 1.80)	−0.64 (−1.35 to 0.05)	−1.06[b] (−1.66 to (−0.41)	−1.59[b] (−2.83 to (−0.61)	0.21 (−0.29 to 0.73)
Number of Latino Health Access services					
None	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
1–3	−20.95 (NA)	−17.46 (−262.92 to 21.14)	−1.91[c] (−2.97 to (−1.00)	−1.17[d] (−2.22 to (−0.24)	−0.19 (−0.75 to 0.36)
4 or 5	−19.56 (−399.72 to 59.69)	−17.32 (−262.78 to 21.28)	−0.40 (−1.12 to 0.31)	0.28 (−0.58 to 1.11)	−0.17 (−0.81 to 0.48)

Abbreviation: NA, not available.

[a] Values are odds ratio (95% CI). All models were developed as logistic regressions. Model 3, Social Services, was implemented in March 2020. Wald χ^2 test was used to determine significance.

[b] Significant at $P < .01$.

[c] Significant at $P < .001$.

[d] Significant at $P < .05$.

PREVENTING CHRONIC DISEASE
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ESSAY

COVID-19 and Chronic Disease: The Impact Now and in the Future

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The Problem of COVID-19 and Chronic Disease

Chronic diseases represent 7 of the top 10 causes of death in the United States (1). Six in 10 Americans live with at least 1 chronic condition, such as heart disease, stroke, cancer, or diabetes (2). Chronic diseases are also the leading causes of disability in the US and the leading drivers of the nation's $3.8 trillion annual health care costs (2,3).

The COVID-19 pandemic has resulted in enormous personal and societal losses, with more than half a million lives lost (4). COVID-19 is a disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) that can result in respiratory distress. In addition to the physical toll, the emotional impact has yet to be fully understood. For those with chronic disease, the impact has been particularly profound (5,6). Heart disease, diabetes, cancer, chronic obstructive pulmonary disease, chronic kidney disease, and obesity are all conditions that increase the risk for severe illness from COVID-19 (7). Other factors, including smoking and pregnancy, also increase the risk (7). Finally, in addition to COVID-19–related deaths since February 1, 2020, an increase in deaths has been observed among people with dementia, circulatory diseases, and diabetes among other causes (8). This increase could reflect undercounting COVID-19 deaths or indirect effects of the virus, such as underutilization of, or stresses on, the health care system (8).

Some populations, including those with low socioeconomic status and those of certain racial and ethnic groups, including African American, Hispanic, and Native American, have a disproportionate burden of chronic disease, SARS-CoV-2 infection, and COVID-19 diagnosis, hospitalization, and mortality (9). These populations are at higher risk because of exposure to suboptimal social determinants of health (SDoH). SDoH are factors that influence health where people live, work, and play, and can create obstacles that contribute to inequities. Education, type of employment, poor or no access to health care, lack of safe and affordable housing, lack of access to healthy food, structural racism, and other conditions all affect a wide range of health outcomes (10–12). The COVID-19 pandemic has exacerbated existing health inequities and laid bare underlying root causes.

The COVID-19 pandemic has had direct and indirect effects on people with chronic disease. In addition to morbidity and mortality, high rates of community spread and various mitigation efforts, including stay-at-home recommendations, have disrupted lives and created social and economic hardships (13). This pandemic has also raised concerns about safely accessing health care (14) and has reduced the ability to prevent or control chronic disease. This essay discusses the impact that these challenges have or could have on people with chronic disease now and in the future. Exploring the impact of COVID-19 should help the public health and health care communities effectively improve health outcomes.

Challenges

The challenges we face as public health professionals are divided into 3 categories. The first category involves the current effects of COVID-19 on those with, or at risk for, chronic diseases and those at higher risk for severe COVID-19 illness. Inherent in this category is the need for balance between protecting people with chronic diseases from COVID-19 while assuring they can engage in disease prevention, manage their conditions effectively, and safely receive needed health care.

The second category is the postpandemic impact of COVID-19 on the prevention, identification, and management of chronic disease. COVID-19 has resulted in decreases of many types of health care utilization (15), ranging from preventive care to chronic disease management and even emergency care (16). As of June 2020, 4 in 10 adults surveyed reported delaying or avoiding routine or emergent medical care because of the pandemic (14). Cancer screenings, for example, dropped during the pandemic (17). Decreases in screening have resulted in the diagnoses of fewer cancers and precancers (18), and modeling studies have estimated that delayed screening and treatment for breast and colorectal cancer could result in almost 10,000 preventable deaths in the United States (19). We have lost ground in prevention across the chronic disease spectrum and in other areas, including pediatric immunization (20), mental health (21,22), and substance abuse (21,22).

Some challenges with health care utilization may be improving, but improvement has not been consistent across all health care visit types, providers, patients, or communities (15). Questions about the impact of the pandemic on chronic disease include:

- What diseases have been missed or allowed to worsen?
- What is the status of prevention and disease management efforts?
- Have prevention and disease management efforts been affected by concerns such as job loss, loss of insurance, lack of access to healthy food, or loss of places and opportunities to be physically active?
- How have effects of the pandemic on health care systems (staff reductions, health practice closures, disrupted services) (23) and public health organizations' deployment of personnel away from ongoing chronic disease prevention efforts been experienced nationally?

The effects of COVID-19, whether negative or positive, on health care and public health systems will certainly affect those with chronic disease. To fully understand the consequences of the pandemic, we need to assess its overall impact on incidence, management, and outcomes of chronic disease. This is particularly salient in communities where health inequities are already rampant or communities that are remote or underserved. Will our postpandemic response be strong enough to mitigate the exacerbation of inequities that have occurred? Can public health agencies effectively build trust in science and community health care systems where trust might never have been fully established or where it has been lost?

The third category relates to the long-term COVID-19 sequelae, both as a disease entity and from a population perspective. Has COVID-19 created a new group of patients with chronic diseases, neurologic or psychiatric conditions, diabetes, or effects on the heart, lungs, kidneys, or other organs (24)? Has it worsened existing conditions or caused additional chronic disease? And, at the population level, have the incidence and prevalence of chronic diseases increased because of pandemic-related health behaviors or other challenges, such as decreased food and nutrition security?

Given the rollout of COVID-19 vaccines and the coming end of the pandemic, this is an important time to examine the impact of COVID-19. Solutions at all levels are needed to improve health outcomes and lessen health inequities among people with or at risk for chronic disease. Solutions are likely to include increasing awareness about prevention and care during and after the pandemic, building or enhancing cross-organizational and cross-sector partnerships, innovating to address identified gaps, and addressing SDoH to improve health and achieve equity. So, what can be done?

Raise Awareness

Additional focus is required on several aspects of awareness about the impact of COVID-19. First, public health and health care practitioners need to allay people's fears and help them safely return to health care. We need to reemphasize chronic disease prevention and care, explain how to safely access care, and convey the host of mitigation efforts made by health care systems, providers, and public health to ensure that environments are safe (eg, mask requirements, social distancing). Emphasis on safety and mitigation applies to both disease prevention (such as encouraging healthy nutrition and physical activity, screening for cancer and other conditions, and getting oral health care) and disease management (eg, educating patients about medications to control hypertension, diabetes, asthma, and other chronic conditions). Efforts must also include helping those with chronic diseases obtain access to and gain confidence in the COVID-19 vaccine. Given current community rates of COVID-19 and the need to reenter care after the height of the pandemic, information can help patients make informed choices about the need for in-person care, communication at a distance, or temporary delays in care that is more discretionary.

To garner support to help affected communities, there is a need to build awareness about how COVID-19 has disproportionately affected particular communities, including the unequal distribution of disease, morbidity, mortality, and resources, such as access to vaccines. Awareness is dependent on access to data at the granular geographic level, including information on the burden of chronic disease and the status of SDoH. Communities need data to effectively address health inequities in the aftermath of the pandemic.

Collaborate on Solutions and Build Trust

Public health plays a significant role in addressing health behaviors (healthy eating, physical activity, avoiding tobacco and other substance use) and community solutions to address SDoH that impact prevention and control of chronic disease. Collaborations at both the individual and system levels, however, are required for success. Collaborative partners include other government and nongovernmental organizations, health care organizations, insurers, nonprofit organizations, community and faith-based groups, schools, businesses, and others. Coalitions and community groups are critical change agents. They have worked with local health departments and others to identify solutions, bring residents into discussions, and implement action. We can learn from them about how best to build trust and foster the innovation they are leading. Solutions must also include direct discussions with residents in affected communities to understand their priorities and effectively address their concerns. These relationships are particularly salient to address SDoH. These factors have been amplified as a direct consequence of COVID-19 and will require a multisector approach to problem solving.

To achieve this will require building trust in both the health care system and the public health system. The pandemic has taken a toll on an already fragile relationship between communities and public health and health care institutions where trust has been absent or insufficient. To begin to address the trust challenge will require investments in outreach, engagement, and transparency. Conversations need to be bidirectional, long-term, and conducted by people who are trusted, who are respectful, and who can identify with affected populations.

Innovate

Creative solutions are needed to engage populations and promote resiliency among those who are disproportionately affected by COVID-19. Efforts that need to be further developed and brought to scale include the following:

- Leveraging technology to expand the reach of health care and health promotion (eg, telemedicine, virtual program delivery, wearables, mobile device applications).
- Providing more services in community settings, as is increasingly modeled in the National Diabetes Prevention Program (25).
- Using community health workers to assist in assessing current conditions and connecting to community resources.
- Further enhancing approaches to increase access to and convenience of services (eg, increasing access to home screenings, such as cancer screening) or monitoring (eg, home blood pressure monitoring) where appropriate.

Health care approaches, such as telemedicine, have expanded greatly during the pandemic and seem likely to continue expansion over time. As these and related efforts grow, practitioners will need to ensure that existing disparities are not magnified. Care is needed to ensure that those with the highest health needs can access services. For example, are technological solutions easily accessible, available in multiple languages, compatible with readily available hardware options, such as telephones rather than laptops? Are culturally appropriate resources available to help people use and value these technologies? In addition, computer availability and internet access will need to be expanded. Challenges such as unemployment, food insecurity, limited transportation, substance abuse, and social isolation will require a multisector effort uniquely adapted to local contexts. To begin, health equity–focused policy analyses and health impact assessments will help policy makers understand better how proposed SDoH-related action might either exacerbate or mitigate chronic disease inequities. These actions will help us develop a deeper understanding of what individual communities need to mobilize and build resilience for the future. We face serious public health and population health concerns that should be the focus in the near term — particularly as equitable access to COVID-19 vaccines is a consideration in every community across the nation. We clearly have an enormous amount of work to do as we enter recovery from the pandemic, but with recovery comes enormous opportunity.

Address Long-Term COVID-19 Sequelae

A challenge related to long-term COVID-19 sequelae is that we do not know yet the extent that COVID-19 exacerbates chronic disease, causes chronic disease, or will be determined a chronic disease unto itself. Those interested in chronic disease prevention and management need to follow the research to understand better the role they will play with this emerging situation. Long-term studies and longitudinal surveillance will help clarify these issues, and there is much research to be done. The duty of the public health community is to help ensure that the most important issues from the perspectives of patients, providers, health care, and public health systems are addressed; that potential solutions are developed and tested; and that eventual solutions are delivered where they are needed most.

How Will the National Center for Chronic Disease Prevention and Health Promotion Contribute?

As the US enters the next phase of pandemic response, the work of National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) of the Centers for Disease Control and Prevention is evolving to address health inequities and drive toward health equity with a multipronged approach. This approach includes enhanced access to data at the local level, a focus on SDoH including a shift in the Notice of Funding Opportunity process that emphasizes a health equity lens, and an expansion of partnerships and communications.

Placing data in the hands of communities is critical for local coalitions to determine their burden of chronic disease and COVID-19, their access to resources, and the best policies and practices to implement. Data will be useful for local public health, governments, and health care systems, but can also help human services, planning, and economic development organizations. An initial step is making available data from the PLACES Project (26), which provides data on 27 chronic disease measures at the census tract level, allowing communities to understand their own chronic disease burden. In addition, modules on SDoH are in development to enhance NCCDPHP data surveillance systems. This will increase the ability to overlay chronic disease data and SDoH data at the community level. The need is also a great for core SDoH measures that allow comparisons of related outcomes across communities. NCCDPHP can augment this effort by contributing to and amplifying the SDoH measures identified for Healthy People 2030 (27).

NCCDPHP is focusing on supporting and stimulating SDoH efforts by concentrating on 5 major areas: built environment, social connectedness, food and nutrition security, tobacco policies, and connections to clinical care. For example, SDoH are the foci of recent Notices of Funding Opportunities (available at https://www.grants.gov). NCCDPHP supports multisector partnerships in numerous funding announcements and launched a joint effort with the Association of State and Territorial Health Officials and the National Association of County and City Health Officials to identify best practices in multisector collaboration to address SDoH (28). Evidence will help build a standard for success to support local coalitions in their work. States and local communities are sites of innovation, and promoting lessons learned can help build broader efforts. To address urgent needs and facilitate change, NCCDPHP must link with other sectors outside of public health and health care. The work to evaluate these efforts and determine the most effective strategies to address SDoH, therefore, will be integrated fully into NCCDPHP.

An expansion of the Racial and Ethnic Approaches to Community Health (REACH) Program (29) and other programs that address health inequities will help to target resources where they are needed most. REACH and a recently released investment in community health workers (30) demonstrate NCCDPHP’s commitment to connecting with populations that are disproportionately affected by chronic disease at the local level. These efforts are aimed at addressing the ramifications of COVID-19 while also amplifying chronic disease prevention efforts. NCCDPHP also intends to enhance the use of a health equity lens, among other approaches, to determine the best use of resources and to help assess outcomes in all programmatic activities.

Finally, communication about the impact of COVID-19 on chronic disease, returning to care, and the extent of health inequities is critical to building trust. Efforts under way include a television and digital media campaign aiming to encourage those with chronic disease to return safely to care (31). In addition to expanding work with partner organizations, both external and internal to government, NCCDPHP will embrace new ways of garnering input from affected communities. Successes and failures experienced by communities during the pandemic will continue to be of the utmost importance to NCCDPHP. In addition, important insights gained from working closely with affected communities will help NCCDPHP continually refine its national chronic disease prevention and control goals and objectives. Activities related to SDoH and health equity, data, and communication will address difficult questions now and into the future. These efforts can only be successful with collaboration and partnerships across multiple sectors.

Conclusion

The impact of SARS-CoV-2, the virus that causes COVID-19, on people with or at risk for chronic disease cannot be overstated. COVID-19 has impeded chronic disease prevention and disrupted disease management. The problems and solutions outlined here are critically important to help those committed to chronic disease prevention and intervention to identify ways forward.

NCCDPHP is adjusting, preparing, and implementing multiple strategies to address the future. Although the work will be challenging, opportunities abound. NCCDPHP is committed to working with the health care community and a variety of partners at federal, state, and local levels to help address the realities of the post-COVID era.

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SYSTEMATIC REVIEW

Screening and Referral Care Delivery Services and Unmet Health-Related Social Needs: A Systematic Review

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Summary

What is already known on this topic?

Little is known about the overall impact of screening and referral programs that address unmet health-related social needs on outcomes related to experience of care, population health, and cost.

What is added by this report?

Although screening and referral programs positively affected outcomes related to experience of care and population health, definitive conclusions about their overall impact could not be determined.

What are the implications for public health practice?

This study synthesizes evidence to inform health care administrators and policy makers considering the expansion of screening and referral programs to address unmet health-related social needs.

Abstract

Introduction

Unmet health-related social needs contribute to high patient morbidity and poor population health. A potential solution to improve population health includes the adoption of care delivery models that alleviate unmet needs through screening, referral, and tracking of patients in health care settings, yet the overall impact of such models has remained unexplored. This review addresses an existing gap in the literature regarding the effectiveness of these models and assesses their overall impact on outcomes related to experience of care, population health, and costs.

Methods

In March 2020, we searched for peer-reviewed articles published in PubMed over the past 10 years. Studies were included if they 1) used a screening tool for identifying unmet health-related social needs in a health care setting, 2) referred patients with positive screens to appropriate resources for addressing identified unmet health-related social needs, and 3) reported any outcomes related to patient experience of care, population health, or cost.

Results

Of 1,821 articles identified, 35 met the inclusion criteria. All but 1 study demonstrated a tendency toward high risk of bias. Improved outcomes related to experience of care (eg, change in social needs, patient satisfaction, n = 34), population health (eg, diet quality, blood cholesterol levels, n = 7), and cost (eg, program costs, cost-effectiveness, n = 3) were reported. In some studies (n = 5), improved outcomes were found among participants who received direct referrals or additional assistance with indirect referrals compared with those who received indirect referrals only.

Conclusion

Effective collaborations between health care organizations and community-based organizations are essential to facilitate necessary patient connection to resources for addressing their unmet needs. Although evidence indicated a positive influence of screening and referral programs on outcomes related to experience of care and population health, no definitive conclusions can be made on overall impact because of the potentially high risk of bias in the included studies.

Introduction

Up to 80% of health outcomes can be attributed to social determinants of health (SDOH), the conditions in which we grow, live, and work (1,2). Adverse SDOH include food insecurity, housing instability, unemployment, and other unmet health-related social needs (3), which often contribute to negative health outcomes, including an increased risk for diabetes, hypertension, and heart disease (4–7). Recently, higher unemployment rates and changes in health insurance coverage due to the ongoing COVID-19 pandemic have further compromised health care access and increased the number of people with unmet needs (8,9).

Health care organizations (HCOs) offer a natural setting for integration of clinical care, public health, and community-based services (10,11). The Centers for Medicare and Medicaid Services (CMS) has recognized the potential value in leveraging the infrastructure of HCOs for addressing health-related social needs. As part of the Accountable Health Communities initiative, CMS provides incentives for HCOs to consider solutions that address unmet needs by potentially improving population health and reducing system costs to drive overall performance (12). One common approach to the screening and referral–based care delivery model includes the identification of unmet needs through a screening questionnaire, followed by a referral component that addresses or mitigates unmet needs through referrals to appropriate resources, and subsequently evaluates the impact of this screening and referral program (12–14) (Figure 1).

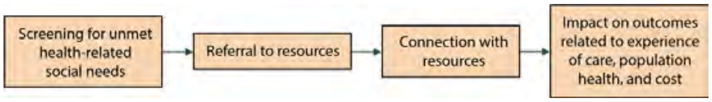

Figure 1. Processes and potential impact on outcomes of screening and referral-based delivery services for addressing unmet health-related social needs among patients in a healthcare setting.

Although implementation of such screening and referral-based programs has increased in recent years (14), we found no review that summarized evidence on the impact of these programs on care outcomes. Therefore, in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (15), we answered the following population, intervention, comparison, and outcomes question (PICO): What is the impact of screening and referral programs targeting unmet health-related social needs in health care settings on outcomes related to experience of care, population health, and costs?

Methods

Data sources

Because CMS only started implementing screening and referral–based care delivery models in 2016 (12), we searched PubMed to identify relevant peer-reviewed articles published over the past 10 years as of March 2020 to capture results from any pilot and demonstration projects before and after this time frame. Search terms were derived with the help of a subject librarian and included the following terms: (“social determinants of health” OR “social determinants” OR “social needs” OR food insecurity OR housing OR transportation OR employment) AND (screening OR needs assessment OR test) AND (referrals OR collaboration OR address needs) AND (“primary care” OR primary health care OR health services) NOT (biological OR psychology OR mental health). Our search terms did not contain an exhaustive list of all social determinants described in the literature. Specific health-related social needs (eg, food insecurity, housing) included in the search indicate the needs commonly addressed by current screening and referral programs. Additionally, we scanned the bibliographies of all articles that met the inclusion criteria and other literature reviews (16,17). To maximize our final article yield, older studies published before January 1, 2010, obtained from bibliographies, were included if they met the inclusion criteria.

Study selection

Articles were included if they were written in English and described an intervention in a health care setting that 1) used a screening tool to identify unmet health-related social needs, 2) referred screened patients with positive results (or positive screens) to resources offering assistance (eg, on-site provision of food or referral to a food bank), and 3) reported any care outcomes resulting from the screening and referral components described in 1) and 2), beginning with program recruitment or referral uptake. After the study selection, all outcomes were categorized into experience of care, population health, and cost-related based on the Institute for Healthcare Improvement (IHI) Triple Aim framework (18), which targets 3 dimensions for optimizing performance in HCOs: 1) improving the patient experience of care through quality and satisfaction; 2) improving health of the patient population, and 3) reducing the per capita cost of care.

Using the Triple Aim framework as a guideline, outcomes related to the patient *experience of care* included outcomes resulting from the referral (eg, patient use of resource) and patient-reported outcomes (eg, self-reported changes in social needs, patient satisfaction with the screening and referral intervention). Outcomes related to *population health* describe any changes in indicators pertaining to patient health (eg, blood pressure trends, diet intake). *Cost-related outcomes* included any changes in health care costs, utilization, or cost-effectiveness evaluation.

Articles were excluded if the intervention was in a non–health care setting (eg, community settings such as food banks), if the care delivery services focused solely on individual behavior-related determinants (eg, smoking, physical inactivity, alcohol consumption) rather than social determinants, or if the program did not include a screening and/or referral component. Articles were also excluded if we could not ascertain whether on-site screening for health-related social needs was performed or if solely process-related, descriptive screening outcomes (eg, number of screenings, number of referrals) were reported.

Screening of titles and abstracts was carried out by 2 reviewers (E.R.E., S.P.) using Microsoft Excel (Microsoft Corporation). Once relevant articles were independently identified, each reviewer completed a full-text review of the selected articles. We planned to resolve discrepancies during the article selection process by using consensus among the authors (E.R.E., S.P., C.B.), but no discrepancies occurred.

Data extraction

From each eligible article, we extracted the following: author name(s), year of publication, place of origin, health care setting(s), target population, study design, sample size, screening tool used, targeted unmet health-related social need(s), referral approach, referral site, outcome(s) assessed, and study results.

Risk of bias assessment and data analysis

Valid and complementary assessment tools for randomized (19) and nonrandomized studies (20) were used to examine risk of bias. For randomized clinical trials, we used the Cochrane tool (19) to make critical assessments (low risk, high risk, and unclear risk) of included studies in 6 domains: sequence generation, allocation concealment, blinding, incomplete outcome data, selective outcome reporting, and "other sources of bias." For nonrandomized studies, we made similar critical assessments (low risk, high risk, and unclear risk) using the RoBANS tool (Risk of Bias Assessment for Nonrandomized Studies) (20) for a slightly different set of 6 domains: selection of participants, confounding variables, measurement of exposure, blinding of outcomes assessment, incomplete outcome data, and selective outcome reporting. For both randomized and nonrandomized studies, the final assessment within and across studies was based on the responses to individual domains.

A qualitative synthesis of results across studies was performed. Meta-analysis was not performed because of heterogeneity in the study populations, interventions, and outcomes of included studies.

Results

A total of 1,821 articles were identified from the PubMed database search (Figure 2). After applying the PICO question and our inclusion criteria, 42 articles were selected for full-text review, of which 18 met the inclusion criteria. An additional 17 articles were included from bibliographies, bringing the total to 35 articles in the final review. Seven (20%) studies were randomized control trials, 6 (17%) were observational studies that compared outcomes within the intervention group to a nonintervention comparison group, and the rest examined outcomes within an intervention group only (n = 22; 63%).

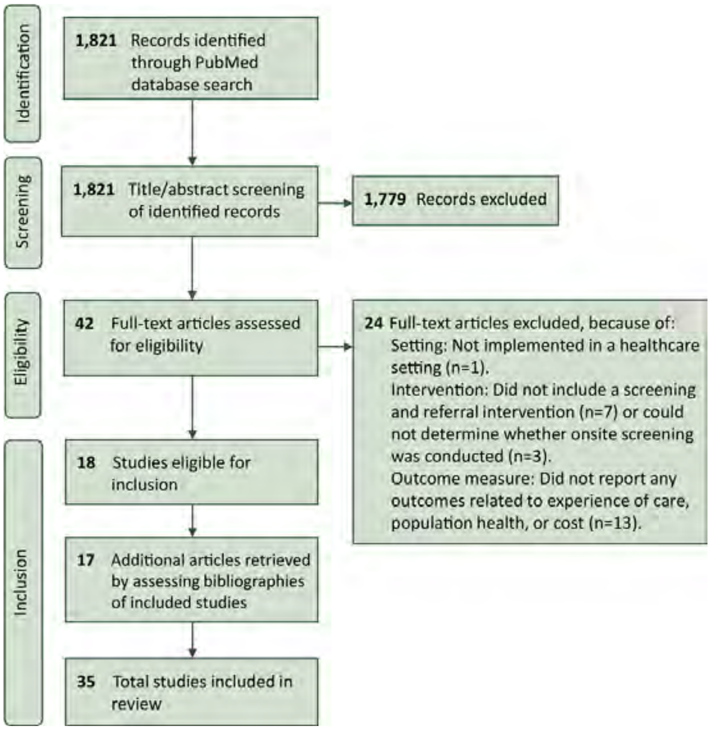

Figure 2. PRISMA (Preferred Reported Items for Systematic Reviews and Meta-Analysis) diagram for identification of included studies.

Risk of bias assessment

Randomized studies demonstrated a potentially high risk (n = 6) or unclear risk of bias (n = 1) (Table 1). Insufficient or lack of information about blinding of participants, personnel, or outcomes indicated that potential selection, performance, and detection biases were present. Additionally, all nonrandomized studies (n = 28) were assessed as having a potentially high risk of bias (Table 2). The most common domains demonstrating high risk were blinding of outcomes assessment (n = 28), confounding variables (n = 19), and participant selection (n = 13).

Settings, populations, and unmet health-related social needs

All included studies (n = 35) had a screening and referral component and originated in the US (Tables 1 and 2). Most screening and referral programs were implemented in pediatric clinics (n = 15) (21,26,29,30,34–37,39,43,47,49,50,54,55) and other primary care practices (n = 11) (22,23,25,27,28,31,32,38,40,41,53); the rest (n =

9) were in other settings (24,33,42,44–46,48,51,52). Included studies defined target populations by health conditions or behavioral risk factors (eg, patients with diabetes, or patients who smoke), and/or demographic characteristics (eg, age, sex).

The social needs addressed included education (eg, poor literacy, health education) (23,24,27,33,38–41,49–52,55), unemployment and income insecurity (eg, vocational training, financial burden) (23,24,26,31,33,36,38–41,43,48–52,55), food insecurity (22–24,26,28,30,31,35–41,43,45–47,49–51,53–55), housing insecurity (eg, poor housing conditions, homelessness) (23,24,26,29,31,35,36,38–41,43,49–52,55), interpersonal safety (eg, intimate partner violence) (21,24,32–36,38,39,43,44,49,55), transportation to health care site (24,31,35,39,41,50,51,55), and others (eg, counseling needs, childcare/eldercare services, access to services) (21,23,24,31–36,38–41,43,49–52,55) (Table 3). Although some programs (n = 13) addressed a single unmet social need (22,27–30,37,44–48,53,54), more than half (n = 21) addressed multiple needs (21,23–26,31–36,38–41,43,49–52,55). One study (42) was a cost-effectiveness analysis of a screening and referral program addressing multiple needs (52).

Screening component

The programs described in the included studies employed various screening tools (eg, the Hunger Vital Sign [https://childrenshealthwatch.org/public-policy/hunger-vital-sign/], Health Leads [https://healthleadsusa.org/]) to identify unmet need(s). Most studies (n = 19) (21,22,25,28,30,31,34,35,37–39,41,44,45,47,50,51,53,54) either used tools that had been previously validated in existing literature (60,61) or used tools developed in-house (n = 11) (23,24,27,29,32,36,40,43,46,48,55). Other studies (n = 4) (26,33,49,52) did not specify a screening tool.

Screening assessments were facilitated by clinic staff (n = 9) (21,28,34,35,37,41,46,50,54), health care providers (n = 6) (23,30,31,39,47,49), and others (n = 7) (33,38,43,45,46,50,55). Some assessments (n = 4) were administered to patients online (25,27,36,40).

Referral component

Studies featured HCOs that partnered with various community-based organizations (CBOs) or expanded their internal resources to include assistance programs that addressed immediate unmet needs. Five studies reported on providing on-site social assistance services including CBO eligibility applications (32,45,49,53) and distribution of food supplies (30,53). Although descriptions of community collaboration were sparse, referral sites included CBOs such as food banks, nutrition programs, intimate partner violence agencies, housing programs, and early childhood education programs.

Additionally, we found 3 referral approaches: indirect, direct, and warm handoff. In an *indirect referral*, health care providers simply hand over information about the referral site(s) to the patient (eg, distribute a list of local food banks and their contact information to patients who have a positive screen for food insecurity). A *direct referral* approach is when the HCO directly forwards a patient's contact information to a referral site contingent on the patient's consent and is often administered through health information exchange tools. The referral site then follows up with the patient to assist in the patient's application or enrollment in programs to alleviate unmet needs. A *warm handoff* is when an on-site intermediary person in the HCO (eg, community health worker, social worker) assists patients who have a positive screen with connecting to the referral site.

Indirect referrals and warm handoffs were the most common referral approaches (n = 29) reported (21–24,26,28–36,38–41,43–46,48–53,55). The rest (n = 5) were studies that reported direct referrals (25,27,37,47,54). Studies with 2 groups either compared outcomes in the intervention group to a control group that received no referral (n = 8) (21,25,26,30,31,34,46,51) or to a control group that received a different type of referral (n = 5) (22–24,27,32).

Qualitative synthesis of outcomes

Most studies (n = 25) (21,23–25,27,29,32–41,43–45,47,49,50,53–55) reported only outcomes related to experience of care (Table 3), which included referral uptake (ie, participants who connected with or used necessary resources expressed as a percentage or ratio of all participants who had a positive screen or consented to a referral) and patient-reported outcomes (ie, self-reported changes in social needs, diet, health, and patient satisfaction). Other studies reported population health outcomes (n = 7) (22,26,30,31,46,48,52), which included changes in indicators of patient health such as systolic and diastolic blood pressure, glycosylated hemoglobin levels (HbA_{1c}), body mass index (BMI), low-density lipoprotein cholesterol, medication adherence, appointment adherence, violent injury recidivism rates, and preventive care outcomes (ie, completing lead tests, developmental screens, infant immunization schedules, or well-infant visit sets). Only 3 studies reported cost-related outcomes (28,42,51), including evaluation of program costs, changes in health care utilization, or cost-effectiveness.

Experience of care outcomes

Referral uptake. Data on participants or participating families who connected with or used necessary resources were expressed either as a percentage of all participants who had a positive screen or as a percentage of those who consented to/received a referral (referral uptake). Although most studies (n = 30) reported some information on patient connection to the referral site, the reported results were highly contextual and varied widely from study to study. For example, some studies reported connection rates as low as 3% (47) while others reported rates as high as 75% (54).

Patient-reported outcomes. Nine studies (21,24,28,36,38,40,41,44,48) reported positive findings on patient-reported outcomes. For example, 1 study interviewing patients with unmet needs (41) reported participants being able to make concrete changes in their lives as a result of screening and referral, including resolving immediate social needs, a healthier diet, or physical and mental/emotional benefits; another study (28) found that participants' self-reported food insecurity decreased by 94.1%.

Three studies (36,38,48) that investigated patient satisfaction reported positive feedback on referral sites and program tools. More than 80% of patients found their referral sites helpful in 1 study (36), and more than 90% of parents enrolled in a community-based resource reported being "very" or "somewhat" satisfied in a different study (38). Similarly, participants with diabetes in another study reported high acceptability across multiple survey items in their program's resource tool (eg, 93% "learned a lot," 98% found "topics relevant") (48).

Health outcomes

Seven (22,26,30,31,46,48,52) studies that examined outcomes related to population health found some positive changes in health indicators. After addressing income insecurity, 7% fewer patients (P = .03) reported skipping doses of medicines because of financial concerns (48). Another study found a drop in the violent injury recidivism rate from an initial 16% to 4.5% by the end of the program (52). Other studies found improved preventive care outcomes, including faster completion of lead tests, developmental screens, infant immunization schedules among participants (77% vs 63% completed by age 7 months, P = .002 and 88% vs 78% by age 8 months, P = .008) (26), and greater likelihood of completing a full set of well-infant visits by 14 months (42% vs 28.7%; $P <$ .001) (30). Changes reported in intervention participants enrolled in screening and referral programs compared with those who did not receive a referral included improvements in systolic blood pressure and diastolic blood pressure trends during pregnancy (46) (P = .004), and a modest differential change in systolic blood pressure of −1.2 mm Hg (95% CI, −2.1 to −0.4), diastolic blood pressure of −1.0 mm Hg (95% CI, −1.5 to −0.5), and improved low-density lipoprotein cholesterol (differential change −3.7 mg/dL; 95% CI, −6.7 to −0.6) among participants with diabetes (31).

Cost-related outcomes

Only 3 studies examined cost-related outcomes. One study targeting food insecurity with a food prescription program (28) found program costs to be $12.20 per person per redemption. Additionally, participants reported an average $57 savings per week on grocery bills. Another study targeting multiple social needs (51) reported a decreased likelihood of health care utilization among the intervention group compared with the control group. Also, a cost-effectiveness study (42) of a hospital-based violent injury prevention intervention (52) yielded 25.6 quality-adjusted life years (QALYs, a standardized measure of disease burden in cost-effectiveness evaluations that typically combines both survival and health-related quality of life to guide decisions on the distribution of limited health care resources) versus 25.3 for the non violent injury prevention group, with net costs of $5,892 per patient versus $5,923 for the non violent injury prevention group.

Impact of referral approach on all outcomes

Studies comparing direct (27,54) to indirect referral reported greater referral uptakes with direct referral. One study (27) found that intervention participants receiving direct referrals reported a greater percentage of children who connected with an education resource (41% vs 18%) and actively attended the development program (25% vs 11%) than intervention participants who received an indirect referral. Another study (54) reported patient connection to referral sites increasing from 5% to 75% when the approach was changed from indirect to direct referral.

Some studies compared indirect referrals paired with additional services (eg, on-site assistance) in the intervention to a control group that received indirect referrals only. One such study (32) found a similar percentage of participants using the referral resource (21.4% vs 17.4%; P = .43) as the control group. However, a greater percentage of intervention participants than control participants connected with the on-site advocate (32.8% vs 4.4%; $P <$ .001). Similarly, another study (23) reported that intervention participants had greater odds than control participants of being employed or enrolled in a job training program (aOR = 44.4), receiving childcare support (aOR = 6.3) and fuel assistance (aOR = 11.9), and lower odds of being in a homeless shelter (aOR = 0.2).

Two studies (22,24) compared outcomes in patients receiving a warm handoff with patients who received an indirect referral. The intervention group receiving warm handoff (22) had decreased HbA_{1c} levels (mean differences of −3.09 vs −1.66; P = .012), improved STC (Starting the Conversation)-Diet scale (62) (mean differences of 2.47 vs 0.06; P = .001), but no difference in BMI (mean differences of –0.17 vs 0.84; P = .43) compared with control participants. Similarly, intervention participants in another study (24) reported fewer unmet social needs (mean change of −0.39 vs 0.22; $P < .001$) and greater improvement in their child's health than control participants (mean change of −0.36 vs 0.12; $P < .001$).

Discussion

The body of evidence on the relationship between unmet health-related social needs and poor patient outcomes has continued to grow in recent years. In response, screening and referral programs have expanded to mitigate unmet health-related social needs among patients in health care settings (12,14).

This review found 35 studies on screening and referral delivery services that reported outcomes related to patients' experience of care, population health, and cost. The delivery service targeted patients with different chronic conditions and demographic characteristics, aiming to mitigate different health-related unmet needs.

We found some indication that screening and referral programs had a generally positive impact on outcomes related to experience of care, population health, and cost. Patient connection to referral sites and patient-reported outcomes such as self-reported diet intake, resolution of unmet health-related social needs, overall well-being, and patient satisfaction increased. Indicators of health such as blood pressure trends, low-density lipoprotein cholesterol, and medication adherence improved. Additionally, results indicated an improvement in QALYs, decreased likelihood of health care utilization, and modest savings associated with these programs.

Overall, included studies revealed a high risk of bias for elements related to study design and evaluation. Thus, we were unable to draw any definitive conclusions about the impact of screening and delivery services on any outcome.

The linkage of patients to resources seemed to be influenced by the type of referral and the degree of navigation within the HCOs and collaboration between the HCOs and the CBOs involved. Results suggested that patients were more successful in connecting with resources when partnered CBOs are more directly involved (ie, direct referral), or if referral efforts were made through on-site intermediaries such as community health workers to direct patients in contacting or applying to referral sites (ie, warm handoff).

Studies have indicated (37,41,47) that referral uptake was influenced by accessibility to referral sites, including patient eligibility criteria and intensity of time and labor required to access resources. For instance, the application process for SNAP (Supplemental Nutrition Assistance Program) is lengthy and complex (63). Such barriers, as speculated in the literature (64), can explain why, despite participating in screening and referral programs, patients can have difficulties in accessing some resources. In short, the degree of referral uptake can be subject to various program characteristics including referral approach, on-site assistance, and accessibility of referral sites.

This review serves as a call to action for policy makers, advocates, and care providers to facilitate screening and referral delivery services through strong collaborations among health care, public health, and community sectors to address unmet health-related and social needs. Such programs can offer a comprehensive solution for health care administrators and insurers looking to improve the health of their patient population, reduce system costs, and optimize overall performance by addressing social determinants of health in their patient populations and delivering high-quality person-centered care. Research with stronger study designs and rigorous evaluation methodologies is needed to establish a strong evidence base of the effectiveness of screening and referral delivery services. Future studies can further explore social-needs screening in mental/behavioral health settings that target individual behavior-related determinants of health (eg, smoking, alcohol abuse) along with social determinants.

To our knowledge, this review is the first study to provide an overview of the impact of screening and referral programs on outcomes related to experience of patient care, population health, and costs. Although our search for articles was performed in accordance with PRISMA guidelines for a systematic review (15), our study was exploratory. We limited our search to peer-reviewed articles and 1 database, which might have excluded other results reported in the gray literature or in other databases.

In summary, literature on the impact of screening and referral programs in HCOs had a tendency toward high risk of bias. Although the evidence indicated promising changes in patient connection to resources, patient-reported outcomes, patient satisfaction, and some health indicators, no definitive conclusions could be made about the impact of such programs on outcomes related to experience of care, population health, and cost. This study can inform public health professionals, administrators, and policy makers about the impact of implementing screening and referral care delivery services in health care settings, paving the way for the expansion of such programs to improve population health.

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Tables

Table 1. Risk of Bias Assessment for Included Randomized Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year (Reference)	Risk of Bias Assessment						
	Random Sequence Generation	Allocation Concealment	Blinding, Participants and Personnel/ Outcomes	Incomplete Outcomes Data	Selective Reporting	Other Sources of Bias	Overall Assessment
Dubowitz H, 2009 (21)	Low	Unclear[a]	High/High	Low	Low	Low	High
Ferrer RL, 2019 (22)	Low	Low	High/High	Low	Low	High	High
Garg A, 2015 (23)	Low	Unclear[a]	Low/Low	Low	Low	Low	Unclear
Gottlieb LM, 2016 (24)	Low	High	High/High	Low	Low	Low	High
Haas JS, 2015 (25)	Low	Unclear[a]	High/Low	Low	Low	Low	High
Sege R, 2015 (26)	Low	Unclear[a]	High/High	Low	Low	High	High
Silverstein M, 2004 (27)	Low	Unclear[a]	Low/High	Low	Low	Low	High

[a] Insufficient information provided to determine whether allocation concealment was performed.

Table 2. Risk of Bias Assessment for Included Nonrandomized Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year (Reference)	Risk of Bias Assessment						
	Participant Selection	Confounding Variables	Measurement of Exposure (Referral Service)	Blinding of Outcome Assessments	Incomplete Outcomes/ Loss to Follow-up	Selective Reporting	Overall Assessment
Aiyer JN, 2019 (28)	Low	High	Low	High	Low	Low	High
Beck AF, 2012 (29)	High	High	Low	High	Low	Low	High
Beck AF, 2014 (30)	High	High	Low	High	Low	Low	High
Berkowitz SA, 2017 (31)	Low	Low	Low	High	Low	Low	High
Coker AL, 2012 (32)	Low	Low	Low	High	Low	Low	High
Dicker RA, 2009 (33)	Low	High	Low	High	Low	Low	High
Dubowitz H, 2012 (34)	Low	Low	Low	High	Low	Low	High
Fiori KP, 2020 (35)	Low	Low	Low	High	Low	Low	High
Fleegler EW, 2007 (36)	High	Low	Low	High	Low	Low	High
Fox CK, 2016 (37)	Low	High	Low	High	Low	Low	High
Garg A, 2010 (38)	Low	High	Low	High	Low	Low	High
Garg A, 2012 (39)	Low	High	Low	High	Low	Low	High
Hassan A, 2015 (40)	Low	High	Low	High	Low	Low	High
Hsu C, 2019 (41)	High	High	Low	High	Low	Low	High
Juillard C, 2015 (42)	High	High	Low	High	Low	Low	High
Klein MD, 2013 (43)	Low	High	Low	High	Low	Low	High
Krasnoff M, 2002 (44)	Low	High	Low	High	Low	Low	High
Marpadga S, 2019 (45)	High	High	Low	High	Low	Low	High
Morales ME, 2016 (46)	High	Low	Low	High	Low	Low	High
Palakshappa D, 2017 (47)	High	Low	Low	High	High	Low	High
Patel MR, 2018 (48)	High	High	Low	High	Low	Low	High
Pettignano R, 2011 (49)	High	High	Low	High	Low	Low	High
Power-Hays A, 2020 (50)	High	High	Low	High	Low	Low	High
Schickedanz A, 2019 (51)	High	Low	Low	High	Low	Low	High
Smith R, 2013 (52)	High	High	Low	High	Low	Low	High
Smith S, 2016 (53)	Low	High	Low	High	Low	Low	High
Stenmark SH, 2018 (54)	Low	High	Low	High	Low	Low	High
Uwemedimo OT, 2018 (55)	Low	Low	Low	High	Low	Low	High

Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
Experience of care outcomes						
Smith S, 2016; San Diego, CA (53)	Setting: 3 student-run free clinics. Population: Adults (aged >18 y)	USDA US Household Food Security Survey 30-day version, targeted food insecurity	Approach: Indirect referral[b] with on-site assistance.[c] Site: Local food pantries, monthly on-site food distributions, and on-site same-day SNAP enrollment	Cross-sectional study, 1-group design (n = 430)	Experience of care (referral uptake[d])	15% (66 of 430) of total patients used a food pantry. 15% (64 of 430) enrolled in SNAP. 48% (208 of 430) of screened patients had diabetes, of whom 97% (201 of 208) received on-site monthly food boxes
Fox CK, 2016; Minnesota (37)	Setting: 1 pediatric weight management clinic. Population: Households with children	Hunger Vital Sign, targeted food insecurity	Approach: Direct referral.[e] Site: Food bank (Second Harvest Heartland) offered on-site assistance with SNAP application	Prospective pilot study, 1-group design (n = 116)	Experience of care (referral uptake[d])	8% (3 of 40) of eligible patients completed SNAP enrollment process.
Palakshappa D, 2017; Pennsylvania (47)	Setting: 6 pediatric clinics. Population: Households with children	Hunger Vital Sign in EHR, targeted food insecurity	Approach: Direct referral.[e] Site: Nonprofit organization (Benefits Data Trust) assisted with applications to government benefits	Prospective mixed-methods study, 1-group design (n = 4,371)	Experience of care (referral uptake[d])	26% (32 of 122) of patients with food insecurity consented to a direct referral. 3% (1 of 32) of patients enrolled in SNAP.
Stenmark SH, 2018; Colorado (54)	Setting: 2 pediatric clinics. Population: Households with children	Hunger Vital Sign, targeted food insecurity	Approach: Indirect referral[b] evolved into direct referral.[e] Site: Nonprofit organization (Hunger Free Colorado) offered assistance with applications to federal and community resources	Descriptive, prospective study, 1-group design, number of screened patients not provided; 1,586 patients were referred	Experience of care (referral uptake[d])	Connection rate between patients and referral site increased from 5% to 75% after the program moved from indirect to direct referral. 6% (100 of 1,586) of patients enrolled in SNAP.

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Reported as the total number of participants who underwent screening. If the study did not report number of screenings, the number of referrals was reported as the sample size.

[b] A referral approach in which health care providers simply hand over information about relevant referral sites to the patient (eg, a list of local food banks and their contact information).

[c] Additional on-site services may include assistance with applying to community-based resources or connection to other resources through a helpdesk, and/or on-site provision of supplies.

[d] Refers to participants who connected to necessary resources expressed as a percentage or ratio of all participants who had a positive screen or those who consented to a referral.

[e] A referral approach that requires the patient’s consent to forward their contact information to the corresponding internal or external resource. The referral site then directly contacts the patient.

[f] A referral approach in which patients are introduced to an on-site intermediary person in the health care organization (eg, community health worker, case manager) who works to connect them to referral sites.

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Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
Marpadga S, 2019; San Francisco, CA (45)	Setting: 1 diabetes clinic. Population: Patients with diabetes	Hunger Vital Sign, targeted food insecurity	Approach: Indirect referral[b] with on-site assistance.[c] Site: Multiple, including programs that offered free groceries, on-site prepared meals, home-delivered meals, and medically tailored meals (Project Open Hand)	Qualitative study; semistructured interviews, 1-group design (n = 240)	Experience of care (referral uptake[d])	13% (31 of 240) of screened patients were interviewed. 32% (10 of 31) of participants connected with food resources: 3% (1 patient) with a program providing free groceries and 29% (9 patients) with a program providing medically tailored meals.
Beck AF, 2012; Cincinnati, OH (29)	Setting: 1 pediatric primary care clinic. Population: Households with children	EHR-based screening, targeted poor housing conditions	Approach: Warm handoff.[f] Site: On-site medical–legal partnership offered help with legal housing problems	Descriptive, retrospective study, 1-group design, number of screened patients not provided, 16 caregivers referred	Experience of care (referral uptake[d])	71% (10 of 14) of referred housing units with outcome data resulted in housing condition repairs. 58% (11 of 19) of building complexes with the same owner received substantial systemic repairs.
Silverstein M, 2004; Seattle, WA (27)	Setting: 4 health clinics. Population: Low-income households with children	Program-developed tool, targeted education	Approach: *Intervention:* Direct referral.[e] *Control*: Indirect referral.[b] Site: US Department of Health and Human Services program (Head Start)	Randomized controlled trial, intervention (n = 123) vs control (n = 123)	Experience of care (referral uptake[d])	Intervention group had more children who connected with the education resource (41%, 50 of 123 vs 18%, 22 of 123; adjusted difference, 17%; 95% CI, 8%–27%) and more children who actively attended the program (25%, 31 of 123 vs 11%, 14 of 123; adjusted difference, 12%; 95% CI, 3%–21%) than the control group.
Dicker RA, 2009; San Francisco, CA (33)	Setting: 1 level I trauma center. Population: Patients aged between 12–30	Screening tool (not specified) targeted risk of reinjury	Approach: Warm handoff[f]. Site: Case management services, including help with court	Program evaluation study, 1-group design, number of screened patients not provided, 44 enrolled	Experience of care (referral uptake[d])	23% of patients with a positive screen for unmet health-related social needs (45 of 195) received full case management services including help with court advocacy, education, vocational training, mental health/drug treatment, employment needs, housing needs, and receiving a driver's

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Reported as the total number of participants who underwent screening. If the study did not report number of screenings, the number of referrals was reported as the sample size.

[b] A referral approach in which health care providers simply hand over information about relevant referral sites to the patient (eg, a list of local food banks and their contact information).

[c] Additional on-site services may include assistance with applying to community-based resources or connection to other resources through a helpdesk, and/or on-site provision of supplies.

[d] Refers to participants who connected to necessary resources expressed as a percentage or ratio of all participants who had a positive screen or those who consented to a referral.

[e] A referral approach that requires the patient's consent to forward their contact information to the corresponding internal or external resource. The referral site then directly contacts the patient.

[f] A referral approach in which patients are introduced to an on-site intermediary person in the health care organization (eg, community health worker, case manager) who works to connect them to referral sites.

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Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
			advocacy, driver's license, educational resources, vocational training, mental health and drug treatment, and more			license.
Coker AL, 2012; Unknown location (32)	Setting: 6 primary care clinics. Population: Women (aged >18 years)	Program-developed tool (56) targeted intimate partner violence	Approach: *Intervention*: Indirect referral,[b] warm handoff,[f] and on-site assistance.[c] *Control:* Indirect referral.[b] Site: Multiple, including coalition services, safety planning, and on-site counseling and support (intervention group only)	Quasi-experimental, longitudinal cohort study, intervention (n = 138) vs control (n = 93)	Experience of care (referral uptake[d])	A similar number of women reported using the referral resource in the intervention and control group (21.4% vs 17.4%; *P* = .43). More intervention women connected with the on-site advocate (32.8% vs 4.4%; *P* < .001) and had lower IPV scores and fewer depressive symptoms (*P* = .07; *P* = .01) than the control.
Klein MD, 2013; Cincinnati, OH (43)	Setting: 3 pediatric clinics. Population: Households with children	EHR-based screening (57) targeted income, child food insecurity, poor housing conditions, domestic violence, parental depression, and anhedonia	Approach: Warm handoff.[f] Site: On-site medical–legal partnership offered help with legal problems	Descriptive cohort study, number of enrolled participants not provided, 1-group design; 1,614 patients referred	Experience of care (referral uptake[d])	1,617 legal cases were pursued by 1,614 referred families. 90% (1,742 of 1,945) of legal outcomes were positive, including improvements in housing conditions, public benefits, education, or provision of legal advice. 10% (n = 203) related to either inability to reconnect with the family or issue resolution.
Uwemedimo OT, 2018; Queens, NY (55)	Setting: 1 hospital-based pediatric practice.	FAMNEEDS targeted parent counseling and education needs, food insecurity, housing/	Approach: Warm handoff[f] before indirect referral.[b] Site: Unspecified partner CBOs	Pre-post intervention study, 1-group design (n = 148)	Experience of care (referral uptake[d])	31% (46 of 148) of households reported using the program-provided resources at 12-month follow-up. More limited English proficiency caregivers used resources (38.4% vs 18.4%, *P* = .03) than English-proficient

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Reported as the total number of participants who underwent screening. If the study did not report number of screenings, the number of referrals was reported as the sample size.

[b] A referral approach in which health care providers simply hand over information about relevant referral sites to the patient (eg, a list of local food banks and their contact information).

[c] Additional on-site services may include assistance with applying to community-based resources or connection to other resources through a helpdesk, and/or on-site provision of supplies.

[d] Refers to participants who connected to necessary resources expressed as a percentage or ratio of all participants who had a positive screen or those who consented to a referral.

[e] A referral approach that requires the patient's consent to forward their contact information to the corresponding internal or external resource. The referral site then directly contacts the patient.

[f] A referral approach in which patients are introduced to an on-site intermediary person in the health care organization (eg, community health worker, case manager) who works to connect them to referral sites.

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Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
	Population: Households with children (<18 y)	utility insecurity, interpersonal safety, transportation, unemployment				caregivers, and more noncitizen caregivers used referrals (37.4% vs 23.1%, *P* = .04) than US citizens.
Garg A, 2015; Boston, MA (23)	Setting: 8 community health centers. Population: Households with infants (<6 mo)	Program-developed tool targeted parent education needs, childcare needs, food insecurity, housing insecurity, unemployment	Approach: *Intervention*: Indirect referral[b] with on-site assistance.[c] *Control*: Indirect referral.[b] Site: Unspecified CBOs	Randomized controlled trial, intervention (n = 168) vs control (n = 168)	Experience of care (referral uptake[d])	Intervention mothers were more likely to enroll in a new community resource (39% vs 24%; aOR = 2.1; 95% CI, 1.2–3.7), had greater odds of being employed or enrolled in a job training program (aOR = 44.4; 95% CI, 9.8–201.4), receiving childcare support (aOR = 6.3; 95% CI, 1.5–26.0), fuel assistance (aOR = 11.9; 95% CI, 1.7–82.9), and lower odds of being in a homeless shelter (aOR = 0.2; 95% CI, 0.1–0.9) than mothers in control group.
Fiori KP, 2020; Bronx, NY (35)	Setting: 1 pediatric clinic. Population: Households with children	EHR-based Health Leads–adapted tool targeted poor access to health care, childcare and eldercare needs, food insecurity, housing insecurity, interpersonal safety, legal needs, transportation	Approach: Warm handoff.[f] Site: Unspecified CBOs	Pragmatic prospective cohort study, 1-group design (n = 4,948)	Experience of care (referral uptake[d])	43% (123 of 287) of patients referred to a community health worker had "successful" referrals. These patients either accessed, obtained, or used the recommended community-based service or support.
Pettignano R, 2011; Atlanta, GA (49)	Setting: 1 pediatric clinic. Population: Households with children with sickle cell disease	Screening tool (not specified) targeted legal needs associated with child needs (eg, childcare, child abuse), education, health insurance, interpersonal safety, unemployment, food insecurity, housing insecurity, and income insecurity	Approach: Warm handoff[f] to HeLP program with on-site assistance.[c] Site: On-site medical–legal partnership offered help with legal problems	Descriptive, retrospective cohort study, number of enrolled participants not provided, 1-group design, 69 patients referred	Experience of care (referral uptake[d])	106 legal cases were pursued by 69 referred households. 93% (n = 99) of the cases were closed. 21% (21 of 99) of the closed cases resulted in measurable gain of benefits including obtaining food stamps, Social Security insurance, family stability, employment, and/or housing and education benefits.

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Reported as the total number of participants who underwent screening. If the study did not report number of screenings, the number of referrals was reported as the sample size.

[b] A referral approach in which health care providers simply hand over information about relevant referral sites to the patient (eg, a list of local food banks and their contact information).

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Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
Garg A, 2012; Baltimore, MD (39)	Setting: 1 pediatric clinic. Population: Households with children	Health Leads targeted education needs, food insecurity, health insurance, housing insecurity, income insecurity, interpersonal safety, transportation needs, unemployment	Approach: Indirect referral.[b] Site: Unspecified CBOs	Prospective cohort study, 1-group design (n = 1,059)	Experience of care (referral uptake[d])	50% (530 of 1,059) of families enrolled in at least 1 community-based resource within 6 months of accessing the on-site Health Leads desk.
Power-Hays A, 2020; Boston, MA (50)	Setting: 1 pediatric hematology clinic. Population: Patients with sickle cell disease	The WE CARE app targeted childcare needs, educational needs, food insecurity, housing insecurity, income insecurity, transportation needs, unemployment	Approach: Indirect referral[b] or warm handoff.[f] Site: Unspecified local CBOs	Qualitative quality improvement project, 1-group design (n = 132)	Experience of care (referral uptake[d])	45% (42 of 92) of patients who were referred and available for follow-up reported reaching out to the CBO.
Hassan A, 2015; Boston, MA (40)	Setting: 1 adolescent/young adult clinic. Population: Patients aged 15–25	Program-developed tool targeted access to health care, education needs, food insecurity, housing insecurity, income insecurity, fitness and safety equipment needs, unemployment	Approach: Indirect referral.[b] Site: Unspecified CBOs	Prospective interventional study, 1-group design (n = 401)	Experience of care (referral uptake[d], patient-reported outcomes)	40% (104 of 259) of patients with a positive screen contacted the referral site of which 50% (52 of 104) had their problem resolved. 60% (155 of 259) did not contact the referral site but 45% (70 of 155) reported having resolved their problem.
Krasnoff M, 2002; Unknown location (44)	Setting: 1 level I trauma center. Population: Women aged 18–65	Partner Violence Screen (58) targeted IPV	Approach: Warm handoff.[f] Site: On-site case manager and other unspecified community-based resources	Observational case study, 1-group design (n = 528)	Experience of care (referral uptake[d], patient-reported outcomes)	84% (475 of 562) of women with a positive screen consented to meeting with an on-site advocate, of whom 54% (258 of 475) then agreed to meet with a case manager. At follow-up, 24% (127 of the 528) of women reported they no longer believed they were at risk for violence from their abuser.
Haas JS, 2015;	Setting(s): 13	Web-based referral	Approach:	Randomized clinical	Experience of care	68.7% (274 of 399) of intervention

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Reported as the total number of participants who underwent screening. If the study did not report number of screenings, the number of referrals was reported as the sample size.

[b] A referral approach in which health care providers simply hand over information about relevant referral sites to the patient (eg, a list of local food banks and their contact information).

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Table 3. Characteristics of Included Studies, Screening and Referral to Identify Unmet Health-Related Social Needs in Health Care Settings

Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
Boston, MA (25)	primary care clinics. Population: Adults that smoke	system HelpSteps targeted multiple social needs	*Intervention*: Direct referral[e] before indirect referral.[b] *Control*: No referral. Site: External specialist (direct referral), unspecified CBOs (indirect referral), and provision of free NRT patches	trial, intervention (n = 399) vs control (n = 308)	(referral uptake[d], patient-reported outcomes)	participants connected with the external tobacco treatment specialist, while 20.1% reported using the HelpSteps referral. Intervention participants who connected with the specialist (21.2% vs 10.4%; $P = .009$) or used the HelpSteps referral (43.6% vs 15.3%; $P < .001$) were more likely to quit than those who did not.
Hsu C, 2019; San Pablo, CA (41)	Setting: 1 primary care practice. Population: Adults	Health Leads targeted childcare needs, food insecurity, health literacy, housing insecurity, income insecurity, transportation	Approach: Warm handoff.[f] Site: Unspecified community-based resources	Qualitative study; semistructured interviews, 1-group design (n = 102)	Experience of care (referral uptake, patient-reported outcomes)	Patients reported concrete changes in their lives including healthier diets, decreased stress or worry, and increased feeling of stability; some reported as resolved immediate food, transportation, or health care needs, and others reported physical or mental/emotional benefits.
Fleegler EW, 2007; Boston, MA (36)	Setting: 2 pediatric clinics. Population: Households with children aged 0–6	Program-developed tool targeted poor access to health care, food insecurity, housing insecurity, income insecurity, and intimate partner violence	Approach: Indirect referral[b] Site: Unspecified local agencies	Cross-sectional descriptive study, 1-group design (n = 450)	Experience of care (referral uptake[d], patient satisfaction)	63% (73 of 115) of referrals received by 79 households led to contact with the referral agency. 82% (60 of the 73) of households considered their referral sites helpful.
Garg A, 2010; Baltimore, MD (38)	Setting: 1 medical home. Population: Households with children	WE CARE-based tool targeted child needs (eg, after-school programs, childcare, child school failure), education needs, food insecurity, health insurance, housing insecurity, public benefits needs, income	Approach: Warm handoff.[f] Site: Unspecified CBOs	Longitudinal cohort pilot study, 1-group design (n = 59)	Experience of care (referral uptake[d], patient satisfaction)	32% (19 of 59) of parents that used the on-site Help Desk reported enrolling in at least 1 community program. 21% (4 of the 19) enrolled in ≥2 community programs. More than 90% of parents who enrolled in a community resource were very or somewhat satisfied.

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		insecurity, IPV, unemployment, safety equipment, and other (eg, smoking, drug or alcohol abuse)				
Gottlieb LM, 2016; San Francisco and Oakland, CA (24)	Setting: 2 safety-net hospitals. Population: Households with children	14-item questionnaire targeted needs related to childcare, education, food insecurity, health insurance, housing insecurity, income insecurity, interpersonal safety, legal aid, transportation, unemployment	Approach: *Intervention:* Warm handoff.[f] *Control:* Indirect referral.[b] Site: Unspecified community, hospital, and government-based resources	Randomized clinical trial, intervention (n = 872) vs control (n = 937)	Experience of care (patient-reported outcomes)	At 4-months postenrollment, intervention participants reported fewer unmet social needs (mean change of −0.39 vs 0.22; $P < .001$) and greater improvement in their child's health than control participants (mean change of −0.36 vs 0.12; $P < .001$).
Dubowitz H, 2009; Baltimore, MD (21)	Setting: 1 pediatric clinic. Population: Households with children aged 0–5	Parent Screening Questionnaire (59) targeted child maltreatment risk factors including parental depression, parental substance abuse, harsh punishment, major parental stress	Approach: *Intervention:* Indirect referral[b] and warm handoff,[f] if needed. *Control:* No referral. Site: Multiple, including local community resources and on-site social workers	Randomized controlled trial, intervention (n = 308) vs control (n = 250)	Experience of care (patient-reported outcomes)	Postintervention, the intervention group had fewer families that filed child protective services reports (13.3% vs 19.2%; $P = .03$), and fewer instances of possible medical neglect including nonadherence (4.6% vs 8.4%; $P = .05$) and delayed immunizations (3.3% vs 9.6%; $P = .002$) than the control group. Control group had more parent-reported harsh punishment ($P = .04$).
Dubowitz H, 2012; Maryland (34)	Setting: 18 pediatric practices. Population: Mothers with children	Parent Screening Questionnaire (59) targeted child maltreatment risk factors including parental depression, parental substance abuse, harsh	Approach: *Intervention:* Indirect referral[b] and warm handoff[f] if needed. *Control*: No referral. Site: Multiple,	Case-control study; intervention (n = 595) vs control (n = 524)	Experience of care (patient-reported outcomes)	Intervention mothers reported less psychological aggression initially and 12 months later (initial effect size $P = .006$; 12-month effect size $P = .047$) and fewer minor physical assaults (initial effect size $P = .02$; 12-month effect size $P = .04$) than control.

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

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Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
		punishment, major parental stress	including local community resources and on-site social workers			
Population health outcomes						
Beck AF, 2014, Cincinnati, OH (30)	Setting: 1 pediatric clinic. Population: Households with infant(s) aged <12 months	Hunger Vital Sign targeted food insecurity	Approach: *Recipients*: Indirect referral[b] and on-site assistance.[c] *Nonrecipients*: No referral. Site: Unspecified CBOs and on-site provision of formula cans	Prospective, difference-in-difference study, recipients (n = 1,042) vs nonrecipients (n = 4,029)	Experience of care (referral uptake[d]), Health	Experience of care: All recipients were more likely to have been referred to social work (29.2% vs 17.6%; *P* < .001), or the medical–legal partnership (14.8% vs 5.7%; *P* < .001) than nonrecipients. Health: By 14 months, recipients versus nonrecipients were more likely to have completed a lead test and developmental screen (both *P* < .001), and a full set of well-infant visits (42% vs 28.7%; *P* < .001).
Sege R, 2015; Boston, MA (26)	Setting: 1 hospital-based pediatric clinic. Population: Households with newborn aged <10 weeks	Screening tool (not specified) targeted food insecurity, housing insecurity, income insecurity	Approach: *Intervention*: Warm handoff.[f] *Control*: No referral. Site: On-site medical–legal partnership	Randomized controlled trial, intervention (n = 167) vs control (n = 163)	Experience of care (referral uptake[d]), Health	Experience of care: Intervention versus control showed accelerated access to resources (baseline, 2.8% vs 1.6%; 6 months, 3.2% vs 2.7%; 12 months, 3.7% vs 3.2%; *P* = .03). Health: Intervention versus control group had more infants that completed their 6-month immunization schedule by age 7 and 8 months (77% vs 63%; *P* < .005 and 88% vs 78%; *P* < .01, respectively), more likely to have ≥5 routine preventive care visits by age 1 year (78% vs 67%; *P* < .01), and less likely to have visited the emergency department by age 6 months (37% vs 50%; *P* = .021).
Patel MR, 2018; Michigan (48)	Setting: 1 endocrinology clinic. Population: Patients with diabetes	Program-developed tool targeted financial burdens	Approach: Indirect referral.[b] Site: Unspecified local and national resources for financial burden and disease management	1-group pre–post pilot study (n = 104)	Experience of care (referral uptake[d], patient satisfaction), Health	Experience of care: More participants were using low-cost resources at 2-month follow-up compared with baseline, such as online diabetes education (40% vs 29%; *P* = .05) and assistance programs related to blood glucose supplies (40% vs 16%; *P* = .03). Participants found the resource tool highly acceptable across 15 indicators (eg, 93%

Abbreviations: BMI, body mass index; CBO, community-based organization; DBP, diastolic blood pressure in mm Hg; EHR, electronic health record; HbA_{1c}, hemoglobin A_{1c}; FAMNEEDS, Family Needs Screening Program; HeLP Program, Health Law Partnership; IPV, intimate partner violence; KIND, Keeping Infants Nourished and Developing; LDL-C, low-density lipoprotein cholesterol in mg/dL; NRT, nicotine replacement therapy; QALYs, quality-adjusted life years; SBP, systolic blood pressure in mmHg; SNAP, Supplemental Nutrition Assistance Program; USDA US HFSS, US Department of Agriculture US Household Food Security Survey; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

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Author, Year; Location (Reference)	Setting; Target Population	Screening Tool and Targeted Unmet Health-Related Social Need	Referral Approach; Referral Site	Study Design, Sample Size[a]	Outcome Assessed	Summary of Results
						"learned a lot," 98% "topics relevant"). Health: Fewer patients reported skipping doses of medicines due to cost concerns (4% vs 11%; *P* = .03) compared with baseline.
Smith R, 2013; San Francisco, CA (52)	Setting: 1 hospital. Population: Victims of violent trauma aged 10–30 years	Screening tool (not specified) targeted high risk for reinjury and others, including need for court advocacy, driver's license, education, employment, family counseling, housing, mental health, vocational/professional training, substance abuse help	Approach: Warm handoff.[f] Site: Unspecified risk-reduction resources	Retrospective cohort study, 1-group design (n = 141)	Experience of care (referral uptake[d]), Health	Experience of care: For 6 years of the program, 254 clients received on-site case management services; a total of 617 needs were identified. 70% (430 of 617) of identified needs were met. Health: The violent injury recidivism rate dropped from an initial 16% to 4.5% by the end of the program.
Berkowitz SA, 2017; Boston, MA (31)	Setting: 3 primary care practices. Population: Adults with chronic disease	Health Leads targeted access to medications, elder care needs, food insecurity, housing insecurity, income insecurity, transportation needs, unemployment	Approach: *Participants:* Warm handoff.[f] *Nonparticipants*: No referral. Site: Unspecified CBOs and public benefits	Pragmatic difference-in-difference evaluation study, participants (n = 1,021) vs nonparticipants (n = 301)	Experience of care (referral uptake[d]), Health	Experience of care: 58% (1,021 of 1,774) of patients with a positive screen enrolled in the program and connected with the on-site advocate. 29.7% of reported needs were closed as "successful," 27.9% as "equipped," 34.9% as "unsuccessful," and 7.1% were handled with a rapid resource referral. Health: Participants versus nonparticipants demonstrated greater improvement in blood pressure (SBP differential change −1.2; 95% CI, −2.1 to −0.4; DBP differential change −1.0; 95% CI, −1.5 to −0.5), and LDL-C (differential change −3.7; 95% CI, −6.7 to −0.6), but no change in HbA_{1c} (differential change −0.04%; 95% CI, −0.17% to 0.10%).
Morales ME, 2016; Chelsea, MA (46)	Setting: 1 obstetric clinic. Population: Women	Program-developed tool targeted food insecurity	Approach: *Recipients:* Indirect referral[b] and on-site assistance.[c]	Retrospective cohort study, 2-group design, recipients (n = 145) vs nonrecipients (n =	Experience of care (referral uptake[d]), Health	Experience of care: 67% (97 of 145) of women referred to the program enrolled. Health: Recipients demonstrated better blood pressure trends during pregnancy (SBP 0.2015 mm Hg/wk lower; *P* = .006 and DBP

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			Nonrecipients: No referral. Site: Food for Families program, which included referral to local food pantries and on-site support with SNAP or WIC enrollment	145)		0.1049 mm Hg/wk lower; *P* = .02). No blood pressure trend among nonrecipients, and no differences in blood glucose trends between the 2 groups (*P* = .40).
Ferrer RL, 2019; San Antonio, TX (22)	Setting: 1 primary care clinic. Population: Patients with type 2 diabetes	Hunger Vital Sign targeted food insecurity	Approach: *Intervention*: Warm handoff.[f] *Control*: Indirect referral.[b] Site: Regional food bank	Randomized controlled trial, intervention (n = 19) vs control (n = 24)	Experience of care (patient-reported outcomes), Health	Experience of care: Intervention group received an average of 7.8 food allotments and were visited at home by a community health worker an average of 2.6 times. Health: Intervention versus control demonstrated a greater drop in HbA_{1c} levels (mean difference of −3.09 vs −1.66; *P* = .01), improved STC-Diet scale (mean differences of 2.47 vs 0.06; *P* = .001), but no significant BMI difference (mean differences of −0.17 vs 0.84; *P* = .43).
Cost-related outcomes						
Aiyer JN, 2019; North Pasadena, TX (28)	Setting: 1 federally qualified health center and 2 school-based clinics. Population: Households with children	Hunger Vital Sign targeted food insecurity	Approach: Indirect referral.[b] Site: Food prescription to local food pantry	1-group design, pre–post mixed methods evaluation study, n = 242	Experience of care (referral uptake[d], patient-reported outcomes), Cost-related (program costs)	Experience of care: 71.1% (172 of 242) of referred patients redeemed their prescription at the food pantry. 94.1% (162 of 172) participants reported a decrease in the prevalence of their food insecurity. Cost-related: Program costs was $12.20 per participant per prescription redemption.
Schickedanz A, 2019; Southern CA (51)	Setting: 1 health care system. Population: Predicted high-utilizer patients	Health Leads targeted child-related needs, educational needs, food insecurity, housing insecurity, income insecurity, transportation	Approach: *Intervention*: Indirect referral.[b] *Control*: No referral. Site: Multiple community-based resources	Prospective difference-in-difference study, intervention (n = 7,107) vs control (n = 27,118)	Experience of care (referral uptake[d]), Cost-related (utilization)	Experience of care: 53% (1,984 of 3,721) of screened participants reported social needs, but only 10% of those connected with resources. Cost-related: Intervention versus control showed 2.2% decline in utilization visits (*P* = .058) over 1-year postintervention, including emergency department visits, inpatient hospitalizations, and ambulatory

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		needs, unemployment	including food banks, housing programs, and other agencies			visits. Greater declines in total utilization for all low-socioeconomic status subgroups in intervention versus control ($P < .001$).
Juillard C, 2015; San Francisco, CA (42)	Refer to Smith R, 2013 (52)	Refer to Smith R, 2013 (52)	Refer to Smith R, 2013 (52)	Cost-effectiveness analysis of Smith R, 2013 (52)	Cost-related (cost effectiveness and cost savings)	Cost-related: Realized substantial health benefits (24 QALYs) and savings ($4,100) if implemented for 100 people.

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ORIGINAL RESEARCH

Community and Research Perspectives on Cancer Disparities in Wisconsin

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PEER REVIEWED

SUMMARY

What is already known about this subject?

Listening sessions and interviews with community and research groups provided unique insight into factors that contribute to cancer disparities, barriers to improving outcomes, and opportunities to improve health.

What is added by this report?

Analyzing data through The Model for Analysis of Population Health and Health Disparities contributed to our understanding of how different groups understand factors associated with disparities and where opportunities for meaningful collaboration exist.

What are the implications for public health practice?

The model allowed us to more fully understand the importance of seeking solutions to cancer disparities through a multisector approach rooted in the specific needs of communities.

Abstract

Introduction

Significant disparities are apparent in geographic areas and among racial/ethnic minority groups in Wisconsin. Cancer disparities are complex and multifactorial and require collaborative, multilevel efforts to reduce their impact. Our objective was to understand cancer disparities and identify opportunities to collaborate across community and research sectors to address them.

Methods

From May 2017 through October 2018, we assembled groups of community members and researchers and conducted 10 listening sessions and 29 interviews with a total of 205 participants from diverse backgrounds. Listening sessions and interviews were scheduled on the basis of participant preference and consisted of a brief review of maps illustrating the breast and lung cancer burden across Wisconsin, and a semistructured set of questions regarding causes, solutions, and opportunities. Interviews followed the same structure as listening sessions, but were conducted between a facilitator and 1 or 2 individuals. Major themes were summarized from all sessions and coded. We used the Model for Analysis of Population Health and Health Disparities to identify areas for collaboration and to highlight differences in emphasis between community participants and researchers.

Results

Participants identified the need to address individual behavioral risks and medical mistrust and to build equitable multilevel partnerships. Communities provided insights on the impact of environment and location on cancer disparities. Researchers shared thoughts about societal poverty and policy issues, biologic responses, genetic predisposition, and the mechanistic influence of lifestyle factors on cancer incidence and mortality.

Conclusion

Listening sessions and interviews provided insight into contributors to cancer disparities, barriers to improving outcomes, and opportunities to improve health. The unique perspectives of each group underscored the need for multisector teams to tackle the complex issue of cancer disparities.

Introduction

Cancer incidence and mortality in the United States have decreased overall in recent years, but not equally across all populations. Disparities may be related to race, ethnicity, socioeconomic status, and geographic location, and their underlying causes are complex and multifactorial (1–3). An interplay of biology, individual behavior, socioeconomic status, social conditions, social norms, and environment contribute to disparities in cancer incidence, late-stage diagnosis, and mortality (4–5). In Wisconsin, where cancer is a leading cause of death, significant disparities are apparent in geographic areas and among racial/ethnic minority groups (6–9). Wisconsin has the nation's second largest Black–White disparity in lung cancer mortality, and the Milwaukee metropolitan area has the largest Black–White disparity in lung cancer mortality among metropolitan areas nationwide (rate ratio = 1.635). Additionally, Wisconsin has the nation's third largest Black–White disparity in female breast cancer mortality (rate ratio = 1.600) (6,9).

Recognizing the impact lung cancer and female breast cancer have in Wisconsin, the Advancing a Healthier Wisconsin Endowment committed a substantial investment to reduce breast and lung cancer disparities (10). The endowment sought an innovative solution that leveraged the strengths of community-based organizations, population health, and basic science. As a first step, the endowment convened a design team of 10 representatives from research and community settings. The team's objective was to engage people from different disciplines and communities with varied perspectives on the causes of breast and lung cancer disparities and to inform effective strategies to collaborate across these sectors. To achieve this, the design team conducted statewide focus groups with diverse participants. Team members recommended calling the groups "listening sessions" because facilitators were there to listen, not examine as in a focus group. We describe the listening-session approach and key findings from the sessions.

Methods

Recruitment

The design team (authors J.O., T.C., K.B., D.F., L.I., S.M., L.P., J.S., A.W., C.W., M.S.) met regularly from March 2017 to October 2018 and used publicly available maps to identify areas of Wisconsin where lung and female breast cancer rates were higher than expected and where rates of the 2 cancers differed from each other (Figure 1) (11). Nine counties of interest were identified on the basis of apparent disparities in breast and lung cancer incidence and mortality. We contacted public health directors from each county department of health by email to explore their interest in organizing listening sessions and interviews. We sent a follow-up email, followed by a telephone call, to directors who did not respond to the initial email. Of the 9 counties, 7 directors expressed interest, and their counties were included: Marinette, Milwaukee, Oconto, Racine, Vilas, Oneida, and Walworth. The county communities were diverse in their populations' racial/ethnic make-up and other socioeconomic indicators (Table 1).

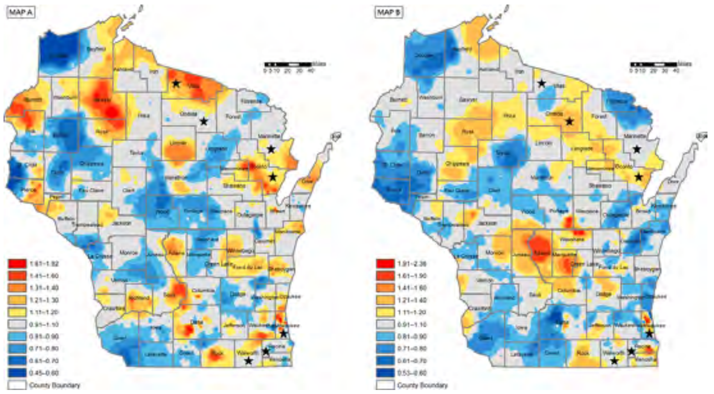

Figure 1. Female breast cancer mortality rate (Map A) and lung cancer mortality rate (Map B), Wisconsin, 2008–2013. The female breast cancer mortality rate is indirectly age standardized and smoothed using adaptive spatial filtering. The lung cancer mortality rate is indirectly age–sex standardized and smoothed using adaptive spatial filtering. A grid of points is used to estimate mortality rates continuously across the map, based on the 20 closest breast cancer deaths and the 40 closest lung cancer deaths. Red areas indicate higher rates than expected and blue areas indicate lower rates than expected, compared with the regional rate. Areas without color indicate rates close to the regional rate. Data source: State Vital Records Office, Wisconsin Department of Health Services 2008-2013 (12). Reprinted with permission of Yuhong Zhou, PhD, and Kirsten Beyer, PhD, MPH, MS, Medical College of Wisconsin.

A total of 205 people participated in either listening sessions or interviews from May 2017 through October 2018. To represent the biomedical science groups (bench, clinical, and population health researchers), we invited 50 researchers from Wisconsin and 26 researchers at a national conference. Forty-seven Wisconsin researchers and 20 national researchers accepted. All participants in the biomedical science groups had expertise in cancer and/or disparities research. For this group, 5 sessions were held with a maximum of 11 participants each. In community groups, public health directors who expressed interest in hosting listening sessions invited members of their community that they believed would have insight on cancer incidence in their community. Community participants were leaders from community and nonprofit organizations, community health workers, nonaffiliated community members, directors of federally qualified health centers and free clinics, and public health professionals. We conducted 5 listening sessions (participant number determined by public health director) and 29 interviews (1–2 participants per session) with community groups.

We also conducted a listening session at a statewide meeting of Wisconsin's Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. For all participants, participating in a listening session or interview was determined by the participant's preference and availability.

Listening sessions and interviews

Our multidisciplinary team of community members and researchers conducted 10 listening sessions and 29 interviews with a total of 205 individuals from diverse backgrounds. We developed a format for successful engagement across diverse groups of communities and researchers (Table 2). All listening sessions and interviews were conducted by design team members (authors T.C., J.O., M.S., K.B., C.W.) or trained facilitators with cancer disparities knowledge, public health expertise, and qualitative data collection experience. Listening sessions and interviews were not audio- or video-recorded because public health officials said that participants would engage more freely if not being recorded. A team member took detailed notes on session content and documented observations related to participant affect or interactions at all interviews and listening sessions. Because sessions were not audio- or video-recorded, documenting body language and behavior added context for qualitative analysis. Following each interview or listening session, the notetaker prepared de-identified summaries, and participants were given the opportunity to review them for completeness and accuracy.

Interviews were scheduled for 60 minutes and listening sessions for 90 minutes. Questions and probes were determined a priori by the design team to capture research and community perspectives on causes and challenges contributing to breast and lung cancer disparities statewide and opportunities to improve health outcomes. To ensure that the verbiage of questions would be understood across community and research populations, the design team tested the applicability of questions across diverse groups with peers and social networks and used their feedback to inform revisions. At listening sessions, the facilitator encouraged participants to openly share their perceptions of their home community, communities statewide, and the environment of cancer research. Participants then examined statewide maps of breast and lung cancer incidence and mortality and discussed whether what they saw in the maps validated or opposed their previous thoughts about community health and cancer disparities. At the end of the listening sessions and interviews, participants were encouraged to ask questions about future directions and were informed of ways to stay connected to the study.

Data analysis

Two trained researchers (T.C., J.O.) coded summaries and observational notes using ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH). In the first round of coding, researchers used open coding to identify themes, key concepts, ideas, beliefs, or events. Researchers met frequently to compare and modify codes and resolve discrepancies through discussion or consultation with a third reviewer. After completing open coding of themes (Table 2), the themes that emerged strongly aligned with The Model for Analysis of Population Health and Health Disparities, a model that illustrates multilevel contributors to cancer disparities, including individual behavior and risk, context, and population factors (13). A second round of coding was then conducted to help identify thematic similarities and differences between researchers and community members to inform opportunities for collaboration or identify experiential gaps that might require further attention (Table 3). All procedures were reviewed and approved by the Medical College of Wisconsin's institutional review board.

Results

Interviews and listening session participants

Listening session and interview participants totaled 205. Twenty-nine interviews were conducted across Wisconsin counties (Marinette, 10 interviews; Oconto, 6; Racine, 7; and Walworth, 6) and consisted of either 1 or 2 participants per interview for a total of 35 people interviewed and 170 participants in listening sessions (Figure 2).

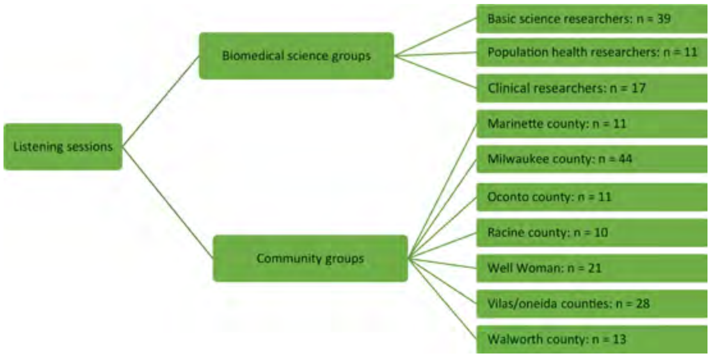

Figure 2. Composition of listening sessions and interviews. A total of 205 participants answered semistructured questions about communities and cancer disparities in Wisconsin. Sixty-seven participants represented basic, population health, and clinical research, and 138 participants represented community perspectives. We also conducted a listening session at a coordinators meeting of Well Woman, the Wisconsin's Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program.

Open coding revealed a broad range of contributors to cancer disparities: biologic contributors, research needs, behaviors and comorbidities, demographic factors, geographic location, environment, social conditions, institutional barriers, and policy issues (Table 2).

Biologic contributors. All sessions acknowledged genetic predisposition for cancer. Modifiable risk factors were believed to be the predominant contributors to cancer disparities, but researchers recognized that some communities were possibly more likely than others to experience geographic disparities through rural isolation and small community size and therefore inherit cancer-causing genes disproportionately.

Research needs. Researchers acknowledged difficulties in recruiting diverse populations for sample collection and clinical trials. One researcher said she had diverse racial and ethnic participation when she began recruitment for a clinical trial, but by the end, “all of the non-White participants had dropped out,” and she had no idea why. Another basic scientist said he was “aware of disparities in cancer incidence” within the type of cancer he studied but was unsure about how to incorporate that into his animal-based research.

Behaviors and comorbidities. All listening sessions discussed the considerable impact of smoking, stress, diet, and lack of physical activity on rates of cancer incidence and mortality. Researchers also discussed the impact of reproductive factors, such as parity, breastfeeding practices, and the use of hormone replacement therapy on breast cancer. Community participants had specific ideas to improve health outcomes that would address local concerns. For example, in one rural area of Wisconsin with high levels of summer tourism, community members said that walking paths in the area would be used by local residents much more often if the paths actually went places (like the grocery store), instead of in circles (for the tourists). Another community participant said that a great opportunity to conduct an intervention would be at “thresherees,” which are gatherings of local agricultural community members during harvest seasons.

Demographic factors. Community health care providers said that many of their current research efforts focused on educating communities and increasing knowledge and awareness of cancer-causing agents. In 5 of the 7 counties visited, health care providers shared that adults in their area were aware that they should eat better, be more active, and either eliminate or reduce tobacco and alcohol consumption, yet had little interest in modifying behavior.

Geographic location. Both community participants and researchers discussed the influence of distance and travel time on health care, but these were not the sole concerns related to access. In 2 separate listening sessions, participants said that they would “have to be dying” to seek care at their local health care facility and would prefer to drive an hour or more to larger cities for what they trusted to be better quality care. In urban settings, mistrust stemmed from experiences and beliefs that care would be delivered differently because of the race, ethnicity, or socioeconomic status of the patient. Researchers and public health experts discussed this mistrust but did not acknowledge its nuances in different demographic groups.

Environment. Community participants expressed concerns about airborne, housing, and workplace exposures to harsh chemicals and environmental pollutants, which differed by region. In northern Wisconsin, industrial chemicals found in paper mills and mining were mentioned, and in agricultural areas throughout the state, exposure to pesticides and herbicides were referenced as concerns. Participants from urban areas expressed more concern about pollution and quality of housing. Researchers acknowledged the impact of the environment on health and were knowledgeable about the high levels of radon in certain Wisconsin communities, but did not focus discussions on any other community-specific exposures.

Social conditions. Population health researchers and community participants shared that a significant disparity between communities exists in the way that tobacco and alcohol are promoted. Sale of tobacco and alcohol is promoted in areas where racial/ethnic and sex and gender minority groups reside, whereas health care, healthy foods, and healthy behaviors are promoted more in suburban, affluent areas with predominantly White populations. In rural communities, participants said, “everybody smokes” and “everybody drinks.” A public health professional said in an interview that tobacco use was so prevalent that when young women become pregnant, they merely switched from cigarettes to chewing tobacco for the duration of their pregnancy. Participants from communities across Wisconsin said that alcohol is expected at all social gatherings.

Institutional barriers. All participants acknowledged the institutional challenges to reducing cancer disparities. Researchers cited challenges in obtaining funding, building new partnerships, and then sustaining connections when funding runs out. In communities, institutional barriers were centered around the limited time or resources to form new partnerships and launch programs and the shortage of physicians in an area. A rural nurse practitioner shared that many community members were unwilling (because of perceptions) or unable (for insurance reasons) to receive care from nurse practitioners or health professionals with nonterminal degrees.

Policy issues. Listening sessions revealed issues with insurance and generic drug costs, societal poverty, and challenges in banning carcinogenic substances. In multiple listening sessions in northern Wisconsin, community participants said that despite the presence of a statewide indoor smoking ban, smoking was still prevalent in taverns, restaurants, and other public places. Community groups discussed agricultural pesticide use and said that determination of which chemicals are allowed is based on their cost and farmers' preference without consideration for the health of community members.

By using the Model for Population Health and Health Disparities as a framework to compare research and community perspectives, we were able to compare areas of emphasis between groups. The model served as a powerful tool to identify areas with shared knowledge for future multisector collaboration (Table 2) and areas where more education was likely needed (Table 3).

Areas with shared knowledge. Areas with shared knowledge indicated topics with potential for rapid, multisector collaboration. For example, all participant groups discussed the contribution of individual risk factors to cancer disparities but had different expertise and interests in the topics discussed. Alcohol consumption was identified as a contributing factor to cancer across groups, and basic science researchers focused on understanding cellular and molecular mechanisms and discussed work being conducted by local experts that could be focused on state-level issues (14). Population health researchers focused on frameworks that drive lifestyle choices, such as the Transtheoretical Model, and successful interventions to improve health outcomes (15,16). Community participants focused on the social and cultural norms specific to their area.

Areas with differences in emphasis between participant groups. Areas where emphasis differed between groups showed that more education would likely be needed to create multisector teams. For example, basic science researchers focused heavily on the mechanisms of DNA and cellular damage and protective factors that need to be better understood. Only researchers mentioned how reproductive and gynecologic factors such as breastfeeding practices, parity (having borne children), and the use of hormone replacement therapy were factors in breast cancer incidence. Community participants had unique insights regarding the physical context of cancer disparities, that is, how the environment and location affect health outcomes. They went into detail about specific agricultural, industrial, workplace, and home exposures that may affect health. For example, in Northern Wisconsin, heavy snowfall can block roads and prevent trucks from delivering propane to heat homes throughout winter and into April and May. To compensate for this, some residents switch to burning wood as a heat source. Wood smoke is a source of benzene, defined as a carcinogen by the International Agency of Research on Cancer. However, limited research has examined the correlation between home heating with open fires or closed burners and cancer incidence (17). Although researchers discussed how social context in general contributes to cancer disparities, community participants had extensive knowledge about the complex, community-specific interplay of social relationships, social conditions, and policy.

Use of maps to stimulate discussion

We found use of maps to be a critical factor in our investigation. Although both community and research groups tended to focus on the maps or the specific geographic elements where disparities were high, the maps were useful in helping participants go beyond their initial thoughts on factors influencing disparities. As a result of sharing maps, researchers who were previously unaware of cancer disparities were eager to learn more and share access to research equipment (such as next generation imaging and sequencing technology), collaborators, and expertise. Community participants in urban areas were largely aware of cancer disparities, but seeing the warm or hot colors on the maps illustrating the additional burden in their region resulted in comments of interest, dismay, confusion, and commitment ("we need to do something about this"). In rural communities, where initial conversations focused on the fresh air, outdoor activities, and environment that are healthier than that of urban settings, participants were surprised by the maps. Seeing the warm or hot colors on their rural regions on the map indicating high cancer incidence and mortality shifted the discussion to possible causes, such as industrial and agricultural exposures, cultural norms, and health care quality.

Discussion

The US Department of Health and Human Services called for the elimination of health disparities and achievement of health equity in Healthy People 2020 (4). Our statewide listening sessions and interviews with community members and researchers uncovered multisector factors that contribute to disparities. Previous studies used this listening session approach to uncover barriers between community and science that need to be addressed to reduce health disparities, such as cultural humility and skepticism and mistrust about research (18,19). In our study, we sought to understand the differences in emphasis that diverse participants in research and community settings would place on causes of cancer disparities. When we used disparities-based frameworks in different settings (such as research vs community settings), focus on aspects of the Model for Analysis of Population Health and Health Disparities (13) shifted. This is likely a major reason that disparities are difficult to address. It is challenging for participants to draw their focus from what is most salient to them and examine broader perspectives. We found that each group offered a unique perspective based on their expertise and experience and acknowledged that other sectors also needed to make a significant impact to reduce cancer disparities. Across communities, there was a shared desire to improve health outcomes, and multiple suggestions were offered as first steps. All groups wanted to reduce disparities and improve health outcomes and identified the following 3 key issues to address.

Major contributors to cancer disparities are complex and vary between regions and communities. The root causes of cancer disparities are complex and multifactorial. Eliminating cancer disparities statewide requires consideration of the unique factors among communities that underlie disparities. Our statewide listening sessions revealed isolated incidents of environmental contamination, deeply ingrained cultural norms, and institutional barriers that all need to be acknowledged. Nationwide, it is clear that a one-size-fits-all approach across diverse community settings is not sufficient. Previous studies have demonstrated that risk factors contributing to mortality and prognoses differ between races and geographic locations (20,21). The Model for Analysis of Population Health and Health Disparities (13) illustrates the impact of many proximal, distal, and intermediate factors on health. When examining the contributors to health disparities outlined in our listening sessions, factors from each category of this framework emerged (Table 3). Unlike smaller studies that highlighted a central focus for interventions, statewide efforts require interventions that can be tailored to the cultural and geographic needs of the communities affected by cancer disparities (18,19).

Shared knowledge between researchers and community members is needed. Researchers and community groups discussed differing priorities regarding cancer disparities. In our listening sessions, researchers expressed a need for more diverse participation in clinical trials and biospecimen donations. This was a recurrent theme across basic, clinical, and population researcher sessions. Aside from issues of medical mistrust, confusion about the importance of clinical trials is prevalent in communities nationwide, and conceptual frameworks have been created to maximize diverse participation in trials (22–24). In our community listening sessions, clinical trials and biospecimen sample donation were not mentioned. Shared understanding, identification, capacity building, and removal of individual and system-level barriers will be required to bridge the gap between community and research priorities (25–28).

Multisector partnerships are needed to eliminate cancer disparities. Our study showed that broad understanding and appreciation for local social, cultural, and biological influences on cancer disparities is needed in a multisector team setting to achieve health equity in Wisconsin. Efforts are needed to bridge gaps in communication regarding sample donation and disease model development, which basic science researchers valued more than did population health researchers or community members. Basic scientists, conversely, had limited expertise in how social conditions and policy influence health disparities. Given the community and research perspectives on cancer disparities that we observed, educational approaches or guided facilitation will be required to create collaborative efforts. One opportunity to accomplish this would be through the development of training programs that intentionally bring interested participants from biomedical research (basic and population science) and community settings together to learn about each other's worlds and to inform research questions that meet community concerns.

One of our most encouraging findings was the acknowledgment across groups of a need for partnerships, improved training, and patient support. Both researchers and community groups acknowledged that funds and time are limited resources; however, they referenced small coalitions and existing partnerships focused on cancer disparities and population health that have had success in outreach programming or grant funding efforts. Although individuals in all sectors expressed willingness to be a part of a larger collaborative group, partnerships between researchers and community generally do not occur organically. These relationships and interactions need to be fostered and facilitated to ensure equity in influence and outcomes. Although a capacity needs to be built to conduct multidisciplinary, cross-cutting work, research and community-based resources, opportunities, and enthusiasm exist to reduce breast and lung cancer incidence and mortality statewide. Ultimately, our study informed effective strategies for multidisciplinary teams to understand cancer disparities and to collaborate across sectors. This approach is recommended for large- or small-scale initiatives to address complex, multifactorial health issues.

Our study had limitations. The design team did not frame its questions around the Model for Population Health and Health Disparities (13). Also, the absence of discussion of an issue did not necessarily mean an absence of understanding or a lack of desire to address an issue at a research or policy level. Listening sessions were approximately 90 minutes long, and in some groups, discussion was extended around some topics, which limited the amount of time for discussion of other topics. Listening sessions were not taped or transcribed; therefore, our analysis relied on the accuracy of notetaking.

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Tables

Table 1. Demographic Characteristics, Wisconsin and 7 Participating Counties, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018

Characteristic	Wisconsin	County						
		Marinette	Milwaukee	Oconto	Oneida	Racine	Vilas	Walworth
Population	5,813,434	40,434	948,207	37,830	35,470	196,584	21,938	103,718
Median household income, $	59,209	47,497	48,742	57,105	54,198	59,749	44,285	61,106
Poverty, %	11.0	12.0	19.1	9.2	9.4	12.6	10.9	10.1
Uninsured aged <65 y, %	6.5	6.2	8.1	6.3	6.3	6.2	10.2	8.5
Race/ethnicity, %								
White	81.1	95.1	51.0	94.8	94.7	71.7	84.8	85.3
Black	6.7	0.6	27.2	0.4	0.7	12.0	0.4	1.2
American Indian	1.2	0.8	1.0	1.5	1.2	0.7	11.1	1.1
Hispanic/Latino	6.9	1.9	15.4	1.8	1.6	13.4	2.8	11.2
Female breast cancer 2012–2016								
Age adjusted incidence rate per 100,000[a]	68.0	62.0	74.6	63.4	78.7	69.7	74.0	68.6
Late-stage diagnosis, % of total cases	32.5	37.2	35.6	36.9	37.3	34.4	27.5	32.2
Age adjusted mortality rate per 100,000[a]	10.7	9.8	11.9	11.7	9.8	10.4	10.7	11.0
Lung cancer 2012–2016								
Age adjusted incidence rate per 100,000[a]	59.8	69.8	69.1	64.6	74.6	68.7	72.0	60.0
Late-stage diagnosis, % of total cases	74.3	78.7	77.0	86.0	87.6	74.5	84.3	77.0
Age adjusted mortality rate per 100,000[a]	41.0	48.9	46.6	46.1	48.3	44.9	41.1	45.6

[a] Age adjusted to 2000 US standard population.

Table 2. Listening Session and Interview Questions Asked and Participant (N = 205) Characteristics, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018

Listening Session and Interview Format	Justification
Characteristic	
Homogeneous	Create an environment where groups feel comfortable sharing experiences.
Facilitated	Enable open conversation that respects cultural, racial/ethnic, or research identities.
Transparent	Ensure the intentions of data collection are clear, and participants understand their ability to stay informed and continue to give feedback throughout the project.
Valid	Seek feedback from a representative from each community after compilation of data, and make modifications, additions, or redactions before dissemination.
Respectful	Establish at the beginning of each listening session or interview that all opinions are valid, and all participants may finish their thoughts without interruption.
Flexible	Tailor sessions to be responsive to participant needs, including group size, style, language, format, and familiarity with the topic of cancer disparities.
Question	**Probe (if needed)**
Research: How would you describe the health of Wisconsin communities? Community: How would you describe the health of your community?	Research: Rank the health of Wisconsin communities and explain. Community: Rank the health of your community and explain. (A = Excellent, F = Terrible)
If money or resources were no issue, what would you do to improve cancer disparities?	Are there assumptions that people make about (your community/research)?
Why do maps of breast and lung cancer incidence and mortality look the way that they do?	Are there things that surprise you or don't surprise you?
Listening session and interview results, contributors to cancer disparities	**Examples**
Biologic contributors	Genetic predisposition
Research needs	Better cancer detection, availability of samples from different populations, funding
Behaviors and comorbidities	Obesity, poverty, alcoholism, smoking, diet, exercise, stress, reproductive factors, breastfeeding, use of hormone replacement therapy
Demographic factors	Health literacy, gender, race/ethnicity, childhood education
Geographic location	Distance to care, location of care, availability of transportation
Environment	Airborne, housing, and workplace exposures, radon, water quality
Social conditions	Social isolation, cultural norms, social support
Institutional barriers	Availability of quality care, patient support, availability of partnerships and funding sources, medical mistrust
Policy issues	Insurance coverage, societal poverty, generic drug availability, adherence to policy

Table 3. Topics Discussed in Listening Sessions and Interviews, Community and Research Perspectives on Cancer Disparities, May 2017–October 2018[a]

Topic of Discussion	Research Participants		Community Participants (n = 158)
	Basic/Clinical (n = 36)	Population Health (n = 11)	
Biologic and genetic pathways			
Availability of technology, samples, and models	X		
Genetic predisposition	X	X	X
Mechanisms of protection or damage	X		
Biologic responses			
Alcohol, obesity, and stress	X	X	X
Individual risk factors			
Medical mistrust, delay to diagnosis, completion, adherence to care	X	X	X
Reproductive/gynecologic factors	X	X	
Individual diet, alcohol, tobacco, and illegal drug use	X	X	X
Individual demographics			
Access to care		X	X
Childhood and community education		X	X
Cultural and acculturation		X	X
Gender and race	X	X	X
Employment and socioeconomic status		X	X
Physical context			
Environment (agriculture, home, community, workplace exposures)	X	X	X
Location (urban, rural, green, isolated)	X	X	X
Social relationships			
Acceptability of alcohol consumption and smoking	X	X	X
Social factors (support, isolation, pride, self-efficacy)		X	X
Social context			
Effectiveness of partnerships	X	X	X
Social capital	X	X	X
Institutional context			
Adequate patient support, care, and physician training	X	X	X
Capacity for multidisciplinary work	X	X	
Guideline concordant care, hospital volume, cancer detection		X	
Need for champions and funding opportunities	X		X
Social conditions and policy			
Environment, housing, and insurance-based policy		X	X
Insurance issues		X	X
Social inequality and societal poverty	X	X	X

[a] X indicates that the topic was discussed in the basic/clinical research, population health research, and/or community groups.

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ORIGINAL RESEARCH

Urban–Rural Disparities in Access to Low-Dose Computed Tomography Lung Cancer Screening in Missouri and Illinois

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PEER REVIEWED

Summary

What is already known on this topic?

Low-dose computed tomography (LDCT) screening for lung cancer is recommended for current and former smokers meeting eligibility criteria. As of 2017, rural areas generally had less geographic access to LDCT screening than urban areas.

What is added by this report?

Despite the recent proliferation of LDCT screening, rural areas in Missouri and Illinois have low levels of access to screening. We observed no association between geographic access to screening and lung cancer mortality.

What are the implications for public health practice?

As LDCT screening becomes more widespread, future studies need to evaluate its effects on population-level lung cancer mortality rates in urban and rural areas.

Abstract

Introduction

Low-dose computed tomography (LDCT) lung cancer screening is recommended for current and former smokers who meet eligibility criteria. Few studies have quantitatively examined disparities in access to LDCT screening. The objective of this study was to examine relationships between 1) rurality, sociodemographic characteristics, and access to LDCT lung cancer screening and 2) screening access and lung cancer mortality.

Methods

We used census block group and county-level data from Missouri and Illinois. We defined access to screening as presence of an accredited screening center within 30 miles of residence as of May 2019. We used mixed-effects logistic models for screening access and county-level multiple linear regression models for lung cancer mortality.

Results

Approximately 97.6% of metropolitan residents had access to screening, compared with 41.0% of nonmetropolitan residents. After controlling for sociodemographic characteristics, the odds of having access to screening in rural areas were 17% of the odds in metropolitan areas (95% CI, 12%–26%). We observed no association between screening access and lung cancer mortality. Southeastern Missouri, a rural and impoverished area, had low levels of screening access, high smoking prevalence, and high lung cancer mortality.

Conclusion

Although access to LDCT is lower in rural areas than in urban areas, lung cancer mortality in rural residents is multifactorial and cannot be explained by access alone. Targeted efforts to implement rural LDCT screening could reduce geographic disparities in access, although further research is needed to understand how increased access to screening could affect uptake and rural disparities in lung cancer mortality.

Introduction

Low-dose computed tomography (LDCT) screening has increased the ability to detect early-stage lung cancer in recent years (1). The National Lung Screening Trial showed that LDCT screening reduces risk of lung cancer death by up to 20%, compared with chest x-ray (1). In light of this evidence, the US Preventive Services Task Force (USPSTF) issued a recommendation to provide annual LDCT screening to adults aged 55 to 80 who have at least a 30 pack-year smoking history, currently smoke or quit in the past 15 years, and have no lung cancer symptoms (2). Medicare subsequently began reimbursing screening of adults aged 55 to 77 (2). Unique among cancer screenings, LDCT reimbursement is contingent on provision of smoking cessation counseling and shared decision making, both of which are also billable services (2).

The burden of these requirements on physician practices, along with the high rate (>95%) of false-positive test results (1), may explain why screening rates are low. Although the number of accredited LDCT centers nationwide increased from an estimated 203 in 2014 to 1,748 in early 2017 (3), a study of 10 geographically diverse US states found that 12.7% of adults aged 55 to 80 met USPSTF criteria for LDCT screening in 2017, but of these adults, only 12.5% reported receiving screening in the previous year (4).

Barriers to LDCT screening persist — rural residents nationwide have less access, defined as distance and driving time, to LDCT screening than their urban counterparts (3,5). Although more than 95% of adults aged 55 to 79 in 8 northeastern states (Connecticut, Delaware, Maryland, Massachusetts, New Jersey, New York, Pennsylvania, Rhode Island) have access to a screening center within 30 miles (Euclidean distance), the proportion in the Midwest (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin) is lower and highly variable (22%–93%) (3).

Our investigation focused on Missouri and Illinois, both Midwestern states in the upper Mississippi Delta, a region marked by high cancer mortality (6). Missouri and Illinois are home to 6.1% of the US population and contain a heterogeneous mix of geographies, from densely populated cities to rural farmland. Both states reflect the nationwide pattern of higher smoking prevalence in rural areas than in urban areas (7).

The 2 states have significantly different policies on health care and tobacco. Illinois was an early expander of Medicaid under the Affordable Care Act, whereas Missouri was not. The state cigarette tax is more than 15 times higher in Illinois ($2.98/pack) than in Missouri ($0.17/pack) (8). Demographically, Missouri has a higher proportion of rural residents than the United States as a whole (29.6% for Missouri vs 19.3% nationwide), whereas Illinois, at 11.5%, has a lower proportion (9). A study published in 2018 identified Missouri as a state with moderate access to LDCT screening and high lung cancer mortality and Illinois as a state with high access to screening and moderate mortality (3).

Given rural–urban differences and the importance of using precise and localized estimates to drive public health priorities (10), we performed a detailed analysis of screening access in Missouri and Illinois. Efforts to reduce rural–urban disparities in LDCT screening and lung cancer mortality require county-specific information on screening “deserts” and mortality hotspots (6). As such, the primary objective of this study was to identify locations in Missouri and Illinois that have high lung cancer mortality and/or cigarette smoking rates but low levels of access to LDCT screening; these locations are priority areas for intervention. We built on previous work (5) by using multilevel, mixed-effects modeling to quantify the association between rurality, sociodemographic characteristics, and access to screening at the census block group level. Additionally, a secondary objective was to conduct an exploratory analysis of the relationship between access to screening and lung cancer mortality.

Methods

Data management

We collected and organized data by using methods similar to those of Eberth et al (3). In May 2019, we obtained addresses of screening centers accredited by the American College of Radiology (11) and Lung Cancer Alliance (now GO_2 Foundation for Lung Cancer) Screening Centers of Excellence (12). We compiled addresses for 356 centers in Missouri, Illinois, and all neighboring states (Arkansas, Indiana, Iowa, Kansas, Kentucky, Michigan, Nebraska, Oklahoma, Tennessee, Wisconsin). We collected addresses from neighboring states because patients may cross state lines to reach the nearest center. When multiple screening centers were located on a single hospital campus, we randomly chose 1 center. Additionally, we removed from analysis 1 center in Indiana that was closed. We performed automatic geocoding in ArcGIS Desktop version 10.6 using the USA Geocoding Service (Esri). We used interactive rematch for screening centers that matched equally well to multiple street addresses.

We manually rematched all unmatched centers and centers matched to a zip code rather than a street address (n = 56 centers) by using a Google Maps API (application programming interface; https://developers.google.com/maps/documentation/geocoding/intro). Consistent with the methods of Eberth et al, we constructed a 30-mile planar buffer around each screening center to represent the area in which that center was deemed accessible (3). A nationwide study comparing driving distance and straight-line distance from all census tracts to the closest hospital found that the 2 measures are highly correlated in the absence of shorelines, mountains, or other physical barriers (13). Missouri and Illinois contain few such barriers; thus, we felt justified in using a 30-mile straight-line buffer. Hospital “deserts” are defined by the lack of a hospital within a 30-mile radius (14). Consistent with Eberth et al, we considered a center accessible to residents of census block groups whose centroids lay inside the buffer (3).

We used these data to calculate the county-wide percentage of residents aged 55 to 79 who have access to LDCT screening within 30 miles. We obtained census block group–level data on age from American Community Survey (ACS) 2013–2017 five-year estimates (15). Of the available categories, the age group 55 to 79 was the closest option to the recommended screening age range of 55 to 80 (15).

Measures

Screening access measure. We dichotomized access to LDCT screening at the census block group–level as presence or absence of at least 1 center within 30 miles of the centroid. At the county level, we quantified access by the proportion of adults aged 55 to 79 who lived in a census block group and met this criterion. Because appropriate data on smoking status were unavailable, we assumed that the ratio of adults aged 55 to 79 to LDCT-eligible adults was roughly constant across all census block groups in a county.

Rurality measures. We used census tract–level rural–urban commuting area (RUCA) codes to measure rurality (16). For modeling purposes, we grouped codes 1 to 3 as metropolitan, codes 4 to 6 as micropolitan, and codes 7 to 10 as small town/rural areas. However, because lung cancer mortality data were available only at the county level, we used the National Center for Health Statistics (NCHS) county-level classification (17) for our exploratory mortality model. NCHS codes range from 1 (large central metro) to 6 (noncore). We used RUCA codes for our main access model because they provide more fine-grained information than NCHS codes on rurality in a census tract and its census block groups.

Sociodemographic characteristics. We obtained demographic census block group–level data from ACS 2013–2017 five-year estimates (15). We defined income as median annual household income (in thousands of dollars), education as percentage of residents aged 25 or older with at least a college degree, and race as the percentage of White residents and the percentage of African American residents.

Lung cancer and smoking measures. We obtained county-level, age-adjusted lung and bronchus cancer mortality rates during 2013–2017 from the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) program via SEER*Stat software version 8.3.6 (18). We used mortality rates (per 100,000) for people aged 60 or older. Given the lead-time bias and additional survival time after lung cancer diagnosis, we believed mortality in this age range was most likely to be affected by a screening program for people aged 55 to 80. We suppressed data from 1 county in Missouri because of a small number (<10) of deaths. We obtained data on 2019 adult smoking prevalence from County Health Rankings (19). We classified adults as smokers if they reported currently smoking every day or most days and having smoked at least 100 cigarettes in their lifetime.

Map development. We obtained census block group shapefiles from the Census Bureau (15) and state-level and county-level shapefiles from Esri (20). We created categories by rounding quintiles to the nearest 10% for access to screening, nearest 10 per 100,000 for lung cancer mortality, and nearest 0.5% for smoking prevalence. Mortality and smoking quintiles were based on national (rather than bi-state) data, to emphasize how Illinois and Missouri compare with other states. We created maps in ArcGIS Desktop version 10.6 (Esri).

Statistical analysis

For the first analysis, our outcome of interest was access to screening within 30 miles of the census block group centroid (binary). Predictor variables were rurality as quantified by RUCA codes (main predictor; categorical), income (continuous), education (continuous), and race (continuous). We used multilevel, mixed-effects logistic regression modeling to determine the association between outcome and predictor variables. In this model, the census block group was the unit of analysis. We defined RUCA codes at the census tract level; all other variables were defined at the census block group level.

Our modeling procedure was as follows: first, we considered bivariate logistic models to examine crude associations between screening access and each predictor. We then used the full additive model with all predictor variables (fixed effects) and random intercepts for each state and county. Counties were nested within states. Census tract was not considered a random effect because of the small number of census block groups in some tracts. We then tested models involving interaction terms and random slopes for various predictors. These terms were all nonsignificant and thus not included in the final model. We calculated the odds ratio (OR), 95% CI, and *P* value associated with each fixed-effect parameter.

Our second, exploratory model used the county as the unit of analysis. We sought to determine the association between access to LDCT screening, defined as the proportion of residents aged 55 to 79 whose census block group of residence is located within 30 miles of a screening center (main predictor), and lung cancer mortality rate in adults aged 60 or older (outcome). Other covariates included adult smoking prevalence, rurality (NCHS code), income, education, race, and state in which the county is located. We used multiple linear regression modeling for this county-level analysis. We defined all variables at the county level, and all variables except NCHS code were continuous. Because only 3 counties in the study area were designated as large central metro (level 1), we performed a sensitivity analysis using a dichotomized rurality variable (levels 1–4 [all metro area counties] vs levels 5–6 [micropolitan and noncore]).

For both analyses, all tests were 2-sided and $P < .05$ was considered significant. We calculated variance inflation factors to assess evidence of multicollinearity. For the main mixed-effects model, we assessed county-level random intercepts for normality. For the multiple regression model, we checked residual plots for normality and constant variance. We performed statistical analyses in R version 3.6.1 (The R Project for Statistical Computing).

Results

Overall, 91.2% of Illinois residents aged 55 to 79 and 78.3% of their Missouri counterparts were within 30 miles of an LDCT screening center. Areas with low access to screening corresponded roughly to the states' most rural regions (Figure 1). These areas of low access included central northern Missouri, the Bootheel region in southeastern Missouri, and southern Illinois (Figure 2A). LDCT screening centers in Illinois and Missouri were located in census block groups whose residents were more likely than residents in the 2-state region as a whole to identify as White (76.6% vs 67.6%) and have at least a college degree (45.1% vs 31.8%). Similarly, weighted median income in census block groups containing screening centers was $72,222, compared with $57,750 across all census block groups.

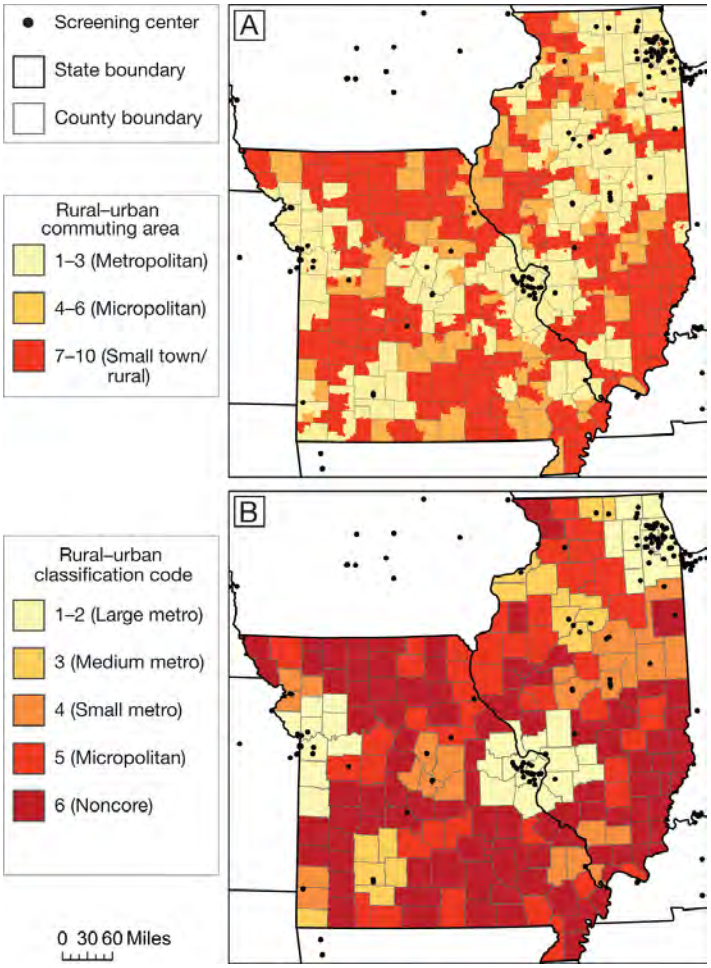

Figure 1. Measures of rurality in Missouri and Illinois and location of low-dose computed tomography screening centers. A, Rural–urban commuting area (RUCA) categories at the census tract level, determined by US Department of Agriculture Economic Research Service (16). B, National Center for Health Statistics (NCHS) rural–urban classification codes at the county level (17). Data on screening centers obtained from American College of Radiology (11) and GO_2 Foundation for Lung Cancer (12). Shapefiles obtained from ESRI (20).

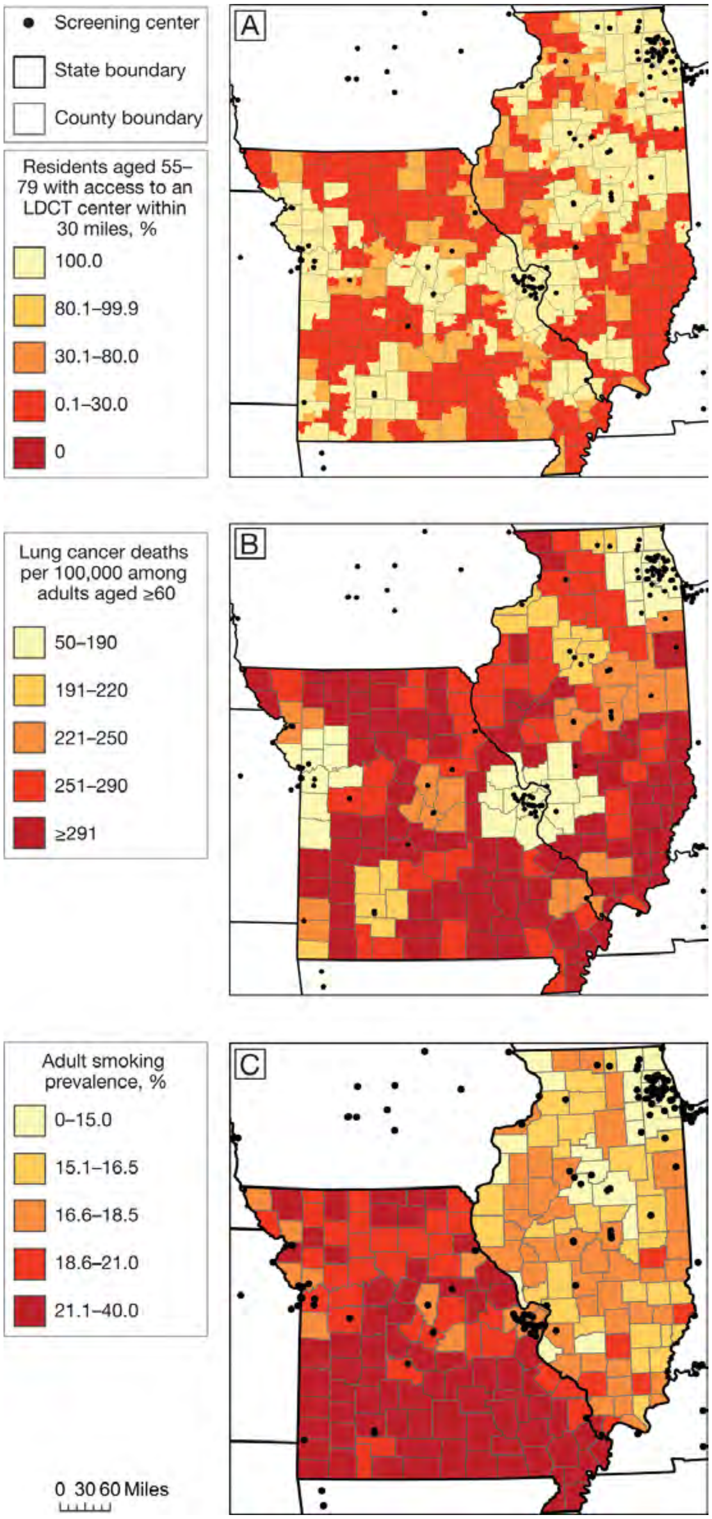

Figure 2. Access to LDCT lung cancer screening, lung cancer mortality, and smoking prevalence in Missouri and Illinois. A, Percentage of residents aged 55–79 with access to an LDCT lung cancer screening center within 30 miles. B, Lung cancer mortality (deaths per 100,000) among adults aged ≥60. C, Adult smoking prevalence. All maps are at the county level, and categories are based on rounded quintiles. Data obtained from American College of Radiology (11), GO$_2$ Foundation for Lung Cancer (12), Surveillance, Epidemiology, and End Results program (18), and County Health Rankings (19). Shapefiles from ESRI (20). Abbreviation: LDCT, low-dose computed tomography.

Both states had pockets of high lung cancer mortality, although smoking rates were consistently higher in Missouri than in Illinois (Figure 2B and 2C). Southeastern Missouri had the highest concentration of both lung cancer mortality and adult smokers.

In metropolitan area cores or nearby commuting areas (RUCA codes 1–3), 97.6% of residents had access to LDCT screening, compared with 41.0% of residents in micropolitan or small town/rural areas (codes 4–10). This difference in access was similar across NCHS county-level codes (Table 1). Furthermore, as rurality increased, we observed higher rates of adult smoking and lung cancer mortality among adults aged 60 or older.

The mixed-effects logistic regression model of access to LDCT screening within a 30-mile radius achieved convergence, and a likelihood ratio test showed that inclusion of random effects significantly improved fit ($\chi^2 = 3417.6$; $df = 2$; $P < .001$). Small town and rural census block groups had significantly lower adjusted odds than metropolitan census block groups of access to screening within a 30-mile radius (OR = 0.17; 95% CI, 0.12–0.26) (Table 2). Screening access in micropolitan areas was similarly lower than in metropolitan areas (OR = 0.17; 95% CI, 0.10–0.27).

In the county-level models, we found no significant relationship between access to LDCT screening and lung cancer mortality after adjusting for smoking prevalence, rurality, and demographic characteristics ($P = .68$) (Table 3). The variables most strongly associated with lung cancer mortality per 100,000 residents were smoking prevalence ($\beta = 9.7$; 95% CI, 4.6 to 14.9), percentage of population aged 25 or older with a college degree ($\beta = -2.7$; 95% CI, −1.5 to −3.9), and residence in Missouri ($\beta = -41.2$; 95% CI, −68.2 to −14.2). Thus, a 1 percentage-point increase in smoking prevalence was associated with a mortality increase of 9.7 per 100,000 residents, and a 1 percentage-point increase in the fraction of individuals aged 25 or older with a college degree was associated with a decrease of 2.7 per 100,000. Rurality and other variables showed no association, and use of a binary rurality variable (all metropolitan vs micropolitan/noncore) yielded nearly identical results.

Discussion

Our study examined access to LDCT screening across diverse urban and rural areas, and in communities of varying sociodemographics. The odds of urban populations having access to screening were more than 5 times greater than those of micropolitan or rural counterparts. After adjusting for smoking prevalence and demographic characteristics, we found no evidence that greater access to screening or greater urbanization is associated with lower county-level lung cancer mortality. However, counties with a larger proportion of college-educated residents or lower smoking prevalence tended to have lower lung cancer mortality.

Several studies reported that rural residents have lower access to LDCT screening (3,5,21), and our study confirms those findings. Our study also found that micropolitan areas have no better access than rural areas. Findings from our study reveal a negligible association between access to LDCT screening and lung cancer mortality rates.

Most likely, the observed lack of association between access to screening and mortality was due to the nascent state of LDCT screening and low uptake during the years of mortality data used in our study (2013–2017) (4). Screening can detect early-stage and slow-growing cancers that would not have otherwise been diagnosed for quite some time. Because lung cancer tends to be diagnosed at late stages with poor survival rates, several years of higher rates of screening may be needed before reduced mortality is seen. The overall delay from screening implementation to decrease in mortality roughly equals the sum of lead-time bias (approximately 1–3 years for LDCT) (22) and the traditional (without screening) survival time. Other variables may have affected our mortality analysis. In Illinois, a major coal-producing state, residential proximity to coal mines is associated with increased lung cancer incidence and mortality (23). Regardless, our analysis represents valuable baseline research and demonstrates the importance of attending to county-level disparities. An increase in LDCT screening uptake would likely reduce lung cancer mortality at the population level. On the basis of colorectal cancer screening research, we believe that greater geographic access to LDCT screening could effectively increase uptake (24). Improving geographic access to a service with low uptake is still worthwhile, because poor access may be contributing to low uptake.

Although rural areas are associated with poorer health outcomes than urban areas (25), we must also consider the urban–rural paradox, which suggests that among urban residents, greater distance to health care facilities is inversely associated with receiving care, but among rural residents, greater distance is positively associated with receiving care (26). Using 2015 data, Odahowski et al found that LDCT screening uptake was similar across metropolitan and nonmetropolitan counties, although low rates in both areas (<4%) make it difficult to understand why uptake is similar and whether the similarity will be maintained over time (27). The similarity in screening uptake rates may result from selection bias: the few people who completed screening may be the most enthusiastic and well-resourced patients in both urban and rural areas. Increased geographic access to LDCT screening may be needed to further increase uptake in rural areas. Further studies using discriminate, comprehensive measures of access and uptake are needed to explore whether geographic availability of screening has a different effect on mortality in urban and rural areas.

Previous research on geographic access to LDCT screening is minimal. To our knowledge, ours is the first study to assess access to LDCT screening, associated demographic determinants, and implications for mortality at a local population level. However, our study has several limitations. First, limited availability of public data necessitated the use of variables from 2 different periods. Demographic and lung cancer mortality data were from 2013–2017, whereas data on smoking prevalence and access to screening were from 2019. Second, we used data from multiple sources, including telephone surveys, online surveys, and government registries. Each source has its own limitations and can contribute to biased model estimates. Third, the ecological study design based on census block group–level and county-level data precludes extensive application of our conclusions about the relationships between rurality, access, and mortality to any 1 person. Fourth, in our exploratory analysis, county-level rates of access to LDCT screening were based on all residents aged 55 to 79, regardless of smoking status or other screening eligibility criteria. By taking this approach, we assumed that the percentage of residents aged 55 to 79 who meet eligibility criteria was roughly constant within a county; we made no assumptions about differences between counties. Finally, we included in our analyses only GO_2 Foundation Screening Centers of Excellence and American College of Radiology accredited centers. Thus, our analyses may have underestimated the proportion of residents, especially in rural areas, who had access to some form of screening. However, accredited LDCT programs may deliver a better level of care than nonaccredited programs (28).

This study underscores the need for further research and creative solutions for increasing LDCT screening in rural areas, especially in the Mississippi Delta region, where significant cancer disparities exist. Not doing so may propagate the urban–rural disparities that exist in other cancer screening programs, such as mammography (25). Further research may be especially important in areas with high rates of smoking and lung cancer mortality, such as southeastern Missouri. In the past few years, mobile LDCT screening has been introduced in dozens of rural communities in Georgia and Tennessee (29). Incorporation of telemedicine could also circumvent the difficulty of finding qualified on-site specialists to interpret LDCT scans and recommend treatment in rural areas. Teleradiology is now a ubiquitous practice, allowing radiologists to bill for LDCT and other interpretations furnished off-site. Some teleoncology programs offer remote interpretation of biopsy specimens (30), which is occasionally required as a follow-up to LDCT screening. Additionally, screening must be coupled with effective smoking cessation interventions to maximize reductions in mortality.

Finally, our results emphasize the need for data-driven, locally targeted programs to increase screening and decrease mortality. In Missouri and Illinois, many areas with high rates of smoking and lung cancer mortality have low access to screening. However, some areas with high rates of smoking and lung cancer mortality, such as the rural counties north of Kansas City, have good access to screening. State or national one-size-fits-all programs to simply add more screening centers may not be helpful in these communities.

Our study adds to the growing body of evidence on urban–rural disparities in access to screening, while exploring the effects of access to LDCT screening on lung cancer mortality. County-specific approaches are needed to increase access to screening in rural areas with high mortality. At the same time, further implementation research is needed to understand how to effectively minimize individual and system-level barriers to rural screening.

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Tables

Table 1. Lung Cancer Screening Access Within 30 Miles, Adult Smoking Prevalence, and Age-Adjusted Lung Cancer Mortality, by Urban–Rural Designations, Missouri and Illinois, 2013–2019

Urban–Rural Designation[a]	No. of Counties	Population Aged 55–79, N (%)[b]	Population With Screening Access, %[c]	Adult Smoking Prevalence, %[d]	Age-Adjusted Lung Cancer Mortality Among Residents Aged ≥60[e]
Large central metro	3	1,378,581 (30.6)	100.0	15.2	214
Large fringe metro	30	1,524,652 (33.8)	98.6	16.0	226
Medium metro	16	351,843 (7.8)	96.4	18.4	244
Small metro	25	416,522 (9.2)	89.3	18.2	250
Micropolitan	46	418,276 (9.3)	42.8	19.2	269
Noncore	97	421,917 (9.4)	34.9	20.0	277

[a] Determined by National Center for Health Statistics (17).

[b] Based on 2013–2017 data (15).

[c] Based on 2019 data on screening center location (11,12). Proportion of population whose census block group of residence is within 30 miles of a screening center; computed as averages of county-level data weighted by number of residents aged 55–79 (as of 2013–2017).

[d] Based on 2019 data (19). Proportion of adults who currently smoke and have smoked ≥100 cigarettes in their lifetime; computed as averages of county-level data weighted by number of adult residents (as of 2013–2017).

[e] Based on 2013–2017 data (18). Rate per 100,000 population; computed as averages of county-level data weighted by number of residents aged ≥60 (as of 2013–2017).

Table 2. Census Block Group–Level (N = 13,834 Census Block Groups) Association Between Degree of Rurality (in 2019) and Access to Lung Cancer Screening Within 30 Miles (in 2019) Adjusted for Demographic Characteristics, Missouri And Illinois, 2013–2017

Model Parameter	Unadjusted Model		Adjusted Model	
	OR (95% CI)	*P* Value	OR (95% CI)	*P* Value
Degree of rurality[a]				
Metropolitan (RUCA codes 1–3)	1.00 [Reference]		1.00 [Reference]	
Micropolitan (RUCA codes 4–6)	0.019 (0.016–0.022)	<.001	0.17 (0.10–0.27)	<.001
Small town or rural (RUCA codes 7–10)	0.017 (0.015–0.020)	<.001	0.17 (0.12–0.26)	<.001
Demographic characteristics[b]				
Median annual household income, in thousands, $[c]	1.03 (1.03–1.03)	<.001	1.01 (1.00–1.02)	.09
Percentage of population aged ≥25 with a college degree[d]	1.05 (1.05–1.06)	<.001	1.01 (1.00–1.03)	.08
Percentage of population that is White[d]	0.91 (0.91–0.92)	<.001	1.02 (1.00–1.03)	.05
Percentage of population that is African American[d]	0.95 (0.94–0.96)	<.001	1.01 (0.99–1.03)	.32

Abbreviations: OR, odds ratio; RUCA, rural–urban commuting area.

[a] Census tract–level RUCA codes used to measure rurality (16).

[b] Determined by American Community Survey 5-year estimates (15).

[c] Odds ratio represents $1,000 increase in median annual household income.

[d] Odds ratio represents 1 percentage-point increase in the corresponding variable.

Table 3. County-Level (N = 210 Counties) Association Between Proportion of Residents With Access to Screening Within 30 Miles (in 2019) and Age-Adjusted Lung Cancer Mortality Among Adults Aged ≥60 (in 2013–2017), Adjusted for Rurality (in 2019), and Demographic Characteristics (in 2013–2017), Missouri and Illinois

Model Parameter	Change in Mortality per 100,000 Population, β (95% CI) [*P* Value]
Percentage of census block groups with access to lung cancer screening within 30 miles	0.04 (−0.15 to 0.23) [.68]
Degree of rurality[a]	
Large central metro	1 [Reference]
Large fringe metro	8.9 (−54.8 to 72.6) [.78]
Medium metro	−8.7 (−74.5 to 57.0) [.79]
Small metro	3.4 (−58.3 to 65.2) [.91]
Micropolitan	2.7 (−60.9 to 66.3) [.93]
Noncore	−4.6 (−68.5 to 59.3) [.89]
State	
Illinois	1 [Reference]
Missouri	−41.2 (−68.2 to −14.2) [.003]
Demographic characteristics	
Percentage of population that reports smoking[b]	9.7 (4.6 to 14.9) [<.001]
Median annual household income, in thousands, $[c]	0.4 (−0.9 to 1.8) [.52]
Percentage of population aged ≥25 with a college degree[c]	−2.7 (−3.9 to −1.5) [<.001]
Percentage of population that is White[c]	0.2 (−1.1 to 1.6) [.76]
Percentage of population that is African American[c]	0.8 (−1.1 to 2.7) [.42]

[a] Determined by National Center for Health Statistics (17).
[b] Determined by 2019 County Health Rankings (19).
[c] Determined by American Community Survey 5-year estimates (15).

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ORIGINAL RESEARCH

Quantification of Potential Inequities in Breast Cancer Incidence in New Mexico Through Bayesian Disease Mapping

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PEER REVIEWED

Summary

What is already known on this topic?

Breast cancer incidence among non-Hispanic American Indian and Alaska Native (AI/AN) women has been quantified in large geographic regions of the United States, showing substantial regional variation in incidence inequities among non-Hispanic AI/AN populations.

What is added by this report?

We found substantial evidence in New Mexico of an overall reduction in breast cancer incidence among at-risk non-Hispanic AI/AN women compared with non-Hispanic White women in certain counties in the state.

What are the implications for public health practice?

Our findings can facilitate targeted statewide and county-level cancer control interventions to mitigate such disparities.

Abstract

Introduction

The incidence of breast cancer among non-Hispanic American Indian and Alaska Native (AI/AN) women varies across the United States. We applied county-level Bayesian disease mapping to quantify potential inequities in 10-year breast cancer incidence in New Mexico to better inform health equity initiatives among its non-Hispanic at-risk AI/AN population.

Methods

We used data from the Surveillance, Epidemiology, and End Results (SEER) program from 2005 through 2014 to identify new cases of breast cancer in New Mexico's 33 counties. To account for spatial variation, a county-level Area Deprivation Index, and the small area estimation problem inherent in these data, we borrowed strength globally and locally by applying Bayesian disease mapping to the counts of age-adjusted county-level breast cancer incidence. We quantified the disparity effect, as measured by the age-adjusted rate ratio, comparing the incidence of breast cancer between at-risk non-Hispanic AI/AN and non-Hispanic White women and assessed whether the ratio differed among counties.

Results

Accounting for over-dispersion and spatial correlation among the 33 counties and a county-level Area Deprivation Index, the posterior mean of the overall age-adjusted rate ratio was 0.384 (95% credible interval, 0.253–0.546). The age-adjusted rate of breast cancer in non-Hispanic AI/AN women was 0.38 times the corresponding age-adjusted rate for non-Hispanic White women; however, a significant reduction in breast cancer incidence was observed in 16 of the 33 counties.

Conclusion

The application of Bayesian disease mapping to these data provided substantial evidence of an overall disparity in breast cancer incidence between at-risk non-Hispanic AI/AN and non-Hispanic White women in New Mexico, which was more marked than previously reported and limited to certain counties. Targeted statewide and county-level health-equity initiatives may lead to a reduction in these disparities.

Introduction

In the past 2 decades, substantial progress has been made in the United States in reducing breast cancer death rates for non-Hispanic White women; however, this reduction has not been shared by non-Hispanic American Indian and Alaska Native (AI/AN) women (1). The corresponding mortality-to-incidence ratio is higher for non-Hispanic AI/AN women than for non-Hispanic White women (1). This inequity has persisted despite breast cancer being amenable to screening and treatment. A possible contributor to the higher mortality-to-incidence ratio may be a lower prevalence of mammography use among non-Hispanic AI/AN women compared with non-Hispanic White women (2). Mammography can detect breast cancer in its early stages when it may respond better to treatment (3). Although use of mammography has recently increased among non-Hispanic AI/AN women, its use remains below Healthy People 2020 targets and lower than among other racial/ethnic subgroups (4).

An important indicator of health status in the non-Hispanic AI/AN population is breast cancer incidence. This incidence has primarily been quantified in large geographic regions of the United States (1,5,6). The less favorable regional-level breast cancer incidence rates reported among non-Hispanic AI/AN versus non-Hispanic White women in the southwestern region of the United States underscore the need to continue to quantify potential inequities in breast cancer outcomes, and at a more granular county level, to facilitate targeted cancer control interventions to mitigate such disparities.

Our aim was to quantify potential disparities in breast cancer incidence between non-Hispanic AI/AN women and non-Hispanic White women in New Mexico overall and in each of its 33 counties during our 10-year study period, 2005 through 2014. New Mexico has 23 federally recognized tribes and, based on 2015 estimates, AI/ANs make up nearly 10.5% of the state's population (7). Because we were interested in obtaining precise local estimates of breast cancer incidence among each racial/ethnic group at the county level as well as assessing broad trends across the state, we used Bayesian disease mapping, which can be implemented to account for spatial variation. It can also account for county-level covariates when quantifying such potential inequities and can address the small area estimation problem inherent in these data by borrowing strength globally and locally across the state (8).

By using Surveillance, Epidemiology, and End Results (SEER) (9) program data from 2005 through 2014, we applied Bayesian disease mapping to address 3 study-specific questions to quantify potential inequities in 10-year breast cancer incidence in New Mexico:

1. Is the overall incidence of breast cancer among at-risk non-Hispanic AI/AN women excessively low compared with non-Hispanic White women?
2. Does the rate ratio, comparing the incidence of breast cancer between at-risk non-Hispanic AI/AN women and non-Hispanic White women, differ among New Mexico counties?
3. Do some counties in New Mexico have a lower breast cancer incidence among at-risk AI/AN women than would be expected?

Research into these questions can contribute to planning public health services and interventions in New Mexico that may lead to reducing disparities in breast cancer outcomes among non-Hispanic AI/AN at-risk women.

Methods

Data preparation

Data were limited to AI/AN and White women of non-Hispanic origin who were aged 15 years or older (Figure 1). From the data on the 38,997 women in the SEER registry who received a diagnosis of breast cancer, 13,135 were diagnosed from 2005 through 2014. County of residence was known for 12,974 of these women, of whom 8,794 were of non-Hispanic origin. After excluding other racial/ethnic groups (109 Asian or Pacific Islander, 164 Black, and 60 unknown race), our population surveillance data consisted of 8,461 women with breast cancer (567 non-Hispanic AI/AN women, 7,894 non-Hispanic White women) diagnosed from 2005 through 2014 across the 33 counties. Data on the number of women at risk were obtained from US Census Bureau data for 2010, the midpoint of our study period, and retrieved in 5-year age intervals (eg, 15–19 y). Although the risk of breast cancer for women aged 15 to 17 is low, to avoid excluding at-risk women aged 18 and 19, we retrieved the number at risk in the 15 to 19 age interval in addition to all higher 5-year age intervals. Therefore, we considered 443,814 non-Hispanic AI/AN and non-Hispanic White women aged 15 years or older at risk for breast cancer. These data were extended to include county-level Area Deprivation Index (ADI) scores developed by Mayo Clinic researchers (10), which were measured from 17 indicators that served as a surrogate for income, employment, housing, and education.

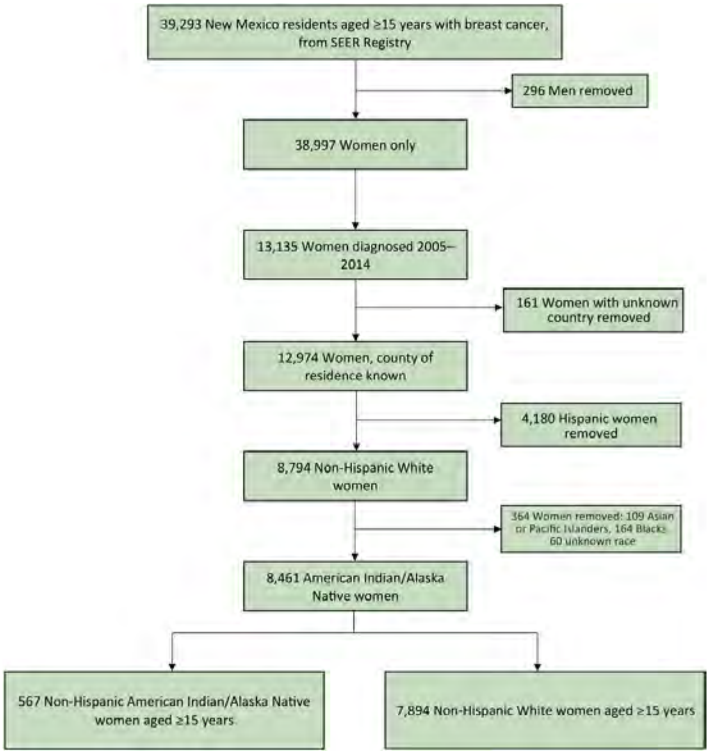

Figure 1. Data flow diagram describing the selection of New Mexico women with breast cancer for inclusion in a study of potential inequities in breast cancer incidence among non-Hispanic American Indian/Alaska Native and non-Hispanic White women. Abbreviation: SEER, Surveillance, Epidemiology, and End Results program. [A text version of this figure is available.]

Statistical analysis

To address questions on disparate incidence, we applied a single Bayesian Poisson hierarchical model to model the county-level, age-adjusted number of women with breast cancer defined as

$$y_{ir}^{*} = \sum_{a} \pi_a \, y_{iar}$$

where y_{iar} denotes the number of women with breast cancer in county i, age group a, racial group r, and π_a denotes the proportion of the 2010 US female population aged 15 years or older in age group a. Here, i ranges from 1 to 33; $a \in \{15-19, 20-24, \ldots, 80-84, 85+\}$ and $r = 0$ (non-Hispanic White population) or $r = 1$ (non-Hispanic AI/AN population). Also, let n_{ir} denote the population size at risk in the i^{th} county for the r^{th} racial group. Then, the hierarchical model proposed to address our study-specific questions can be expressed as

$$y_{ir}^{*} \sim Poisson(n_{ir}\lambda_{ir}), i = 1, \ldots, 33; r = 0, 1$$

$$\log(\lambda_{ir}) = \beta_0 + \beta_1 x_1 + \beta_2 x_2 + \beta_3 x_1 x_2 + \theta_{ir} + \phi_{ir}$$

with x_1 denoting an indicator variable, which takes the value 1 if $r = 1$ (non-Hispanic AI/AN population) and zero if $r = 0$ (non-Hispanic White population), and x_2 denoting an indicator variable, which takes the value 1 if county-level ADI is in the lower 20th percentile and zero otherwise.

The inclusion of the interaction term permitted the disparity effect to be different at each level of the county-level variable x_2. The prior distribution for each parameter β_1, β_2, and β_3 was set to a normal distribution with mean 0 and variance 1,000, while a flat prior was assumed for β_0. The θ_{ir} captured region-wide heterogeneity via an ordinary, exchangeable normal prior,

$$\theta_{ir} \sim N(0, \tau_h),$$

where τ_h is a variance term. These random effects captured extra-Poisson variability (or over-dispersion) in the log-relative risks that varied globally (ie, over the entire state). Finally, the random effects ϕ_{ir} are the parameters that make this a spatial model by capturing regional clustering. That is, they modeled extra-Poisson variability in the log-relative risks that varied locally, so that nearby counties would have more similar rates. Spatial association was defined through a neighborhood structure where 1 county was related to other counties that shared a common border and determined by an adjacency matrix. To specify the spatial association, we assumed a race-specific improper conditional autoregressive (CAR) (11) specification for $\phi_{\cdot r}$ such that for each racial group r we have

$$\phi_{\cdot r=0} \sim \mathrm{CAR}(\tau_b; r = 0) \text{ and } \phi_{\cdot r=1} \sim CAR(\tau_c; r = 1)$$

The variance parameters τ_h, τ_b, and τ_c were given standard deviation uniform prior distributions in the range of 0 to 100 (12). The inclusion of both spatially uncorrelated (θ) and spatially correlated (ϕ) heterogeneity effects also addressed the small area estimation problem by borrowing strength globally and locally, respectively.

We used Markov chain Monte Carlo (MCMC) sampling to estimate posterior quantiles for the proposed Bayesian Poisson hierarchical model; R (R Foundation) and OpenBUGS (13) were used to fit the proposed hierarchical model. Estimated posterior quantiles were based on 3 chains, including a burn-in period for each chain. A long run of the sampler was required because of high levels of autocorrelation; therefore, samples were thinned by using only every fiftieth step in the sampler as a strategy for dealing with the otherwise overwhelming amounts of MCMC output (14). Consequently, posterior distributions were based on 60,000 samples, or 20,000 per chain. The deviance information criterion (DIC) was used to assess model adequacy (15). In our application, a difference in DIC greater than 2 was used to ascertain if the DIC was exhibiting a preference.

To answer our first question, we reported and interpreted the estimated posterior mean and 95% credible interval for the overall rate ratio defined as the ratio of the statewide average rates in each racial category (non-Hispanic AI/AN vs non-Hispanic White), or $\frac{\bar{\lambda}_{\cdot 1}}{\bar{\lambda}_{\cdot 0}}$, where $\bar{\lambda}_{\cdot 1} = \frac{\sum_i n_{i1}\lambda_{i1}}{\sum_i n_{i1}}$ and $\bar{\lambda}_{\cdot 0} = \frac{\sum_i n_{i0}\lambda_{i0}}{\sum_i n_{i0}}$. To answer the second question, we present the estimated posterior means and corresponding 95% credible intervals for each county-level rate ratio (non-Hispanic AI/AN vs non-Hispanic White women), defined as $\frac{\lambda_{i1}}{\lambda_{i0}}$ for the i^{th} county. Finally, within the non-Hispanic AI/AN population, we reported and interpreted the estimated posterior mean and 95% credible interval for each county-level rate ratio (ie, the non-Hispanic AI/AN county-level rate vs the statewide average rate within non-Hispanic AI/AN), or $\frac{\lambda_{i1}}{\bar{\lambda}_{\cdot 1}}$, to answer our last question.

Results

Of the 443,814 at-risk women in our 2010 sample, 75,048 (16.9%) were non-Hispanic AI/AN. For each of the 33 New Mexico counties in New Mexico, we calculated the county-level ADI based on 2012 socioeconomic data according to the lower 20%, middle 60%, and upper 20% (Figure 2). The 20th and 80th percentile ADI were 101.6 and 120.8, respectively, and the median ADI was 110.2 (range, 39.2–149.8); higher values correspond to increased socioeconomic disadvantage.

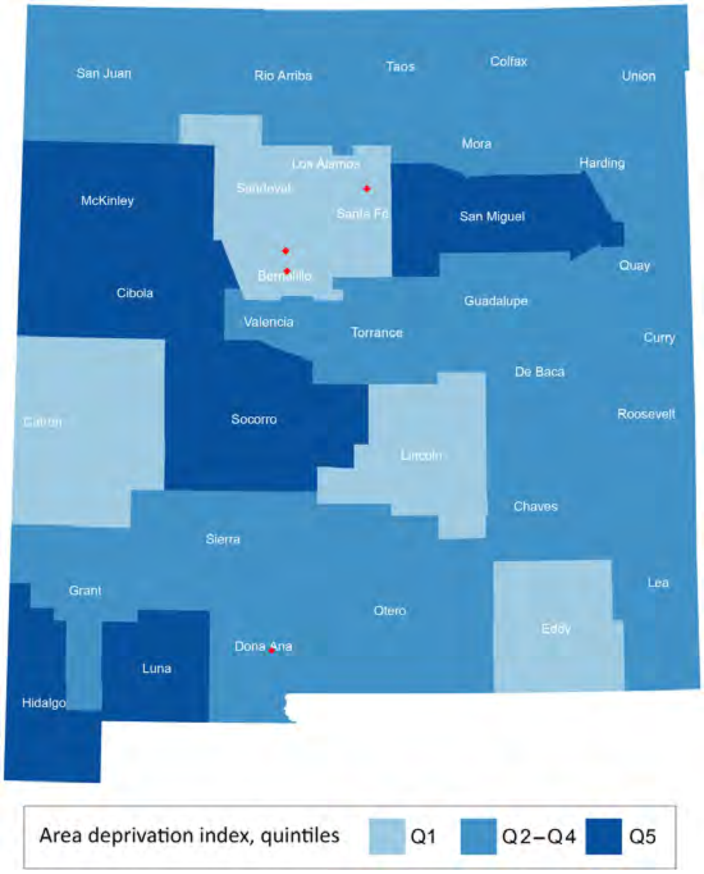

Figure 2. County-level Area Deprivation Index (ADI) quintiles for 33 New Mexico counties in 2012 categorized as the lower 20% (Q1), middle 60% (Q 2–4), and upper 20% (Q5). Higher quintiles indicate increased socioeconomic disadvantage. Red diamonds depict major cites (Albuquerque in Bernalillo County, Las Cruces in Dona Ana County, Rio Rancho in Sandoval County, and Santa Fe in Santa Fe County). ADI scores were developed by Mayo Clinic researchers (10), and are derived from 17 indicators that served as surrogates for income, employment, housing, and education.

In the estimated posterior quantities from fitting the proposed model (Table 1), the expected [standard deviation] estimate of the standard deviation associated with the spatially correlated heterogeneity effects suggested strong spatial patterning in the non-Hispanic AI/AN population ($\sqrt{\tau_c}$: 0.567 [0.499]), whereas this was not the case in the non-Hispanic White population ($\sqrt{\tau_b}$: 0.143 [0.110]). We mapped the sum of the posterior averages of the county-specific random effects ϕ and θ that were exponentiated within the non-Hispanic White population and the corresponding non-Hispanic AI/AN population (Figure 3). Interpreting the excess variability observed in the data in this fashion isolates the upper half of the state as an area of generally increased risk of breast cancer diagnosis in both maps, but those northern areas of increased risk are largely concentrated in the north-central regions in the non-Hispanic White population; furthermore, the northern areas of elevated risk of breast cancer diagnosis are more pronounced in the non-Hispanic AI/AN population. Although the areas of low risk of breast cancer diagnosis in the non-Hispanic AI/AN population are seen across the lower half of the state, the regions of low risk within the non-Hispanic White population are confined to the southeastern portion of the state.

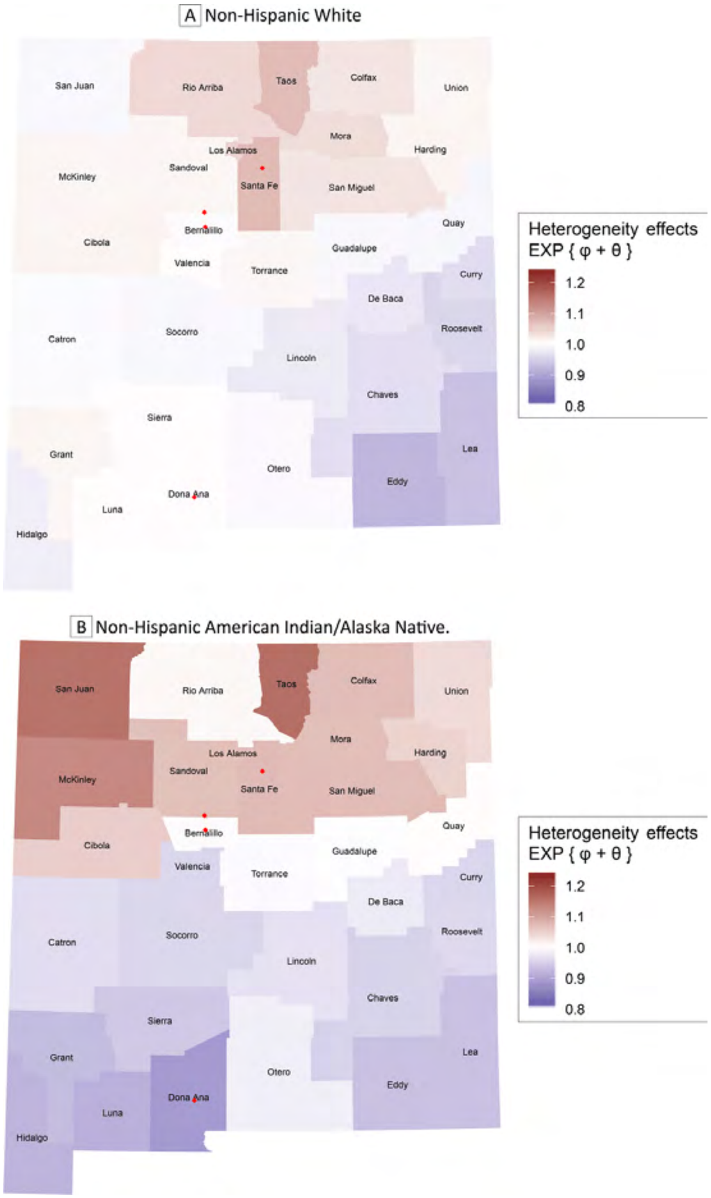

Figure 3. Exponentiated sum of the posterior average county-level heterogeneity effects obtained from the proposed model. Map A gives the results for non-Hispanic White women and Map B gives the results for non-Hispanic American Indian/Alaska Native women. Red diamonds depict major cites (Albuquerque in Bernalillo County, Las Cruces in Dona Ana County, Rio Rancho in Sandoval County, and Santa Fe in Santa Fe County).

The posterior mean of the overall, age-adjusted rate ratio was 0.384 (95% credible interval, 0.253–0.546). These data provide evidence of a significant overall disparity effect across New Mexico. The estimated rate of breast cancer in non-Hispanic AI/AN women was approximately 0.38 times the corresponding age-adjusted rate for non-Hispanic White women. Making allowance for the unobserved confounders θ and ϕ as well as allowing the disparity effect to be different across the 2 levels of the county-level ADI variable, we calculated the posterior mean for the age-adjusted rate ratio for each county on the basis of the proposed model (Table 2). For 16 of the 33 counties, the 95% credible intervals for the age-adjusted rate ratios were less than 1, while for the remaining 17 counties the 95% credible intervals included the null value of 1. It is worth noting that the 7 smallest posterior means for the age-adjusted rate ratios coincided with the 7 counties in the lowest 20th percentile for ADI. We also estimated posterior mean and 95% credible interval for each county-level rate ratio in the non-Hispanic AI/AN population. Compared with the average rate of breast cancer incidence in the non-Hispanic AI/AN population, the relative risk of breast cancer was largely constant across all counties, and all 95% credible intervals for the age-adjusted rate ratios were wide and included 1. Because the results depended on prior specifications, we examined sensitivity to prior specification. On the basis of these sensitivity analyses, our conclusions remained unchanged.

The DIC for the proposed model was 160.9. To assess the value of including the indictor variable for ADI in the proposed model, 2 additional models were considered, namely, the proposed model excluding the 2-way interaction term between the indicator variables for ADI and racial group (DIC = 158.1) and the proposed model excluding both the 2-way interaction term and the indicator variable for ADI (DIC = 162.8). The DIC expressed a preference for the reduced model that included the indicator variable for ADI. After adjusting for the unobserved confounders θ and ϕ and racial group, the posterior mean of the age-adjusted risk ratio, comparing the estimated rate of breast cancer between the ADI in the lower 20th percentile versus above, was 1.240 (95% credible interval, 0.952–1.578). These data suggest that the estimated rate of breast cancer in less socioeconomically disadvantaged counties, as defined by the lower 20th percentile, was 1.24 times the corresponding age-adjusted rate for counties more socioeconomically disadvantaged, although the 95% credible interval was not entirely to the right of the null value of 1. Based on this reduced model, the posterior mean of the overall age-adjusted rate ratio (non-Hispanic AI/AN vs non-Hispanic White women) was 0.385 (95% credible interval, 0.253–0.545), which was virtually the same as the overall age-adjusted rate ratio obtained from the proposed model that included the 2-way interaction term. Although the DIC expressed a preference for the model without the 2-way interaction term, we focused on the less parsimonious model that included the 2-way interaction term when quantifying the county-level age-adjusted rate ratios to permit a potential disparity effect to vary across the 2 levels of the county-level variable ADI.

Discussion

We focused on quantifying potential inequities in 10-year breast cancer incidence in New Mexico and in each county to better inform health equity initiatives for non-Hispanic AI/AN women at risk for breast cancer. We used the age-adjusted rate ratio, comparing the incidence of breast cancer between at-risk non-Hispanic AI/AN and non-Hispanic White women, to quantify the disparity effect and based it on county-level age-adjusted counts of observed breast cancer cases diagnosed from 2005 through 2014 in New Mexico. Although traditional methods that calculate age-adjusted standardized incidence ratios are appropriate for large geographic areas, they are often unsuitable when the goal is to quantify local risk in small geographic areas, such as counties, while adjusting for potentially relevant covariate information; the local sample sizes in each county were too small to obtain reliable estimates with the desired levels of statistical precision by using traditional methods (16). To obtain a reliable estimate of the disparity effect in each county and overall, we applied Bayesian disease mapping to these population surveillance data. Bayesian disease mapping is a model-based approach that offered a means to improve county-level incidence estimates by borrowing more information from neighboring counties than from counties farther away, thereby smoothing extreme rates based on small local sample sizes toward local, neighboring values. Furthermore, this modeling-based approach accounted for the number of women at risk as well as a county-level ADI.

We found evidence of a substantial overall disparity effect across New Mexico. The age-adjusted rate of breast cancer among non-Hispanic AI/AN women was approximately 0.38 times the corresponding age-adjusted rate for non-Hispanic White women. The lower and upper limits of the corresponding 95% credible interval were 0.253 and 0.547, respectively. This overall finding appears in keeping with previous studies (1,5). By using age-adjusted breast cancer incidence rates in the southwest region for 2010 through 2015, Melkonian and colleagues in 2019 reported a corresponding age-adjusted rate ratio of 0.57 (5). Before that, White and colleagues in 2014 reported an age-adjusted rate ratio in the Southwest region of 0.49 during their study period, 1999–2009 (1).

Although previous studies have shown substantially lower breast cancer incidence rates among non-Hispanic AI/AN than non-Hispanic White women, there were regional differences in the age-adjusted rate ratios (1,5,17). In these epidemiologic studies, aggregated data over large geographic regions of the United States were used to quantify the age-adjusted rate ratios of breast cancer in each region. The southwest region comprises 5 states: Arizona, Colorado, Utah, Nevada, and New Mexico. Because activities such as health education, health statistics, and public health services are commonly implemented at the state rather than the regional level, we selected New Mexico for our study. Our findings can be directly accessible to New Mexico state health authorities to evaluate such disparities in their state and act to address them. Furthermore, federal funding for public health infrastructure such as mammography centers is commonly awarded at the state level so that knowing the state-level breast cancer burden in the non-Hispanic AI/AN population could facilitate targeted requests for federal and state funding. In our study, we observed a significant reduction in the age-adjusted breast cancer incidence rate in 16 of 33 New Mexico counties; 17 counties had no significant reduction.

Our study had limitations. First, although we were able to include county-specific covariates in our analytic approach, excess variability remained despite including our county-level ADI variable. We had considered 2 additional county-level covariates, an indicator for a health professional shortage area (whole area shortage vs none or partial) and an indicator for percentage of at-risk non-Hispanic AI/AN women (>5% vs ≤5%); however, adding these 2 county-level covariates to explain some of the spatial patterns in the county-level age-adjusted counts of breast cancer had a negligible effect. Identifying county-level covariates that have higher explanatory power has the potential to guide future measures to reduce disparities in breast cancer incidence. Second, although we wanted to highlight local, county-level detail and also capture broad trends across New Mexico, the county-level age-adjusted counts of breast cancer cases were sparse, leading to wide credible intervals, particularly when quantifying the county-level rate ratio in the non-Hispanic AI/AN population (ie, the non-Hispanic AI/AN county-level rate vs the statewide average rate within non-Hispanic AI/AN). Longer observation periods would likely mitigate this issue; furthermore, extending our model to account for temporal effects that may arise as a result of applying a longer observation period would be straightforward. A third limitation of our study is that our data were based on a 10-year time period 2005–2014, which means these data were 6 years old at the time this article was written. Socioeconomic, cultural, and health-system barriers to mammography among AI/AN women have been identified over the last decade (18–20), and interventions are in development to reduce such barriers and increase satisfaction among AI/AN women with mammography (21). Furthermore, access to breast cancer screening for non-Hispanic AI/AN women and medically underserved populations in general has increased through outreach strategies such as mobile mammography and the use of lay health advisors (22–24). More recent data may show that the gap in breast cancer incidence between non-Hispanic AI/AN and non-Hispanic White women has since been reduced.

Our application of Bayesian disease mapping to these population surveillance data from New Mexico provided substantial evidence of a significant overall reduction in the breast cancer incidence rate in at-risk non-Hispanic AI/AN women compared with non-Hispanic White women, which was more marked than previous reports. Targeted statewide health equity initiatives may reduce disparities in breast cancer incidence among non-Hispanic AI/AN women at risk for breast cancer, whereas targeted county-level initiatives may directly reduce disparities in breast cancer incidence.

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Tables

Table 1. Estimated Posterior Quantities From Fitting the Proposed Model, New Mexico Breast Cancer Incidence Study, 2005–2014[a]

Description of Explanatory Variable	Parameter	Mean (SD)	95% Credible Interval
Intercept	β_0	−7.009 (0.090)	(−7.189 to −6.836)
x_1 non-Hispanic AI/AN vs non-Hispanic White	β_1	−0.937 (0.360)	(−1.763 to −0.346)
x_2 ADI in lower 20th percentile vs otherwise	β_2	0.229 (0.132)	(−0.035 to 0.486)
2-Way interaction ($x_1 \times x_2$)	β_3	−0.303 (0.551)	(−1.373 to 0.812)
Random effects			
Spatial component: non-Hispanic White	$\sqrt{\tau_b}$	0.143 (0.110)	(0.003 to 0.411)
Spatial component: non-Hispanic AI/AN	$\sqrt{\tau_c}$	0.567 (0.499)	(0.029 to 1.859)
Dispersion parameter	$\sqrt{\tau_h}$	0.070 (0.054)	(0.004 to 0.205)
Overall rate ratio (non-Hispanic AI/AN vs non-Hispanic White), $\bar{\lambda}_{\cdot 1}/\bar{\lambda}_{\cdot 0}$		0.384 (0.075)	(0.253 to 0.546)

Abbreviations: ADI, Area Deprivation Index; AI/AN, American Indian/Alaska Native.

[a] Estimates of posterior quantities were obtained from Markov chain Monte Carlo sampling. The 20th percentile for the ADI was 101.6; higher values correspond to increased socioeconomic disadvantage. The overall rate ratio was defined as the ratio of the average rates within each racial category (non-Hispanic AI/AN vs non-Hispanic white), or $\frac{\bar{\lambda}_{\cdot 1}}{\bar{\lambda}_{\cdot 0}}$, where $\bar{\lambda}_{\cdot 1} = \frac{\sum_i n_{i1}\lambda_{i1}}{\sum_i n_{i1}}$ and $\bar{\lambda}_{\cdot 0} = \frac{\sum_i n_{i0}\lambda_{i0}}{\sum_i n_{i0}}$ and $i = 1, \ldots, 33$ corresponding to the 33 counties in New Mexico. The deviance information criterion was 160.9.

Table 2. County-Specific Posterior Means and 95% Credible Intervals for the Rate Ratios, New Mexico Breast Cancer Incidence Study, 2005–2014[a]

County	ADI Quintiles[b]	Non-Hispanic AI/AN vs Non-Hispanic White Women, Posterior Mean Rate Ratio (95% Credible Interval)	Non-Hispanic AI/AN Population, Posterior Mean Rate Ratio (95% Credible Interval)
Bernalillo	Q1	0.311 (0.121–0.600)	0.883 (0.387–1.527)
Catron	Q1	0.346 (0.066–0.927)	0.964 (0.204–2.428)
Chaves	Q2–Q4	0.446 (0.092–0.991)	0.963 (0.211–1.968)
Cibola	Q5	0.440 (0.175–0.834)	0.994 (0.459–1.637)
Colfax	Q2–Q4	0.488 (0.109–1.284)	1.121 (0.278–2.785)
Curry	Q2–Q4	0.490 (0.064–1.348)	1.051 (0.149–2.772)
De Baca	Q2–Q4	0.460 (0.095–1.073)	0.998 (0.228–2.123)
Dona Ana	Q2–Q4	0.407 (0.066–0.910)	0.915 (0.160–1.889)
Eddy	Q1	0.372 (0.058–1.061)	0.954 (0.160–2.556)
Grant	Q2–Q4	0.432 (0.067–1.062)	0.975 (0.162–2.225)
Guadalupe	Q2–Q4	0.456 (0.108–1.037)	1.009 (0.261–2.094)
Harding	Q2–Q4	0.477 (0.112–1.162)	1.075 (0.282–2.455)
Hidalgo	Q5	0.492 (0.048–1.436)	1.075 (0.114–2.979)
Lea	Q2–Q4	0.480 (0.069–1.215)	0.994 (0.153–2.346)
Lincoln	Q1	0.335 (0.081–0.822)	0.920 (0.242–2.049)
Los Alamos	Q1	0.370 (0.080–1.072)	1.093 (0.264–3.024)
Luna	Q5	0.432 (0.063–1.058)	0.967 (0.154–2.196)
McKinley	Q5	0.462 (0.228–0.808)	1.041 (0.662–1.471)
Mora	Q2–Q4	0.460 (0.132–1.044)	1.066 (0.346–2.254)
Otero	Q2–Q4	0.437 (0.112–0.930)	0.973 (0.273–1.915)
Quay	Q2–Q4	0.455 (0.109–1.026)	1.008 (0.264–2.093)
Rio Arriba	Q2–Q4	0.416 (0.131–0.816)	0.969 (0.341–1.677)
Roosevelt	Q2–Q4	0.463 (0.085–1.087)	0.986 (0.198–2.141)
San Juan	Q2–Q4	0.478 (0.250–0.820)	1.063 (0.696–1.519)
San Miguel	Q5	0.465 (0.132–1.078)	1.068 (0.338–2.290)
Sandoval	Q1	0.339 (0.120–0.715)	0.965 (0.387–1.849)
Santa Fe	Q1	0.326 (0.106–0.737)	0.987 (0.363–2.071)
Sierra	Q2–Q4	0.419 (0.092–0.903)	0.940 (0.222–1.825)
Socorro	Q5	0.422 (0.106–0.860)	0.936 (0.260–1.680)
Taos	Q2–Q4	0.492 (0.139–1.296)	1.180 (0.378–2.964)
Torrance	Q2–Q4	0.432 (0.123–0.889)	0.975 (0.305–1.812)
Union	Q2–Q4	0.499 (0.092–1.341)	1.124 (0.225–2.876)
Valencia	Q2–Q4	0.421 (0.100–0.882)	0.946 (0.247–1.772)

Abbreviation: ADI, area deprivation index; AI/AN, American Indian/Alaska Native; Q, quintile.

[a] The overall rate ratio (95% credible interval) comparing non-Hispanic AI/AN vs non-Hispanic white was 0.384 (0.253–0.546).

[b] The ADI for 2012; higher values correspond to increased socioeconomic disadvantage.

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SYSTEMATIC REVIEW

HbA$_{1c}$ Performance in African Descent Populations in the United States With Normal Glucose Tolerance, Prediabetes, or Diabetes: A Scoping Review

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PEER REVIEWED

Summary

What is already known on this topic?

Type 2 diabetes disproportionately affects African descent groups, yet contributing factors are often overlooked. Studies show that glycated hemoglobin A$_{1c}$ (HbA$_{1c}$) underperforms as a screening and diagnostic tool among ethnic cohorts of this population.

What is added by this report?

This review demonstrates that current HbA$_{1c}$ cutoffs overestimate glycemic status in African Americans and underestimate glycemic status in Afro-Caribbeans and Africans. It identifies gaps in the scientific literature, especially among Afro-Caribbeans.

What are the implications for public health practice?

Type 2 diabetes screening and diagnostic tests must account for genetic, biochemical, and socioeconomic factors. To ensure early type 2 diabetes detection, heterogeneity within African descent groups must be recognized, and more reliable testing strategies must be identified.

Abstract

Introduction

African descent populations in the United States have high rates of type 2 diabetes and are incorrectly represented as a single group. Current glycated hemoglobin A$_{1c}$ (HbA$_{1c}$) cutoffs (5.7% to <6.5% for prediabetes; ≥6.5% for type 2 diabetes) may perform suboptimally in evaluating glycemic status among African descent groups. We conducted a scoping review of US-based evidence documenting HbA$_{1c}$ performance to assess glycemic status among African American, Afro-Caribbean, and African people.

Methods

A PubMed, Scopus, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) search (January 2020) yielded 3,238 articles published from January 2000 through January 2020. After review of titles, abstracts, and full texts, 12 met our criteria. HbA$_{1c}$ results were compared with other ethnic groups or validated against the oral glucose tolerance test (OGTT), fasting plasma glucose (FPG), or previous diagnosis. We classified study results by the risk of false positives and risk of false negatives in assessing glycemic status.

Results

In 5 studies of African American people, the HbA$_{1c}$ test increased risk of false positives compared with White populations, regardless of glycemic status. Three studies of African Americans found that HbA$_{1c}$ of 5.7% to less than 6.5% or HbA$_{1c}$ of 6.5% or higher generally increased risk of overdiagnosis compared with OGTT or previous diagnosis. In one study of Afro-Caribbean people, HbA$_{1c}$ of 6.5% or higher detected fewer type 2 diabetes cases because of a greater risk of false negatives. Compared with OGTT, HbA$_{1c}$ tests in 4 studies of Africans found that HbA$_{1c}$ of 5.7% to less than 6.5% or HbA$_{1c}$ of 6.5% or higher leads to underdiagnosis.

Conclusion

HbA$_{1c}$ criteria inadequately characterizes glycemic status among heterogeneous African descent populations. Research is needed to determine optimal HbA$_{1c}$ cutoffs or other test strategies that account for risk profiles unique to African American, Afro-Caribbean, and African people living in the United States.

Introduction

People of African descent in the United States have a disproportionate burden of type 2 diabetes; prevalence is higher in African descent populations, 14%, compared with White populations of European descent (White populations), 9% (1). Additionally, African descent populations are represented as a single group, despite being comprised of African American (91%), Afro-Caribbean (4.7%), and African (3.7%) people (2,3). Limited evidence examines how intraethnic differences in cardiometabolic risk criteria, social determinants of health, and genetic admixture affect diabetes risk in these 3 populations (4,5). Current glycated hemoglobin A_{1c} (HbA_{1c}) cutoffs (HbA_{1c} 5.7% to less than 6.5% for prediabetes; HbA_{1c} of 6.5% or higher for type 2 diabetes), determined from predominantly White population cohorts (4–8), may perform suboptimally in evaluating glycemic status in this diverse population of African American, Afro-Caribbean, and African populations (9–12). African American people may have higher HbA_{1c} values across the glycemic spectrum (9,13), and African immigrants may have lower HbA_{1c} values compared with White people (14). To ensure accurate detection of type 2 diabetes, there is a need to understand the ability of HbA_{1c} to correctly classify type 2 diabetes status and to evaluate intraethnic variation among African American, Afro-Caribbean, and African people (15–17).

Compared with random glucose, fasting plasma glucose (FPG), and the 2-hour oral glucose tolerance test (OGTT), HbA_{1c} has multiple benefits. It does not require fasting, tracks plasma glucose over the preceding 2 to 3 months, and better predicts complications such as cardiovascular disease (4,18). The HbA_{1c} test is stable, unaffected by external variables (eg, exercise, recent meals, and environmental stressors), and easily added to blood tests (19,20). However, interpretation of HbA_{1c} results is affected by the reduced lifespan of red blood cells in patients with type 2 diabetes, anemia, and hemoglobinopathies, conditions which disproportionately affect African descent populations (21–25).

The goal of our study was to conduct a scoping review of US-based peer-reviewed evidence documenting HbA_{1c} performance in African American, Afro-Caribbean, and African populations in the United States with the objectives of 1) summarizing evidence on HbA_{1c} performance in each subethnic group; 2) demonstrating variations in HbA_{1c} performance by each subethnic group; and 3) identifying potential future areas of research.

Methods

Data sources

In early January 2020, we searched PubMed, Scopus, and Cumulative Index to Nursing and Allied Health Literature (CINAHL) for peer-reviewed studies published between January 1, 2000, and January 1, 2020, by using complex search strings that were tested and developed in partnership with our institution's health sciences librarian (L.A.F.). The search string included medical subject headings (MeSH) terms and key words such as "African continental ancestry group," "African Americans," "Caribbean," and "West Indian" to describe population groups and "Glycated Hemoglobin A," "hemoglobin A_{1c}," and "hba_{1c}" to describe the testing indicator of interest for type 2 diabetes (Appendix).

Study selection

Throughout the review process, we screened articles for studies meeting the following inclusion criteria:

1. Articles were original studies published between January 2000 and January 2020, that evaluated HbA_{1c} performance in African descent groups.
2. Study populations included African Americans, Afro-Caribbeans, or Africans.
3. Study participants were living in the United States.
4. Study was a database analysis, epidemiologic study, or clinical study.
5. HbA_{1c} performance was reported specifically in one or more of the African descent groups.
6. HbA_{1c} performance was assessed in healthy populations or for screening or diagnosis of prediabetes or type 2 diabetes.
7. HbA_{1c} performance was assessed by statistical methods (eg, sensitivity, specificity, and positive predictive value), compared with other tests in the same population, or compared African descent populations to other racial groups.

During the study selection process, we included studies that compared various diabetes screening tests against HbA_{1c}, including the OGTT, FPG, and glycated protein tests, to avoid excluding major findings. Although the OGTT is considered optimal for comparison, it is far more costly, resource intensive, and time consuming than the FPG and glycated protein tests (6–8); additionally, research supports the use of other tests along with OGTT or in place of OGTT to enhance detection of diabetes (7,18–22). Because African descent populations are less likely to be adequately represented in clinical research and simultaneously experience health care inequities (4,19), we wanted to be inclusive of all the data, in comparison to HbA_{1c}, that were available for the populations.

On the basis of the title and abstract review, we excluded articles that did not match the set inclusion criteria above (Figure). Two authors (L.K. and S.B.) conducted independent title and abstract reviews. In the full-text review, we excluded articles with insufficient data (eg, case studies), narrative reviews, and articles that fell under a previously set exclusion criterion not detected during the title and abstract review. Full-text articles for potential studies were reviewed by 2 authors (L.K. and S.B.) independently. When multiple exclusion criteria were met, we categorized the article by the exclusion criterion that appeared first in title, abstract, or full text review. A third author (M.H.R.) verified that the exclusion criteria were relevant throughout the article.

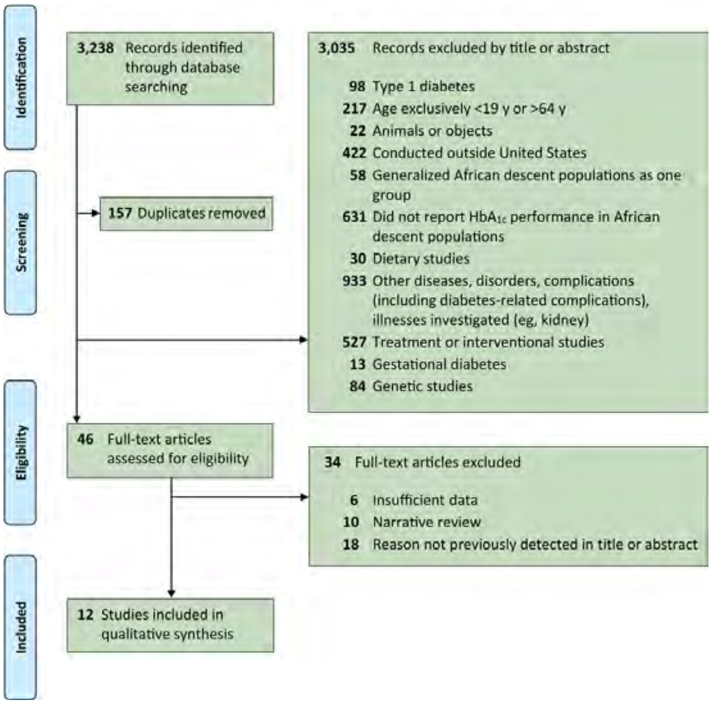

Figure. Flow diagram of the study selection process for glycated hemoglobin A_{1c} (HbA_{1c}) testing performance in African descent populations in the United States, using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses). Studies were published January 1, 2000, to January 1, 2020.

During the identification process, 3,238 records were identified through database searching. In the screening phase, 3,081 records were screened after 157 duplicates were removed. Records were excluded by using a title and abstract review (n = 3,035) by the following exclusion criteria: topic was type 1 diabetes (n = 98); age was exclusively less than 19 years or greater than 64 years (n = 217); topic was animals or objects (n = 22); study was conducted outside the United States (n = 422), study generalized African descent populations as one group (n = 58); study did not report HbA_{1c} performance in African descent populations (n = 631); topic was a dietary study (n = 30); topic was other diseases, disorders, complications (including diabetes-related complications), or illnesses (eg, kidney) (n = 933); topic was a treatment or interventional study (n = 527); topic was gestational diabetes (n = 13); or topic was a genetic study (n = 84). After this screening process, the remaining 46 full-text articles were assessed for eligibility. Of these, 34 full-text articles were excluded based on the following exclusion criteria: insufficient data (n = 6); being a narrative review (n = 10); or for a reason not previously detected in the title or abstract (n = 18). The inclusion stage yielded 12 studies to be included in qualitative synthesis.

Data extraction

We created a data extraction sheet to record the study author and name, populations (sample size, male/female breakdown, race/ethnicity distribution, age, and study location), HbA_{1c} laboratory methods, study design, HbA_{1c} evaluation methods, findings, and HbA_{1c} performance. We successfully retrieved any missing information by 1) searching through cited articles from which the studies retrieved data; 2) identifying parent studies and protocol descriptions given in prior publications; and 3) emailing corresponding authors. HbA_{1c} performance was classified using 2 labels: 1) greater risk of false positive (GRFP) label indicated that the HbA_{1c} test may result in overdetection of glycemic status (eg, type 2 diabetes) that the study is measuring or 2) greater risk of false negatives (GRFN) label indicated that the HbA_{1c} test may result in underdetection of glycemic status. This classification system (GRFP or GRFN) was based on text analysis of the language used by the authors of each study in the way they interpreted their results (eg, lower sensitivity, lower specificity, more misdiagnoses). This allowed for standardization of labeling findings from different study designs. GRFP was assigned if studies reported 1) higher HbA_{1c} values in African descent participants compared with other ethnic groups (eg, White participants) at the same glycemic level; 2) lower sensitivity because of less true positives; or 3) lower specificity because of more false positives. GRFN was assigned if studies reported 1) lower HbA_{1c} values in participants compared with other ethnic groups at same glycemic level; 2) lower sensitivity because of more false negatives; or 3) or lower specificity because of less true negatives. Discrepancies in the review process and data extraction were resolved with input from a third author (M.H.R.).

Included studies were grouped based on study population (African American, Afro-Caribbean, and African) and then organized in alphabetical order by the first author's last name. Studies were labeled numerically as 1 through 12 based on this ordering.

Results

Of the 12 articles that met the inclusion criteria, studies numbered 1 through 7 analyzed HbA_{1c} performance among African American people (26–32), study number 8 analyzed HbA_{1c} performance among Afro-Caribbean people (33), and studies numbered 9 through12 analyzed HbA_{1c} performance among African people

(34–37). All studies were conducted with people living in the United States (Table 1).

The population size of the studies varied from 83 to 16,056 participants, with the sex representation ranging from 69% male/31% female to 0% male/100% female (Table 1). The study cohorts consisted of 20.2% to 100% African descent populations. The overall age range across the different studies was 18 to 92 years and the mean age was between 37 and 64 years when reported (Table 1).

HbA_{1c} laboratory analysis methods were high performance liquid chromatography (HPLC) for studies 1, 2, 4, 5, and 9 through 12 (26,27,29,30,34–37), or immunoassays for studies 3 and 6 through 8 (28,31–33) (Table 1).

The study designs included either clinical data collection (studies 1 and 5 through 12) (26,30–37) or analyses of established databases (studies 2 through 4) (27–29), with publication dates ranging from 2010 to 2019 (Table 1). Study 1 was a retrospective study of patients who underwent HbA_{1c} testing from May 2008 to February 2009 (Table 1) (26). Study 2 was a cross cross-sectional analysis within the longitudinal Coronary Artery Risk Development in Young Adults (CARDIA) study (Table 1) (27).

In these studies, HbA_{1c} performance was evaluated by comparing HbA_{1c} results in African descent populations to HbA_{1c} results in other ethnic groups (eg, White people) (studies 1, 2, 5, and 7) (26,27,30,32), evaluating HbA_{1c} test results against the 2-hour OGTT, FPG, glycated plasma proteins test results, or previous diagnosis in the same participants (studies 3, 6, and 8–12) (28,31,33–37), or both (study 4) (29) (Table 2). Studies conducted among African American people showed that the HbA_{1c} test almost always had a GRFP in this population. Studies 1, 2, 4, 5, and 7 demonstrated that HbA_{1c} values were higher in African Americans when compared with Whites across a range of glycemic states (26,27,29,30,32). Additionally, Study 7 showed that HbA_{1c} values were higher in African American people when compared with both White people and Hispanic people, leading to the potential of overdiagnosis of type 2 diabetes in African American people (32). Using OGTT as a standard test for diagnosis of glycemic status, studies 4 and 6 demonstrated that using HbA_{1c} results in overdiagnosis of type 2 diabetes when HbA_{1c} is 6.5% or higher (29,31). Study 3 showed that African American people may experience an overdiagnosis of prediabetes or type 2 diabetes at HbA_{1c} of 5.7% to less than 6.5%; however, study 6 showed that an HbA_{1c} cutoff of less than 5.7% does not eliminate the possibility of a type 2 diabetes diagnosis (28,31) (Table 2).

In the Afro-Caribbean population, HbA_{1c} testing at the 6.5% or higher cutoff has a GRFN (33). Using FPG as a standard for diagnosis of type 2 diabetes, study 8 showed that more participants were correctly diagnosed as having type 2 diabetes if the cutoff was lowered to 6.26% or higher, suggesting that HbA_{1c} values are generally lower in Afro-Caribbean people (Table 2).

The Africans in America studies 9 through 12 all showed that HbA_{1c} has a GRFN in African people at the HbA_{1c} cutoff of 5.7% to less than 6.5% for prediabetes and HbA_{1c} cutoff of 6.5% or higher for type 2 diabetes (34–37). Using OGTT as a diagnostic standard for glycemic status, studies 9 through 12 demonstrated that using an HbA_{1c} cutoff of 5.7% to less than 6.5% will lead to underdiagnosis of prediabetes in Africans. Additionally, study 9 showed that using an HbA_{1c} cutoff of 6.5% or higher will lead to an underdiagnosis of type 2 diabetes in Africans (34) (Table 2).

Discussion

We assessed 12 studies that evaluated the ability of HbA_{1c} to correctly identify African American, Afro-Caribbean, and African people with prediabetes or type 2 diabetes. Studies among African American people found that HbA_{1c} of 5.7% to less than 6.5% or HbA_{1c} of 6.5% or higher led to overdiagnosis. In one study of Afro-Caribbean people, HbA_{1c} of 6.5% or higher had a greater risk of false negatives (GRFN). Among African people, HbA_{1c} of 5.7% to less than 6.5% or HbA_{1c} of 6.5% or higher led to greater risk of underdiagnosis.

Overdiagnosis of diabetes was likely among African American people in 3 ways. African American people had consistently higher HbA_{1c} levels than White people regardless of glycemic status (26,27,29,30,32). Furthermore, half of normoglycemic African American people had HbA_{1c} values greater than 5.7% (28); and lastly, African American people were more likely to be diagnosed with type 2 diabetes by HbA_{1c} of 6.5% or higher alone but not by OGTT (29,31). Although study 6 did suggest a GRFN at HbA_{1c} less than 5.7%, by misdiagnosing some participants as having normal glycemic status if their HbA_{1c} was less than 5.7% (31), the finding is limited by the smaller sample size of 83 participants when compared with the other studies. This finding must be investigated further.

In Afro-Caribbean people, the HbA_{1c} cutoff of 6.5% is likely to result in underdiagnosis of type 2 diabetes because study 8 showed that more participants were correctly diagnosed as having type 2 diabetes if the cutoff was lowered to 6.26% (33). However, this finding may not be generalizable to other Afro-Caribbean populations because of the smaller sample size and limitation of the study population to Haitian American people. Additionally, because only 1 study provided this conclusion, generalizability is further limited. For African people, underdiagnosis of prediabetes and type 2 diabetes is also likely at the standard HbA_{1c} cutoffs because diagnosis was missed by HbA_{1c} despite being detected by OGTT (34–37). The findings among African people hold true regardless of hemoglobin variant or obesity status (35,36).

Genetics are often thought to be responsible for the differences of HbA_{1c} performance in African descent populations (24,40–43). In fact, genetic analysis in study 5 shows that the HbA_{1c} difference was primarily because of the genomic principal component analysis (PCA) factor in African American people when compared with White people (30). The study demonstrated that the PCA factor was associated with increased HbA_{1c} values in African American people. However, genetics do not fully explain HbA_{1c} differences among African American people (44), because increases in HbA_{1c} may be mediated by social determinants of health (eg, chronic financial strain as seen in study 3) or chronic inflammation (sIL-6R) (28,45). Additionally, G6PD variant or deficiency is often correlated with lower HbA_{1c} values in various populations (40), especially in African American people and African people because of its higher prevalence in these groups (14,46,47). Similarly, the sickle cell trait is associated with lower HbA_{1c} values in African descent populations (21,25). However, study 1 showed that the sickle cell trait may not actually correlate to changes in HbA_{1c} values for African American people (26). Findings regarding associations of genetics with HbA_{1c} are still being researched in this population. Research accounting for genetically linked HbA_{1c} differences in Afro-Caribbean people is also lacking. Genetic polymorphisms between African American people and Haitian people have been researched and show that differences in the *PPARGC1A* gene will correlate to risk of type 2 diabetes in African American people as opposed to protective associations with type 2 diabetes in Haitian people, suggesting that other genetic associations may explain differences in diabetes for Haitian people (48). Although little research explains the role of genetics in HbA_{1c} differences for Haitian people, one likely contributor to lower HbA_{1c} values may be the G6PD variant because of its higher prevalence in populations of African descent (47). Nevertheless, opposing findings regarding the role of genetics in influencing HbA_{1c} values (eg, PCA factor is associated with higher HbA_{1c} whereas the sickle cell trait is associated with lower HbA_{1c}) make it difficult to ascertain the overall impact genetics has in causing the differences in HbA_{1c} that were found for the African descent populations and therefore require further evaluation.

Socioeconomic factors and health behaviors such as diet, smoking, and exercise may explain some differences in glycemic control and HbA_{1c} values among the 3 groups. Higher income and educational attainment appear to decrease the odds of diabetes among African immigrants, whereas only higher education lowers the odds for African American people (5). Neither education nor income appear to affect diabetes risk among Afro-Caribbean people (5,49). Additionally, study 3 found that financial stress and chronic inflammation were associated with higher HbA_{1c}. Chronic inflammation resulting from social and environmental stressors, including experiences of racism, correlate to higher HbA_{1c} in nondiabetic adults (50). In terms of health behaviors, compared with African American people, African and Afro-Caribbean people are less likely to smoke. As African and Afro-Caribbean immigrants settle in the United States, they are affected by dietary acculturation often characterized by increased caloric intake and diets higher in refined carbohydrates, animal protein, fat, and sodium (5). Although diet may affect glycemic control, it is unlikely that diet explains the differences in HbA_{1c} performance illustrated in this study. These socioeconomic factors highlight the diversity of experience within African descent groups, which is often overshadowed by perceived homogeneity of the "Black" experience in the United States. Since immigration to the United States presents unique socioeconomic circumstances that can affect factors like HbA_{1c} (4), impacts of these circumstances are important to analyze distinctly from global concerns.

With these factors affecting HbA_{1c} performance, results must be interpreted with caution. Some alternative diagnostic tests are suggested to aid or replace HbA_{1c} for classification of glycemic status. For example, FPG in combination with HbA_{1c} increases the sensitivity for type 2 diabetes diagnosis in African people (study 10) (35). A stronger relationship between HbA_{1c} and FPG at higher FPG levels in most ethnic groups has been suggested as well (51). Study 8 suggests that FPG may be a better measure of glycemic status than HbA_{1c} in Afro-Caribbean people (33). At the same time, studies 3, 6, and 9 through 12 suggest that OGTT more accurately measures glycemic status than HbA_{1c} in both African American and African people (28,31,34–37). Comparisons between HbA_{1c} and OGTT in Afro-Caribbean people are lacking and should be studied further.

Convenient nonfasting alternatives for type 2 diabetes testing are other glycated proteins (eg, glycated albumin, fructosamine, and other advanced glycation end products) either in combination with or in place of HbA_{1c} (36,37,52–55). Although this approach is supported in multiethnic studies, these glycated proteins should be evaluated specifically in African descent groups.

Several limitations exist for the findings of our review. Despite constructing a comprehensive search, articles published in peer reviewed journals that were not indexed in PubMed, Scopus, and CINAHL may have been missed. The search contained nouns and adjectives as identification for African descent countries and regions of origin and HbA_{1c} testing. However, study participant groups may be based on self or researcher categorization rather than actual region, country, or ethnic group of the participant.

Findings must be interpreted with caution because of this subjective labeling within studies. Additionally, we did not use a specific protocol to evaluate the quality of the included studies, as this is not a part of scoping review methodologies and can increase risk of bias (56,57). Another limitation that must be considered is that time may pass between HbA_{1c} testing and alternate testing in some studies and glycemic status of individuals can change in that time; this limitation will usually exist in this nature of clinical research methodology and therefore must be recognized when evaluating the conclusions from those studies.

According to our review process, there is only 1 study protocol in the United States that examines performance of diabetes screening tests among African immigrants to the United States (34–37). However, studies 9 through 12 demonstrate distinct comparisons within this cohort that illustrate significant conclusions about HbA_{1c} performance. This is because the protocol is ongoing, and the number of participants increased over time. In turn, this also lends strength to the findings, because the similarity in protocol is balanced by the increasing diversity of the sample for each study design.

Finally, the lack of existing studies for Afro-Caribbean people in the United States presents a substantial limitation; our findings for this group must be interpreted cautiously. Further research is needed to understand the performance of HbA_{1c} and evaluate alternate tests in place of the HbA_{1c} in specific African descent populations, especially Afro-Caribbean people. Unique settings like New York City, where 32% of the African descent population is Afro-Caribbean and 4% is African (58), may serve as key locations for public health researchers to investigate type 2 diabetes screening and diagnostics.

Our review also has several strengths. In partnership with our institution’s research librarian, we tested several search constructions and selected the searches that provided the broadest selection within the scope of our topic. Additionally, we searched 3 databases without limiting article type or study designs on title and abstract review and had 2 reviewers independently screen the articles. This improved the selection of articles available for review and reduced selection bias. Finally, we were able to provide clear findings by constructing a label categorization scheme (GRFP/GRFN) that allowed for grouping of studies that used different comparative analytic and statistical methods to analyze HbA_{1c}.

In African descent populations in the United States, the utility of HbA_{1c} is limited in screening for glycemic status, determining care methods, assessing risk of type 2 diabetes complications, or analyzing health disparities. Current HbA_{1c} cutoffs for prediabetes and type 2 diabetes may overestimate glycemic status in African American people and underestimate glycemic status in Afro-Caribbean and African people. Reasons for variations in HbA_{1c} have been attributed to genetic, biochemical, and socioeconomic factors. Alternate testing such as OGTT, FPG, and other glycated blood proteins in place of or in combination with HbA_{1c} may better assess glycemic status in African descent populations. Intraethnic HbA_{1c} heterogeneity within the African descent groups must be recognized, and identification of more reliable type 2 diabetes screening and diagnostic tests is urgent.

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Tables

Table 1. Study Characteristics for Articles Reporting on Glycated Hemoglobin A$_{1c}$ (HbA$_{1c}$) Performance Among African Descent Populations Living in the United States, 2010–2019

Study	First Author (Year); Study	N; Sex	Race/Ethnicity[a] (%)	Age, y	Location	Study Design	HbA$_{1c}$ Laboratory Analysis Method
African American							
1	Bleyer (2010) (26)	N = 885; 43.2% male and 56.8% female	43.5% African American; 56.5% White	≥18	Winston-Salem, North Carolina	Clinical; retrospective study	Cation-exchange column chromatography on an automated HPLC instrument (Variant II Turbo, Bio-Rad Laboratories).
2	Carson (2016); CARDIA study (27)	N = 2,692; 45.5% male and 54.5% female	44% African American; 56% White	Mean (SD): 45.3 (3.6)	Minneapolis, Minnesota; Chicago, Illinois; Birmingham, Alabama; Oakland, California	Database analysis	Whole blood aliquot by ion-exchange HPLC using a Tosoh G7 (Tosoh Bioscience).
3	Cutrona (2015); FACHS (28)	N = 312; 100% female	100% African American	26–92; Mean (SD): 47 (7)	Ames, Iowa; Athens, Georgia	Database analysis	Whole blood aliquot by turbidimetric immunoinhibition (University of Iowa Clinical Pathology Laboratories).
4	Getaneh (2011); NHANES III and DIAMOND Study (29)	N = 16,056[b]; 48.1% male and 51.9% female	4.3% Dominican; 28.9% Hispanic; 26.9% African American; 39.9% White	Range of mean ages: 38.2–63.3	NHANES III: United States. DIAMOND: New York, New York	Database analysis	Diamat HPLC from Bio-Rad Laboratories.[c]
5	Hivert (2019); DPP (30)	N = 2,658; 33% male and 67% female	55.5% White; 20.2% African American; 17.0% Hispanic; 4.4% Asian; 2.9% American Indian	≥25; Mean (SD): 50.7 (10.7)	27 US clinical centers[d]	Clinical	Ion-exchange HPLC instrument (Variant; Bio-Rad Laboratories).
6	Homko (2012) (31)	N = 83; 7.2% male and 92.8% female	100% African American	Mean (SD): 53 (10.4)	Philadelphia, Pennsylvania	Clinical	CDC-approved automated point-of-care analyzer (DCA 2000, Bayer Corporation): monoclonal antibody recognizes glycated N terminus of β chain of hemoglobin.
7	Meigs (2014); BACH Prediabetes Study (32)	N = 1,387; 37.4% male and 62.6% female	27.3% African American; 29.6% Hispanic; 43.0% White	34–87	Boston, Massachusetts	Clinical	Tina-Quant HbA$_{1c}$ generation 2 assay with analytic measurement range of 3.4%–18% (Quest Diagnostics).
Afro-Caribbean							
8	Exebio (2012) (33)	N = 128[e]	100% Haitian American	≥35	Miami, Florida	Clinical	Whole blood with close tube sampling, in duplicate

Abbreviations: AIA, Africans in America; BACH, Boston Area Community Health; CARDIA, Coronary Artery Risk Development in Young Adults; CDC, Centers for Disease Control and Prevention; DIAMOND, Diabetes Among Dominicans and Other Minorities in Northern Manhattan; DPP, Diabetes Prevention Program; FACHS, Family and Community Health Study; HPLC, high performance liquid chromatography; NHANES III, the third National Health and Nutrition Examination Survey; NIH, National Institutes of Health; NGSP, National Glycohemoglobin Standardization Program.

[a] For all studies, White refers to Caucasian, Non-Hispanic White, and/or European White.

[b] Participant data extracted from Table 1, "Sociodemographic Characteristics of Dominicans and the Third National Health and Nutrition Examination Survey Populations, Stratified by Hemoglobin A$_{1c}$-Based Diabetes Diagnosis" (29).

[c] Laboratory analysis data extracted from "Plan and Operation of the Third National Health and Nutrition Examination Survey, 1988–94. Series 1: Programs and Collection Procedures" (38).

[d] Location data extracted from "The Diabetes Prevention Program. Design and methods for a clinical trial in the prevention of type 2 diabetes" (39).

[e] Breakdown for sex/gender not available.

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Table 1. Study Characteristics for Articles Reporting on Glycated Hemoglobin A_{1c} (HbA_{1c}) Performance Among African Descent Populations Living in the United States, 2010–2019

Study	First Author (Year); Study	N; Sex	Race/Ethnicity[a] (%)	Age, y	Location	Study Design	HbA_{1c} Laboratory Analysis Method
							(coefficient of variation <1.7%), with Roche Tina Quant Second Generation A1c immunoassay method of Laboratory Corporation of America.
African							
9	Briker (2019); The AIA Study (34)	N = 430; 65% male and 35% female	100% African immigrants in the United States	Mean (SD): 38 (10)	Bethesda, Maryland	Clinical	NGSP-certified instruments: BioRad Laboratories Classic Variant (n = 32), Bio-Rad Laboratories Variant II (n = 158), and BioRad Laboratories D10 (n = 240) used sequentially by the NIH Clinical Center for HPLC.
10	Sumner 1 (2015); The AIA Study (35)	N = 216; 68% male and 32% female	100% African immigrants in the United States	20–64; mean (SD): 37 (10)	Bethesda, Maryland	Clinical	NGSP-certified instruments: Classic Variant, Variant II, and D10 for HPLC (Bio-Rad Laboratories). Whole blood samples in 90 participants analyzed by boronate affinity chromatography method on NGSP-certified Premier Hb9210 analyzer (Trinity Biotech).
11	Sumner 2 (2016); The AIA Study (36)	N = 236; 69% male and 31% female	100% African immigrants in the United States	20–64; Mean (SD): 39 (10)	Bethesda, Maryland	Clinical	NGSP-certified instruments: Variant II and D10 for HPLC (Bio-Rad Laboratories).
12	Sumner 3 (2016); The AIA Study (37)	N = 217; 69% male and 31% female	100% African immigrants in the United States	20–64; Mean (SD): 39 (10)	Bethesda, Maryland	Clinical	NGSP-certified instruments: Variant II and D10 for HPLC (Bio-Rad Laboratories).

Abbreviations: AIA, Africans in America; BACH, Boston Area Community Health; CARDIA, Coronary Artery Risk Development in Young Adults; CDC, Centers for Disease Control and Prevention; DIAMOND, Diabetes Among Dominicans and Other Minorities in Northern Manhattan; DPP, Diabetes Prevention Program; FACHS, Family and Community Health Study; HPLC, high performance liquid chromatography; NHANES III, the third National Health and Nutrition Examination Survey; NIH, National Institutes of Health; NGSP, National Glycohemoglobin Standardization Program.

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[d] Location data extracted from "The Diabetes Prevention Program. Design and methods for a clinical trial in the prevention of type 2 diabetes" (39).

[e] Breakdown for sex/gender not available.

Table 2. Evaluation of Glycated Hemoglobin A$_{1c}$ (HbA$_{1c}$) Performance: Greater Risk of False Positives Versus Greater Risk of False Negatives Among African Descent Populations Living in the United States, 2010–2019

Study	HbA$_{1c}$ Evaluation Method	Findings	Performance
African American			
1	Compared with other ethnic groups (ie, White people)	Main finding: Higher HbA$_{1c}$ values for African American than for White people at all fasting glucose levels (26). Additional findings: • Relationship between HbA$_{1c}$ and simultaneous serum glucose did not differ between African American people with and without the SCT. • SCT does not impact relationship between HbA$_{1c}$ and serum glucose concentration, and does not account for differences between African American and White people.	Greater risk of false positives
2	Compared with other ethnic groups (ie, White people)	Main finding: African American people without previous diagnosis of type 2 diabetes by OGTT had higher mean values of HbA$_{1c}$ than White people (β = 0.19% points; 95% CI = 0.14–0.24) (27). Additional finding: HbA$_{1c}$ values were compared for participants free of type 2 diabetes based on the OGTT.	Greater risk of false positives
3	Compared with other measures (ie, previous diagnosis)[a]	Main finding: Chronic financial strain increased sIL-6R, an inflammatory marker, and HbA$_{1c}$ (28). Additional finding: Although African American women had no previous prediabetes or type 2 diabetes diagnosis, 54% had HbA$_{1c}$ >5.7%.	Greater risk of false positives
4	Compared with other ethnic groups (ie, White people); Compared with other measures (ie, FPG and OGTT)	Main findings: • For African American people (N = 408) classified as having normal glucose tolerance by either FPG or OGTT, HbA$_{1c}$ misclassified 3.5% of them as having type 2 diabetes (29). • HbA$_{1c}$ diagnosed type 2 diabetes in 67% of African American people and 37.9% of White people.	Greater risk of false positives
5	Compared with other ethnic groups (ie, White people)	Main finding: HbA$_{1c}$ was higher in African American (mean [SD], 6.2% [0.6]) than in White people (mean [SD], 5.8% [0.4]) (30). Additional findings: • Genomic analysis showed that 3 genetic factors contributed to the differences in HbA$_{1c}$: PCA factor, SCT, and GRS. • 60% of HbA$_{1c}$ differences between African American and White people are explained by first genomic PCA factor (degree of African ancestry). • SCT explained 16% of the difference and GRS explained 14% of difference in HbA$_{1c}$ between African American and White people.	Greater risk of false positives
6	Compared with other measures (ie, OGTT)	Main findings: • For patients with type 2 diabetes diagnosis by HbA$_{1c}$, OGTT classified 48.3% with type 2 diabetes, 38.7% with IGT, and 12.9% with normal glucose tolerance.	Greater risk of false positives at HbA$_{1c}$ ≥6.5% and greater risk of false negatives at HBA$_{1c}$ ≤5.6%

Abbreviations: OGTT, 2-hour oral glucose tolerance test; FPG, fasting plasma glucose; IGT, impaired glucose tolerance; PCA, principal component analysis; GRS, genetic risk score; SCT, sickle cell trait; ROC, receiver operating characteristic.

[a] Exact temporality between the previous diagnosis and HbA$_{1c}$ testing was not provided within the study, with an estimate of less than 12 months extrapolated from the study design. Findings from this study may represent new onset diabetes. This provides a limitation in the conclusive findings for HbA$_{1c}$ performance in this study.

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Table 2. Evaluation of Glycated Hemoglobin A_{1c} (HbA_{1c}) Performance: Greater Risk of False Positives Versus Greater Risk of False Negatives Among African Descent Populations Living in the United States, 2010–2019

Study	HbA_{1c} Evaluation Method	Findings	Performance
		• HbA_{1c} ≤5.6% does not exclude type 2 diabetes or IGT. Among 33.7% of patients with HbA_{1c} ≤5.6%, 64.3% had IGT or type 2 diabetes (31). Additional findings: • 15.9% of patients had HbA_{1c} ≥6.5%. • HbA_{1c} ≥6.5% indicates type 2 diabetes or IGT, with 50% sensitivity and 90% specificity. • HbA_{1c} ≥6.5% had positive predictive value of 48%. • HbA_{1c} ≤5.6% showed 17.2% sensitivity and 100% specificity.	
7	Compared with other ethnic groups (ie, Hispanic and White people)	Main finding: Mean HbA_{1c} levels were higher in African American (5.68%) than in Hispanic (5.57%) and White people (5.47%) (32). Additional findings: • With every 1% increase in European ancestry, there was a 0.002% decrease in HbA_{1c}. • Individuals with 100% African American ancestry had an HbA_{1c} value that was 0.27% higher than those with 100% European ancestry.	Greater risk of false positives
Afro-Caribbean			
8	Compared with other measures (ie, FPG)	Main findings: • At HbA_{1c} ≥6.5%, sensitivity was 73% and specificity was 89%. • At HbA_{1c} ≥6.26%, sensitivity was 80% and specificity was 74% (33). Additional finding: The area under the ROC curve for HbA_{1c} as a diagnostic indicator of type 2 diabetes was 0.86.	Greater risk of false negatives
African			
9	Compared with other measures (ie, OGTT)	Main findings: • For 32 individuals with type 2 diabetes, HbA_{1c} detected type 2 diabetes in 32% and OGTT detected type 2 diabetes in 68% of individuals with HbA_{1c} <6.5%. • For 178 individuals with prediabetes, HbA_{1c} detected prediabetes in 57% of individuals and OGTT detected prediabetes in 43% of individuals. Additional finding: Using HbA_{1c} alone missed a diagnosis of type 2 diabetes in 60% of African people and a prediabetes diagnosis in 40% of African people (34).	Greater risk of false negatives
10	Compared with other measures (ie, FPG and OGTT)	Main finding: Among subjects with IGT by OGTT, HbA_{1c} ≥5.7% had sensitivity of 53%, 54%, and 47% for the total, normal, and variant hemoglobin groups, respectively (35). Additional findings: • HbA_{1c} with FPG demonstrated sensitivity of 64%. • HbA_{1c} diagnostic sensitivity did not vary by variant hemoglobin status.	Greater risk of false negatives
11	Compared with other measures (ie, OGTT	Main finding:	Greater risk of false

Abbreviations: OGTT, 2-hour oral glucose tolerance test; FPG, fasting plasma glucose; IGT, impaired glucose tolerance; PCA, principal component analysis; GRS, genetic risk score; SCT, sickle cell trait; ROC, receiver operating characteristic.

[a] Exact temporality between the previous diagnosis and HbA_{1c} testing was not provided within the study, with an estimate of less than 12 months extrapolated from the study design. Findings from this study may represent new onset diabetes. This provides a limitation in the conclusive findings for HbA_{1c} performance in this study.

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Table 2. Evaluation of Glycated Hemoglobin A_{1c} (HbA_{1c}) Performance: Greater Risk of False Positives Versus Greater Risk of False Negatives Among African Descent Populations Living in the United States, 2010–2019

Study	HbA_{1c} Evaluation Method	Findings	Performance
	and glycated albumin)	Among subjects with prediabetes by OGTT, HbA_{1c} of 5.7% to less than 6.5% had 37% sensitivity in nonobese African immigrants and 64% sensitivity in obese African immigrants (36).	negatives
		Additional finding: For HbA_{1c} of 5.7% to less than 6.5% combined with glycated albumin ≥13.77%, sensitivity increased to 72% for nonobese African immigrants.	
12	Compared with other measures (ie, OGTT and glycated albumin)	Main findings: • When type 2 diabetes was detected by glycated plasma proteins (albumin or fructosamine; n = 24), average HbA_{1c} was mean (SD) 5.2% (0.4). • OGTT detected prediabetes in 74 individuals (13 of 74 had low HbA_{1c}) (37).	Greater risk of false negatives
		Additional findings: • HbA_{1c} detected ≤50% of African immigrants with prediabetes. • HbA_{1c} combined with the glycated albumin test increases sensitivity to 80% for diagnosing prediabetes.	

Abbreviations: OGTT, 2-hour oral glucose tolerance test; FPG, fasting plasma glucose; IGT, impaired glucose tolerance; PCA, principal component analysis; GRS, genetic risk score; SCT, sickle cell trait; ROC, receiver operating characteristic.

[a] Exact temporality between the previous diagnosis and HbA_{1c} testing was not provided within the study, with an estimate of less than 12 months extrapolated from the study design. Findings from this study may represent new onset diabetes. This provides a limitation in the conclusive findings for HbA_{1c} performance in this study.

Appendix. Search Strings Used in a Scoping Review of HbA$_{1c}$ Performance in African Descent Populations in the United States With Normal Glucose Tolerance, Prediabetes, and Diabetes

Database	Search String
PubMed	(africa[tiab] OR african[tiab] OR africans[tiab] OR “africa”[MeSH Terms] OR afro[tiab] OR black[tiab] OR “african continental ancestry group”[MeSH Terms] OR “african americans”[MeSH Terms] OR Angola[tiab] OR Angolan[tiab] OR Benin[tiab] OR Beninese[tiab] OR Botswana[tiab] OR Motswana[tiab] OR Batswana[tiab] OR “Burkina Faso”[tiab] OR Burkinabe[tiab] OR Burundi[tiab] OR Burundian[tiab] OR Cameroon[tiab] OR Cameroonian[tiab] OR “Cape Verde”[tiab] OR “Cape Verdean”[tiab] OR “Central African Republic”[tiab] OR “Central African”[tiab] OR Chad[tiab] OR Chadian[tiab] OR Comoros[tiab] OR Comorian[tiab] OR “Republic of the Congo”[tiab] OR Congolese[tiab] OR Djibouti[tiab] OR Djiboutian[tiab] OR “Equatorial Guinea”[tiab] OR “Equatorial Guinean”[tiab] OR Equatoguinean[tiab] OR Eritrea[tiab] OR Eritrean[tiab] OR Ethiopia[tiab] OR Ethiopian[tiab] OR Gabon[tiab] OR Gabonese[tiab] OR Gambia[tiab] OR Gambian[tiab] OR Ghana[tiab] OR Ghanaian[tiab] OR Guinea[tiab] OR Guinean[tiab] OR “Guinea-Bissau”[tiab] OR “Bissau-Guinean”[tiab] OR “Ivory Coast”[tiab] OR Ivorian[tiab] OR Kenya[tiab] OR Kenyan[tiab] OR Lesotho[tiab] OR Mosotho[tiab] OR Basotho[tiab] OR Liberia[tiab] OR Liberian[tiab] OR Madagascar[tiab] OR Malagasy[tiab] OR Malawi[tiab] OR Malawian[tiab] OR Mali[tiab] OR Malian[tiab] OR Mauritania[tiab] OR Mauritanian[tiab] OR Mauritius[tiab] OR Mauritian[tiab] OR Mozambique[tiab] OR Mozambican[tiab] OR Namibia[tiab] OR Namibian[tiab] OR Niger[tiab] OR Nigerien[tiab] OR Nigeria[tiab] OR Nigerian[tiab] OR Rwanda[tiab] OR Rwandan[tiab] OR “Sao Tome and Principe”[tiab] OR Senegal[tiab] OR Senegalese[tiab] OR Seychelles[tiab] OR Seychellois[tiab] OR “Sierra Leone”[tiab] OR “Sierra Leonean”[tiab] OR Somalia[tiab] OR Somalian[tiab] OR “South Africa”[tiab] OR “South African”[tiab] OR “South Sudan”[tiab] OR “South Sudanese”[tiab] OR Sudan[tiab] OR Sudanese[tiab] OR Swaziland[tiab] OR Swazi[tiab] OR Tanzania[tiab] OR Tanzanian[tiab] OR Togo[tiab] OR Uganda[tiab] OR Ugandan[tiab] OR Zambia[tiab] OR Zambian[tiab] OR Zimbabwe[tiab] OR Zimbabwean[tiab] OR anguilla[tiab] OR anguillian[tiab] OR “Antigua and Barbuda”[tiab] OR antiguan[tiab] OR barbudan[tiab] OR aruba[tiab] OR aruban[tiab] OR bahamas[tiab] OR bahamian[tiab] OR barbados[tiab] OR barbadian[tiab] OR belize[tiab] OR belizean[tiab] OR bermuda[tiab] OR bermudian[tiab] OR “British Virgin Islands”[tiab] OR caribbean[tiab] OR “Cayman Islands”[tiab] OR “Costa Rica”[tiab] OR “Costa Rican”[tiab] OR cuba[tiab] OR cuban[tiab] OR curacao[tiab] OR curacaoans[tiab] OR dominica[tiab] OR “Dominican Republic”[tiab] OR dominican[tiab] OR grenada[tiab] OR grenadine[tiab] OR guadeloupe[tiab] OR guadeloupean[tiab] OR guyana[tiab] OR guyanese[tiab] OR haiti[tiab] OR haitian[tiab] OR honduras[tiab] OR honduran[tiab] OR jamaica[tiab] OR jamaican[tiab] OR martinique[tiab] OR martiniquais[tiab] OR montserrat[tiab] OR montserratian[tiab] OR nevis[tiab] OR nicaragua[tiab] OR nicaraguan[tiab] OR panama[tiab] OR panamanian[tiab] OR “Puerto Rico”[tiab] OR “Puerto Rican”[tiab] OR “St. Barts”[tiab] OR “St. Christopher”[tiab] OR “St. Croix”[tiab] OR “St. Johns”[tiab] OR “St. Kitts and Nevis”[tiab] OR “St. Lucia”[tiab] OR “St. Martin”[tiab] OR “St. Thomas”[tiab] OR “St. Vincent”[tiab] OR vincentian[tiab] OR suriname[tiab] OR surinamese[tiab] OR “Trinidad and Tobago”[tiab] OR trinidadian[tiab] OR trini[tiab] OR tobagonian[tiab] OR “US Virgin Islands”[tiab] OR venezuela[tiab] OR venezuelan[tiab] OR “Virgin Islands”[tiab] OR “West Indies”[tiab] OR “West Indian”[tiab]) AND (“Glycated Hemoglobin A”[mesh] OR “hemoglobin A1c”[tiab] OR “hba1c”[tiab] OR “A1C”[tiab]) AND (“2000/01/01”[PDAT]: “2020/01/01”[PDAT])
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Cumulative Index to Nursing and Allied Health Literature (CINAHL)	(hba1c OR glycosylated hemoglobin A OR glycated hemoglobin OR “hemoglobin A1c” OR “glycated hemoglobin A”) AND (africa OR african OR africans OR afro OR black OR african americans OR blacks OR caribbean OR Angola OR Angolan OR Benin OR Beninese OR Botswana OR Motswana OR Batswana OR “Burkina Faso” OR Burkinabe OR Burundi OR Burundian OR Cameroon OR Cameroonian OR “Cape Verde” OR “Cape Verdean” OR “Central African Republic” OR “Central African” OR Chad OR Chadian OR Comoros OR Comorian OR “Republic of the Congo” OR Congolese OR Djibouti OR Djiboutian OR “Equatorial Guinea” OR “Equatorial Guinean” OR Equatoguinean OR Eritrea OR Eritrean OR Ethiopia OR Ethiopian OR Gabon OR Gabonese OR Gambia OR Gambian OR Ghana OR Ghanaian OR Guinea OR Guinean OR “Guinea-Bissau” OR “Bissau-Guinean” OR “Ivory Coast” OR Ivorian OR Kenya OR Kenyan OR Lesotho OR Mosotho OR Basotho OR Liberia OR Liberian OR Madagascar OR Malagasy OR

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IMPLEMENTATION EVALUATION

Reducing Tobacco Use in Oregon Through Multisector Collaboration: Aligning Medicaid and Public Health Programs

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PEER REVIEWED

Summary

What is known on this topic?

Tobacco use can be reduced with evidence-based cessation strategies such as improving access to cessation counseling and medications as well as community-based interventions.

What is added by this report?

We describe the efforts of a state health agency to improve access to cessation benefits and reduce tobacco use through the creation and implementation of a novel incentive metric for Oregon's Medicaid delivery organizations.

What are the implications for public health practice?

Medicaid and public health agencies can work together to reduce tobacco use through policy and systems levers both inside and outside of clinics.

Abstract

Introduction

Tobacco use is the leading cause of preventable death and disease in the United States. Oregon's coordinated care model for Medicaid provides an opportunity to consider novel ways to reduce tobacco use.

Purpose and Objectives

We sought to evaluate the changes in tobacco cessation benefits, patient access to cessation interventions, and cigarette smoking prevalence before and after introduction of the statewide Coordinated Care Organization (CCO) cigarette smoking incentive metric for Medicaid members.

Intervention Approach

Medicaid and public health collaborated to develop a novel population-level opportunity to reduce tobacco use. In 2016, an incentive metric for cigarette smoking was incorporated into Oregon's CCO Quality Incentive Program, which holds Oregon's CCOs accountable for providing comprehensive cessation benefits and for reducing tobacco use prevalence among members.

Evaluation Methods

We evaluated the changes in tobacco cessation benefits, patient–provider discussions of smoking cessation, and cigarette smoking prevalence before and after the introduction of the statewide CCO cigarette smoking incentive metric.

Results

All 15 CCOs now cover cessation counseling (telephone, individual, and group) and pharmacotherapy (all 7 FDA-approved medications). The number of CCOs requiring prior authorization for at least 1 FDA-approved pharmacotherapy decreased substantially. From 2016 through 2018, the percentage of Medicaid members who reported that their health care providers recommended cessation assistance increased above baseline. The incentive metric and aligned interventions were associated with a reduction in cigarette smoking prevalence among Medicaid members, as indicated by the electronic health record metric. Thirteen of 15 CCOs demonstrated a reduction in smoking prevalence with the statewide prevalence rate decreased from 29.3% to 26.6%.

Implications for Public Health

Since incentive metric implementation, progress has been made to reduce tobacco use among CCO members. Cross-agency partnerships between Medicaid and public health contributed to these successes.

Introduction

Tobacco use is the leading cause of preventable illness and death in the United States. In 2018, 19.7% of people used any tobacco product, and use was disproportionately higher among those who have Medicaid (27.8%) (1). In Oregon, tobacco use is associated with more than 8,000 deaths each year (2) and costs Oregon $2.9 billion annually in medical expenditures, lost productivity, and premature death (3). The negative effects of tobacco are most damaging to low-income Oregonians, members of certain racial and ethnic groups, tribal members, members of the LGBTQ community, and people with mental illness, all of whom use tobacco at higher rates than their counterparts and have the most severe health consequences as a result (4). Data from Oregon's 2017 Behavioral Risk Factor Surveillance System (BRFSS) indicate that the prevalence of tobacco use is higher among Oregon adults enrolled in Medicaid: 27% of Oregon adults enrolled in Medicaid smoke cigarettes, compared with 15% of those with other types of insurance (4) (Box).

Box. Cigarette Smoking and Tobacco Use Definitions

The term "cigarette smoking" in this article is used to describe the process of inhaling tobacco smoke from combustible cigarettes. "Tobacco use" is broader and generally includes the use of cigars, e-cigarettes, smokeless tobacco, and other tobacco and vaping products.

Reducing tobacco use requires a multifaceted approach that prevents youth and young adults from initiating tobacco use, eliminates tobacco-related health disparities in all populations, minimizes exposure to secondhand smoke, and helps tobacco users quit (6). Key elements of this approach include promoting and improving access to affordable and effective cessation services, as well as ensuring that the places people live, work, play, and learn are tobacco-free and reinforce individuals' desire to quit or never start using tobacco.

The evidence-based clinical strategies that underpin this comprehensive approach, along with evidence of successful cross-sector collaboration between public health and health care, are well documented in the literature (7–9). The US Preventive Services Task Force (USPSTF) conducts systematic reviews and has identified evidence-based clinical interventions to reduce tobacco use. The USPSTF gives a grade "A" to the recommendation (defined as a recommended service because of high certainty that the net benefit is substantial) that clinicians ask all adults about tobacco use, advise users to quit, and provide behavioral counseling interventions and pharmacotherapy approved by the US Food and Drug Administration (FDA) (10). Furthermore, the Centers for Disease Control and Prevention identified 3 key evidence-based health systems interventions that are proven to accelerate tobacco use reduction — increasing access to cessation counseling and medications, removing barriers to access such as copays or coinsurance, and promoting the increased use of cessation benefits by tobacco users (11).

Oregon's creation of coordinated care organizations (CCOs) in 2012 (12) provided an unprecedented opportunity to reduce tobacco use among Medicaid members through implementation of the evidence-based systems and policy changes just described. CCOs are health care plans that coordinate health care delivery for the Oregon Health Plan (OHP, Oregon's Medicaid program). CCOs were introduced as a key component of Oregon's coordinated care model with the goal of transforming Oregon's health system to provide incentives to better health and better care at lower costs. As part of the CCO Quality Incentive Program, CCOs are required to report annually on quality improvement and health outcome metrics, hereafter referred to as *incentive metrics*, for which they receive payment for performance if they meet certain benchmarks or targets (13). A variety of existing tobacco measures were considered for adoption, but none met the level of desired population impact. Existing tobacco measures (eg, through the National Quality Forum) (14) hold no accountability for the outcome of decreasing tobacco use. Instead, these measures focus on screening individual patients for tobacco use (a process measure alone), or a step up, measure whether a patient received an intervention of counseling, pharmacotherapy, or both. In developing an innovative Medicaid payer metric with a population health lens, the critical areas identified as necessary to an effective measure included coverage of the suite of evidence-based interventions, including minimum standards of pharmacotherapy and counseling, and accountability for reducing tobacco use prevalence (ie, ensuring that the interventions were actually effective and resulted in a decrease in smoking rates, arguably a more patient-oriented outcome). Holding plans, rather than providers alone, accountable may increase the effectiveness of the metric on population health outcomes. The use of substantial financial incentives also promotes investment in achieving the metric. During development of this program, we were not aware of any other states looking into holding health plans accountable for tobacco use prevalence or using financial incentives for this work, making this a highly innovative approach. Although additional developments on national tobacco measures that could be used for prevalence have occurred, we are unaware of any state programs using these measures for health plan accountability or to provide incentives for performance.

In 2016, a novel incentive metric for cigarette smoking was implemented, holding CCOs accountable for providing comprehensive cessation benefits as well as reducing tobacco use prevalence among members. As a result, public health, Medicaid, and the CCOs are aligned with the common goal of reducing tobacco use in Oregon.

Purpose and Objective

We sought to evaluate the changes in tobacco cessation benefits, patient access, and cigarette smoking prevalence before and after the introduction of the statewide CCO cigarette smoking incentive metric for Medicaid members in 2016.

We describe 1) the history of related tobacco efforts that led to the creation of the incentive metric; 2) the current state and local policy and system infrastructure that supports CCO success on tobacco use reduction; and 3) the impact of these efforts on tobacco cessation benefits and cigarette smoking rates for Oregon's Medicaid population.

Intervention Approach

Oregon's history of cross-agency collaboration on tobacco reduction

The introduction of the cigarette smoking incentive metric is grounded in a history of collaboration between public health and health care partners throughout the Oregon Health Authority (OHA). The Tobacco Prevention and Education Program (TPEP), housed in the Public Health Division, began operating in 1997 with the passage of Measure 44 (15), which increased the price of tobacco in Oregon and dedicated a portion of the tobacco taxes to tobacco prevention and education (16). In 1997, the OHP (Medicaid) Prioritized List of Health Services added coverage for tobacco cessation services (17). In 1998, Oregon became one of the first states to offer free cessation services to all people in Oregon through the statewide tobacco quitline (18). Given the support for addressing tobacco use comprehensively (through taxes, Medicaid coverage, and public health), both TPEP and Medicaid provided staff resources to jointly implement a series of performance improvement projects with the goal of incentivizing the Medicaid managed care plans to promote tobacco cessation benefits to pregnant women, adolescents, and clients with chronic diseases, such as asthma, diabetes, and cardiovascular disease (19). When CCOs were established in 2012, public health and Medicaid staff were ready to work together to identify a common set of benefit design recommendations for tobacco cessation. These early cross-agency initiatives provided the foundation for a sustained and robust partnership across OHA to reduce tobacco use.

Oregon's tobacco prevention and cessation infrastructure

OHA currently leads tobacco reduction initiatives across multiple divisions that are responsible for both Medicaid and statewide public health outcomes. Since the inception of the TPEP program in 1997, cigarette smoking has decreased by more than 50% (4). TPEP's work contributed to this success through implementation of evidence-based policy strategies such as increasing smoke-free environments in collaboration with local public health partners and tribes, increasing public awareness about the dangers of tobacco use through statewide education and advertising campaigns, and supporting access to cessation services through the statewide quitline. TPEP also maintains a robust tobacco surveillance and evaluation system to track, measure, and analyze tobacco-related data, and to use findings to inform program and policy approaches (20).

The Medicaid program also has taken a comprehensive approach to reduce tobacco use among Medicaid members. In Oregon, the state legislature determines the Medicaid benefit package by drawing a funding line on the state's Prioritized List of Health Services, with services "above the line" being covered and those "below the line" not being covered. The Health Evidence Review Commission (HERC) is a governor-appointed commission representing physicians, community members, and CCOs that manages Oregon's unique Prioritized List, which emphasizes covering services that are evidence-based, maximize population health, and control costs. HERC has assigned a very high priority to tobacco cessation and since 2016 requires that all CCOs offer Medicaid patients the "gold standard" evidence-based cessation interventions, including FDA-approved pharmacotherapy and behavioral counseling (21).

The Metrics and Scoring Committee, another statewide governor-appointed committee, is responsible for identifying incentive metrics for the CCO Quality Incentive Program (22). Performance metrics are increasingly used to promote change in health systems, clinical practice, and payer strategies and to create accountability (23). Although health plans frequently use process metrics such as whether members are offered tobacco cessation counseling services, health plans are generally not held accountable for outcome metrics such as tobacco use prevalence in their member population. The Metrics and Scoring Committee has driven innovation and performance improvements in Oregon by expanding CCO incentive measures to include outcome metrics such as the tobacco use reduction outcome measure.

Introduction of the tobacco incentive metric

CCO incentive metrics are selected each year by the Metrics and Scoring Committee. Throughout the year, the Committee considers proposals for new incentive metrics from various sources, including public testimony from community members, presentations from state agency staff and subject matter experts, recommendations from its Technical Advisory Workgroup, and in some years, a widely distributed stakeholder survey. The committee has adopted incentive metric selection and retirement criteria that it uses to determine which (and when) new metrics should be added or existing metrics removed from the CCO incentive metric set. Several key criteria that the committee considers include alignment with other metric sets and consistency with other state priorities.

A tobacco prevalence metric was proposed for inclusion in the CCO incentive metric set soon after the establishment of CCOs in 2012; however, the only potential data source for a health plan–level, Medicaid-specific prevalence metric was the annual Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, and stakeholders expressed concerns that the survey sample was insufficient to fairly capture quality improvement efforts by health plans to reduce prevalence. Throughout 2014 and 2015, potential incentive metric options — both process and outcome measures — were discussed. Before the committee approved a metric for the 2016 performance year, public health advocates provided expert testimony on the importance of focusing on tobacco use prevalence. The release of Oregon's State Health Improvement Plan in 2015 identified the prevention and reduction of tobacco use as a top priority, which also helped to elevate and sustain interest in the issue.

After the tobacco incentive metric was approved, the technical advisory workgroup developed the metric specifications based on Meaningful Use standards required for electronic health records (EHRs) and HERC requirements for tobacco cessation benefits.

Supporting CCOs for success in reducing tobacco prevalence

Since the introduction of the incentive metric in 2016, various OHA divisions and committees have been working together to ensure alignment across state-level programs, policies, and systems and to support CCOs in their efforts to reduce tobacco prevalence.

Cross-agency alignment. Concurrent with the introduction of the incentive metric, HERC modified the Prioritized List of Health Services in 2015 to clarify the CCO requirement to cover effective clinical strategies, including behavioral health interventions (eg, quitlines, clinical counseling) and FDA-approved pharmacotherapy. Public health and HERC also worked to ensure that comprehensive, gold-standard cessation benefits (as defined by both HERC and the 2010 Patient Protection and Affordable Care Act) (24) were aligned across the Prioritized List, the public health guidance documents, and the surveys that assess CCO performance on the metric. In addition, the OHA Transformation Center works in partnership with public health to provide technical assistance and training to CCOs and providers on best practices to prevent and reduce tobacco use (25). This service includes clinical provider trainings, technical assistance on policy strategies, and trainings on how to use quitline data.

Multisector Intervention Statements. Several years ago, HERC developed a concept of Multisector Intervention Statements to address the fact that improvement in health outcomes may sometimes be more efficiently achieved by using strategies that occur outside of a clinician–patient in-person visit (26). The idea is to apply the same evidence standards as those for traditional clinical interventions so that health care plans can invest in the most effective evidence-based interventions to improve health outcomes, even if they are outside of the traditional health care setting.

In 2016, HERC reviewed high-quality systematic reviews and compiled the information in a summary of effective community-level interventions for tobacco use prevention and reduction plus a specific evidence evaluation for tobacco use during pregnancy. Using the findings of these reviews, HERC issued a multisector intervention statement (27,28) on tobacco use that outlines effective evidence-based interventions targeted at the community or population level, such as tobacco taxes and smoke-free laws. The goal of the multisector intervention statement is to provide CCOs the information they need to reduce cigarette smoking prevalence in their memberships and larger communities and to encourage them to play a role in implementing evidence-based community-level strategies alongside their local public health counterparts.

Connecting local public health departments and CCOs. OHA has also worked to connect the statewide network of TPEP in all counties and tribes with their regional CCOs to replicate the comprehensive scope of tobacco use prevention and cessation activities at the local level. Often TPEP provides data and implement policy and systems change strategies, while CCOs implement clinical improvement strategies. The introduction of a cigarette smoking incentive metric focused on prevalence reduction presents an opportunity for local public health and CCOs to form strategic partnerships to implement strategies that work. The Sustainable Relationships for Community Health grant program administered by the OHA Public Health Division serves to accelerate these local cross-sectoral partnerships by bringing CCO, local public health, clinical, and community-based partners together several times a year to work together on large-scale systems changes to reduce and prevent tobacco use. The OHA Public

Health Division also works to connect local TPEP with other local partners, like maternal and child health programs that prioritize cessation in pregnant women, and alcohol and other drug prevention programs that address similar addiction issues.

Evaluation Methods

The incentive metric for cigarette smoking prevalence was designed to have multiple components and to be phased in slowly to ensure that CCOs were meeting minimum cessation benefit requirements and that they and their contracted providers had sufficient infrastructure to support reporting on cigarette smoking prevalence from EHRs before being accountable for reductions in smoking prevalence. With these design parameters in mind, the resulting incentive metric has 3 components: 1) providing the minimum cessation benefit package, as defined by HERC, 2) reporting of EHR-based prevalence data, and 3) reducing cigarette smoking prevalence among CCO members (29).

Each component of the cigarette smoking incentive metric is worth a certain percentage of the total metric calculation, and each year CCOs must meet a certain overall performance target to earn incentive dollars. The component percentages have shifted over time (Table 1). In the first 2 years of the incentive metric, a CCO could earn incentive dollars by meeting the first 2 components without having to also meet or exceed a prevalence target. By the third year of the incentive metric (2018), CCOs could only earn incentive dollars if their cigarette smoking prevalence for Medicaid members aged 13 years or older was at or below 25 percent. The progressive nature of the metric (in which the required cumulative percentage increases over time from 60% to 75%) allows for stepwise implementation and achievement of the different components.

When the cigarette smoking incentive metric was introduced in 2016, coverage of tobacco cessation benefits varied significantly across the CCOs. Embedding cessation benefit requirements into the metric specifications was intended to ensure that all Medicaid beneficiaries statewide would have access to a “benefit floor.” To meet the minimum cessation benefit requirement, each CCO must cover both counseling and FDA-approved cessation medications, as well as remove barriers to accessing the benefit (Table 2). This requirement is ascertained by a CCO survey developed by OHA staff and focuses on understanding the details of the cessation benefit each CCO offers. It is fielded annually and completed online by CCO staff who are responsible for incentive metric reporting (30).

EHR-based reporting defines the cigarette smoking prevalence rate as the number of cigarette smokers among those who had an office visit with the provider during the year who have smoking and/or tobacco status recorded (Figure). The EHR-based reporting collects 3 smoking prevalence rates. The first is the rate of screening for smoking and/or tobacco use. The second is the cigarette smoking prevalence rate, and the third is the tobacco use prevalence rate. Tobacco use includes cigarettes and other tobacco products, such as snuff and chew. Rate 2, the smoking prevalence rate, is defined as the number of cigarette smokers who had an office visit with a provider during the measurement year, who have their smoking and/or tobacco use status recorded. The EHR-based prevalence rate is self-reported by CCOs and the data submission includes prevalence data for individual clinics within each CCO’s provider network. Oregon does not audit the data submissions; however, it conducts multiple layers of validation on the data to ensure accurate reporting, including 1) comparison of a CCO’s data submission to the prior year (including at the individual provider level); 2) reviewing data submissions for outliers, both across the CCOs and within a CCO’s provider network; and 3) reviewing data submissions for inconsistencies. Any of these face validity checks may result in following up with the CCO for clarification or data resubmission to ensure accuracy as part of the overall CCO incentive metric review and validation process.

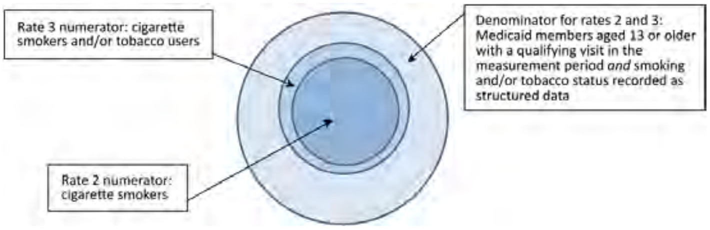

Figure. Electronic health record–based prevalence measure specifications, rate 2, Oregon’s CCO Quality Incentive Program, 2016–2018.

Results

The comparison of CCO cessation benefits for 2014 (pre-incentive metric) and 2018 (post-incentive metric) is presented in Table 3. The cigarette smoking prevalence CCO incentive metric was first reported for calendar year 2016. In 2018, all 15 CCOs met their cessation benefit requirement, all 15 successfully reported prevalence data from EHRs, and cigarette smoking prevalence had declined in 13 CCOs since 2017 (31). Post implementation of the incentive metric, all 15 CCOs reported covering all 3 types of counseling (telephone, individual, and group) and all 7 FDA-approved medications, compared with only 14 CCOs covering all counseling types and 9 CCOs covering all medications in 2014. The number of CCOs that require prior authorization for 1 or more FDA-approved pharmacotherapies also decreased from 2014 to 2018 (from 16 CCOs requiring prior authorization for at least 1 down to 9 CCOs). No CCOs had copays or lifetime dollar limits for smoking cessation benefits.

In addition to benefit package improvements, Oregon also demonstrated a decline in its Medicaid cigarette smoking prevalence, as measured through EHRs between 2016 and 2018 (29.3% in 2016, 28.0% in 2017, and 26.6% in 2018) (31). Although 13 of the 15 CCOs demonstrated a decline in cigarette smoking prevalence between 2017 and 2018 on the basis of their EHR-reported prevalence data, considerable variation in cigarette smoking prevalence still exists across CCOs, ranging from 20.2% to 36.6% in 2018, based on a total of 254,111 patients (31).

Other recent statewide evaluations through CAHPS (an annual random survey of Medicaid recipients in Oregon) indicate that the CCO incentive metric has been successful in increasing provider attention to cessation. Since 2015, adult Medicaid tobacco users who reported that their doctors offered them cessation medications and other strategies to help quit has increased above baseline, with a high in 2017 and persistent gains above baseline through 2018 (Table 4) (31).

Limitations

This study has several key limitations. Although a focus on combustible cigarette use is critical, this metric did not focus on other forms of nicotine use that are also of concern: cigars, e-cigarettes, smokeless tobacco, and other tobacco and vaping products. Unmeasured confounders may exist, such as national trends that may have been the primary driver of the improvement in smoking cessation prevalence rather than Oregon's CCO incentive metric alone. Despite this limitation, this novel outcome metric aligns public health and Medicaid to focus on a critical public health issue and improved access to evidence-based smoking cessation aids at a minimum. If the impact of this metric is smaller than reported, other benefits may still be derived from it, including holding health plans accountable to population health metrics and alignment between health plans and public health to improve outcomes with interventions spanning clinical and other sectors. Future studies could further triangulate key drivers of prevalence improvement by further investigating the use of pharmacotherapy, quitlines, counseling, and community-based interventions. The final limitation relates to generalizability. Other states and health plans may find it challenging to adopt metrics such as the Oregon smoking cessation metric. However, given the lack of viable comprehensive outcome measures on smoking cessation and the ongoing significant morbidity and mortality associated with smoking, it may be worthwhile for other systems to invest in adoption of a similar novel outcome metric.

Implications for Public Health

Oregon's innovative work creating an incentive metric that requires health plans to cover comprehensive evidence-based tobacco cessation benefits and be held accountable for smoking prevalence has contributed to a substantial population decrease in smoking prevalence in Oregon and improved access to evidence-based cessation aids for OHP (Medicaid) members. This success depended on coordination and alignment across Medicaid and public health coupled with the use of financial incentives and effective data monitoring. Oregon has also worked effectively across sectors such as in the case of a statewide opioid initiative (32), and increasingly this type of cross-sector collaboration is being looked to as an effective means to improve population health nationwide (8,33,35).

In addition to the statewide successes, the cigarette smoking incentive metric has created an unprecedented opportunity for local public health and health care partners to collaborate at the community level to implement effective strategies for preventing and reducing tobacco use. These efforts have led to CCOs investing time and resources in working on prevention strategies outside of the clinical setting, engaging more in their communities, and collaborating with local public health authorities.

For health plans to truly be accountable for population health outcomes, those distal outcomes need to be measured and incentivized. Reliance on process-based metrics such as the proportion of primary care providers screening for tobacco use is arguably insufficient. Similarly, if the goal is accountability to improved population health, requiring health plans simply to provide a benefit or even measure the times patients received pharmacotherapy or counseling (standard smoking cessation metric measures) is not enough. Instead, requiring plans to be accountable for the health outcome (ie, reduced smoking) by using effective data reporting, concrete guidance and contractual requirements, required minimum coverage, and financial incentive metrics to drive the change, population health improvements are achievable. However, major barriers exist to health insurers addressing prevention activities at a clinical population level or community health level, including silos between public health and Medicaid health plans, lack of funding streams to facilitate delivery of nonclinical interventions, limited coordination between clinical systems and community resources, legal barriers to Medicaid paying for nontraditional services, and concerns about upfront costs of investing in additional services and strategies.

As Oregon and other states continue to work to maximize population health with regard to tobacco use, continually promoting evidence-based strategies, regardless of the setting in which they are delivered, is important. What HERC seeks to do with the Multisector Intervention Statements is provide a menu of evidence-based options, some clinically focused and others exclusively based in the community, allowing plans to decide which of these interventions makes sense, given their priorities and community relationships and the cost–benefit ratio for each. To address the issue of tobacco in our communities, both prevention of tobacco initiation and effective treatment of tobacco use disorder are paramount to effectively reducing tobacco use prevalence.

Oregon's innovative work in developing an incentive metric that requires CCOs to address tobacco prevalence through evidence-based strategies extending beyond the clinical setting can be a model for other states and payers seeking to effect major population health change by increasing engagement and accountability of payers and health systems. Although CCOs have improved benefits since the adoption of the incentive metric and there is some indication of clinical providers improving their practice, room for improvement still exists using the strong foundation that HERC guidance, benefit requirements, and incentive metric strategies have set.

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Tables

Table 1. Components of the CCO Cigarette Smoking Prevalence Incentive Metric, Oregon's CCO Quality Incentive Program, 2016–2018[a]

Metric Component	2016	2017	2018
Weighted % for meeting the cessation benefit requirement (must pass); if a CCO does not meet this requirement, it cannot earn incentive dollars for this metric	40	33	25
Weighted % for reporting EHR-based prevalence data	40	33	25
Weighted % for meeting prevalence target	20	33	50
Required cumulative % to pass the metric; if the percentage is not achieved, the CCO cannot receive the incentive dollars	60	66	75

Abbreviations: CCO, coordinated care organization; EHR, electronic health record.

[a] Oregon had 16 CCOs in 2016, and 15 in 2017–2018.

Table 2. Minimum Cessation Benefit, as Required by CCO Incentive Metric, Oregon's CCO Quality Incentive Program, 2016–2018

Counseling (Per Quit Attempt)	FDA-Approved Cessation Medications[a] (Per Quit Attempt)	Access to Cessation Benefit
• Individual counseling, at least 4 sessions of at least 10 min each • Group counseling • Telephone counseling, multi-call benefit[b]	• Nicotine gum • Nicotine patch • Nicotine lozenge • Nicotine nasal spray • Nicotine inhaler • Bupropion SR[c] • Varenicline	• No prior authorization needed to access nicotine gum, patches, or lozenges • No copayments, coinsurance, or deductibles • No annual or lifetime dollar limits • Must offer at least 2 quit attempts per year

Abbreviations: CCO, coordinated care organization; FDA Food and Drug Administration; SR, sustained release.

[a] Cessation medications must also meet minimum quantity requirements per quit attempt.

[b] Telephone counseling benefits can be provided by in-house CCO staff or through a contract with a quitline vendor; however, the state-funded tobacco quitline services were not counted as a CCO-covered benefit.

[c] Oregon also provided clarification to CCOs on how to distinguish bupropion SR for cessation from bupropion SR for depression. CCOs must include coverage for bupropion SR for cessation.

Table 3. Survey of CCO Tobacco Cessation Benefits for 2014 and 2018, Oregon's CCO Quality Incentive Program

CCO Characteristic	No.[a] (%)	
	2014	2018
Covers all 3 types of counseling (telephone, individual, group)	14 (87)	15 (100)
Provides coverage for all 7 FDA-approved cessation medications	9 (56)	15 (100)
Requires prior authorization for at least 1 FDA-approved pharmacotherapy	16 (100)	9 (60)
Contracts with a quitline vendor for telephone counseling	10 (63)	11 (73)
Requires copayments for any cessation medications	0	0

Abbreviation: CCO, coordinated care organization; FDA, US Food and Drug Administration.

[a] Oregon had 16 CCOs in 2016, and 15 in 2017–2018.

Table 4. Oregon Medicaid Members Who Reported Their Health Care Provider Recommended Cessation Assistance, Oregon's CCO Quality Incentive Program, 2016–2018[a]

Characteristic	2011	2015	2016	2017	2018
Percentage of adult members who use tobacco and whose health care provider recommended medication to help quit	24.0	26.9	27.4	34.3	32.5
Percentage of adult members who use tobacco and whose health care provider recommended strategies to help quit	25.0	23.1	23.1	29.1	27.0

Abbreviations: CAHPS, Consumer Assessment of Healthcare Providers and Systems survey; CCO, coordinated care organization.

[a] Although CAHPS Medical Assistance with Smoking Cessation questions usually combine 3 response options ("sometimes," "usually," and "always") for reporting, Oregon uses just 2 response options for the CCO measurement program ("usually" and "always"). When compared with the national Medicaid 90th percentile for these questions, measured in the same way, Oregon falls short: 32.5% compared with 60.3% and 27.0% compared with 54.1% in 2018, respectively.

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ORIGINAL RESEARCH

"We're, Like, the Most Unhealthy People in the Country": Using an Equity Lens to Reduce Barriers to Healthy Food Access in Rural Appalachia

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PEER REVIEWED

Summary

What is already known on this topic?

The prevalence of obesity is disproportionately high among people living in rural areas, yet many policy, systems, and environmental interventions designed to improve healthy food access in these environments have not been successful.

What is added by this report?

An equity-oriented obesity prevention framework can guide investigators in identifying or tailoring acceptable interventions unique to a community's needs.

What are the implications for public health practice?

Community input to intervention development is crucial to the success of environmental changes to expand healthy food access in rural areas.

Abstract

Introduction

Obesity disproportionately affects rural communities, and Appalachia has some of the highest obesity rates in the nation. Successful policy, systems, and environmental (PSE) interventions to reduce obesity must reflect the circumstances of the population. We used a health equity lens to identify barriers and facilitators for healthy food access in Martin County, Kentucky, to design interventions responsive to social, cultural, and historical contexts.

Methods

We conducted 5 focus groups in Martin County, Kentucky, in fall 2019 to obtain perspectives on the local food system and gauge acceptability of PSE interventions. We used grounded theory to identify perceived barriers and facilitators for healthy eating.

Results

Thirty-four adults (27 women; median age, 46 years) participated in 5 groups. One prominent theme was declining interest in farming; many participants believed this decline was generational. One participant noted, "Most of my adult male relatives worked in the coal mines, and they worked 6 days a week. . . . My grandpa had the garden, but then my dad's generation is the one quit gardening." Another shared, "You would probably have to have someone to teach [gardening]." Instead of enhancing farmers markets, participants suggested building community capacity for home gardens to increase vegetable consumption.

Conclusion

Our findings demonstrate the importance of obtaining community input on the development of PSE interventions to mitigate inequities in obesity. Although farmers market interventions were deemed not feasible, other solutions to enhance access to produce were identified. Developers of community-responsive PSE interventions to improve healthy eating in rural, food-insecure locations should consider using an equity-oriented prevention framework to ensure acceptable interventions.

Introduction

Rural communities in the United States have disproportionately higher rates of preventable obesity-related illness and death compared with their urban counterparts (1). Characteristics of some rural regions, such as Appalachia, present challenges that exacerbate the high rates of obesity and related health conditions in certain populations (2,3). The lack of reliable food retailers in Appalachia reflects a malfunctioning food system unable to support healthy eating patterns (4). In addition, persistent poverty and unemployment are linked to a high prevalence of preventable mortality in Appalachia (2,5).

Social, political, and historical contexts influence the effectiveness of programs and interventions aimed at promoting healthy food choices (6). These contexts are unique to each community, with distinctive regional characteristics among Appalachian communities (7). Policy, systems, and environmental (PSE) interventions and strategies designed for communities with a disproportionately high prevalence of obesity, such as communities in Appalachia, are needed. However, established approaches have been largely ineffective in adult populations that have inequities (8); therefore, new and novel frameworks for designing and implementing successful, equitable interventions are necessary.

The Getting to Equity (GTE) framework provides a guide for implementing obesity prevention activities that gives priority to health equity principles (9,10), an approach that is potentially important in Appalachia (Figure). Each quadrant in the framework represents a type of intervention approach. The upper 2 quadrants, which include increasing healthy options and reducing deterrents, focus on potential policy-change and systems-change interventions. The lower 2 quadrants, which include building on community capacity and improving social and economic resources, reflect individual and community resources and capacity. Each identified strategy in each quadrant has shown promise or relevance in the mitigation of health disparities. Kumayika argues that balance and synergy are needed among the strategies (4 quadrants) to be effective at producing sustainable, positive change (10).

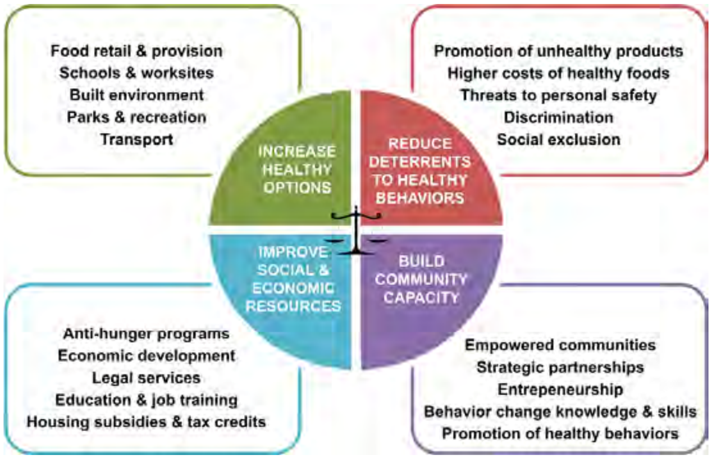

Figure. Getting to Equity framework for obesity prevention. Source: Kumanyika (9). Reprinted with permission from the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC.

Our study, in Martin County, Kentucky, was part of the larger, multiyear High Obesity Program, which has the overall aim of reducing rural obesity and decreasing the risk of preventable mortality (11). Although the High Obesity Program is multifaceted, it emphasizes increasing geographic or financial access to healthy foods. In addition, the High Obesity Program requires use of existing infrastructure in rural communities, such as the Cooperative Extension Service and community coalitions. The aim of this study was to use the GTE framework to identify barriers to and solutions for increasing access to healthy foods in a rural, resource-poor environment.

Methods

We conducted our focus group study in September and October 2019 in Martin County, in eastern Kentucky, which is adjacent to West Virginia. Approximately 39% of residents live in poverty, and the county struggles with high unemployment (12.4%) and outmigration (a 13.4% reduction in population from April 2010 to July 2019) (12). According to the Food Access Research Atlas, more than 33% of county residents live 20 miles or more from the nearest supermarket, which would classify the entire community as a food desert (13). Approximately 1 in 5 Martin County households are considered food insecure (14). One of the few community assets to promote healthy eating in the county is the nonprofit organization Grow Appalachia. Established at Berea College in 2009, the mission of Grow Appalachia is to increase access to fresh fruits and vegetables by building capacity to successfully grow home gardens. Grow Appalachia is active in Martin County, supplying participants with assistance to grow food (15).

In summer 2019, we purposively recruited adults from Martin County for participation in focus groups. The Martin County Extension agent recruited participants, as did community coalition members. We placed informational flyers in the Martin County Extension Office and posted information on its Facebook page. Eligibility criteria for participation were being 18 or older, speaking English, and residing in Martin County. Participants completed written informed consent and completed a brief sociodemographic survey. Participant assignment to focus groups was random with 1 exception: staff members of a local middle school were recruited to participate in a focus group held at that location. A trained moderator facilitated the focus groups (K.M.C.) using a written moderator guide (Box), and 2 research team members took notes (E.D., R.G.). All focus groups took place in September and October either in the Martin County Extension Office or in the local middle school and lasted approximately 1 hour. Participants received a $25 voucher for a local grocery store as an incentive to participate. The University of Kentucky Institutional Review Board approved this study.

Box. Questions for Focus Groups on Healthy Eating in Appalachia

Where are the places you can purchase food in your community?

- How easy it is to get fruits and vegetables at these locations?
- Do many people in your community purchase food at farmers markets?
- Where can people go in your community to get food if they are unable to purchase it? (eg, food pantries, churches)

Do you think your community is designed to promote healthy eating choices? Why or why not?

- What factors in your community make it easier to eat healthy?
- What factors in your community make it harder to eat healthy?
- Would you consider transportation a barrier?

What other resources do you think would be helpful to have in your community to allow people to purchase fruits and vegetables?

What would be some ways to motivate or encourage people in your community to eat fruits and vegetables?

(Bullet points refer to probes the moderator could use for further discussion, if needed.)

We summarized the data from the brief sociodemographic survey, and we compared the sociodemographic composition of focus group participants with the composition of the Martin County population as reflected by data from the US Census Bureau (12). Focus groups discussions were audio recorded and transcribed verbatim. Multiple investigators reviewed focus group transcripts using a grounded theory approach (16). Investigators used an iterative inductive–deductive approach to identify themes on assets and barriers to healthy eating in the community. These themes formed the basis of codes that were analyzed in NVivo software version 12 (QSR International). Investigators then used the GTE framework to categorize themes according to the 4 quadrants of intervention approaches and selected illustrative quotes for each theme. We conducted this analysis during January–March 2020.

Results

Thirty-four adults participated in 5 focus groups. The median age of participants was 46 years, and 27 were women (Table 1). All participants were non-Hispanic White, and most participants had some college education or were college graduates. Compared with the Martin County general population, study participants were less racially/ethnically diverse, slightly older, and had higher levels of education.

Investigators established several independent but interconnected themes related to healthy eating. Participants identified myriad barriers to healthy eating (Table 2) and a smaller number of assets in the community that promote healthy eating. These assets included Grow Appalachia and Cooperative Extension Service programming, both of which address barriers identified by participants to growing food, including knowledge of how to grow a garden and the ability to grow and sell food for a profit. Deep-rooted community pride was also made evident as an asset. These assets collectively lie within the GTE quadrant of building community capacity. Several participants drew connections between Grow Appalachia and their capacity to grow and consume produce year-round.

> Where I was in the Grow Appalachia project, they paid for all my seeds and everything. . . . I bet there was between tools and everything, well over a $1,000 put into my garden.

> I was a participant in [Grow Appalachia], and I enjoyed it. . . I already knew a lot, but I have learned a lot more about canning and different things . . . we grew tomatoes, cucumbers, green beans, corn, zucchini, squash . . . peppers.

> [Referring to Grow Appalachia] What helped me most from that program was, um, my husband passed away 3 years ago, and since then it's been really hard to get it plowed. I have a plow, but it's big and I can't operate it. . . . That was so helpful to me, to get it plowed that first time.

Because of community support from programs like Grow Appalachia, participants expressed the idea that residents could grow their own produce for consumption. Participants also described a distribution network that existed across the community in which residents shared produce with neighbors and family members, rather than selling it.

> I do share. I've not sold anything this year; it was the first year I had that big a garden. But yeah, my grandma, my parents, whoever, they want to drive out and help. I told them if they want to come help pick it, they can have some.

> Yeah, I can answer that for myself there. When I raise things, I mean, I don't sell it. I don't believe in selling it. If I have got, usually I got a whole bunch, I give it away.

> I know when I had a garden, and I had extra produce, I would tell people you can have anything you want they just have to come get it.

Participants revealed a keen awareness of the decline in the local farmers market. They connected the decline to generational shifts in career opportunities. As coal mining gained popularity in the region, people prioritized mining over farming.

> Most of my adult male relatives worked in the coal mines, and they worked 6 days a week. My dad left before sunrise and home after

> dark. . . . My grandpa had the garden, but then my dad's generation is the one that quit gardening.

Moreover, although a clear desire for homegrown produce was apparent among community members, the lack of interest in farming may result from the local view that cultivating homegrown produce is labor-intensive. Participants indicated that farming is not a lucrative endeavor in this region, further deterring interest among this population. Thus, the farmers market continues to dwindle in this county because of a lack of participating growers.

> Dad sells at the farmers market, and he has noticed it seems to be declining a little bit, especially as the year goes on. It starts out pretty strong, he says, but as the year goes on. . . . I don't know if they get burned out on produce, everyone gets used to eating fast food and stuff.

> There's no money in it. For the work and time and effort you put into it, if you don't just enjoy doing it, there is no money in it. You can't do it and make your car payment every month. You couldn't use it as a second income. There is no way to be profitable with it. Unless you are doing it on a mass scale.

Participants described opportunities for encouraging homegrown produce, including enhanced knowledge of food preservation and opportunities to learn from those who have become experts through practice; however, most participants perceived opportunities as limited in their community.

> But it was, like, a couple in my church that does that stuff, and they kind of walked me though it and showed me. And I just wish we had more resources to show us how to do those things.

> Like our garden, I think I would plant a lot more, if I knew more about how to do the canning.

> Yeah, you know, he'll have, you know, lots of, you know, a lot of people have corn. Corn, you know, I'm pretty sure everybody has corn normally certain times of year, but green beans too quick. And you know, he always has lots of squash, and cucumber, tomatoes and stuff like that, and packs it up and takes it all home.

> We like a certain thing, we want cucumbers, and we want green beans, and we want tomatoes, and my kids don't really look at nothing else when we come. So, like you said, more green beans please.

Although preferences were established, participants described being motivated to make healthy choices to set an example for younger generations.

Discussion

Using the GTE framework for obesity prevention, our study identified many barriers to, and a smaller number of solutions for, increasing access to healthy foods in the Appalachian region of Kentucky. Applying an equity-oriented lens to understanding rural food access requires recognition of fundamental conditions that shape individual experiences and the rejection of biases that blame individuals for circumstances beyond their control (10). Our findings reflect the decline of farming as an occupation in rural Appalachian communities, yet many participants spoke of home gardening as a self-sustaining food source for themselves or a network of people, such as family members or neighbors. Garden produce unused by the grower, we learned, is distributed to the community through an informal economy of food bartering and sharing. Food, in this fashion, acts as its fundamental purpose, a commodity valued at a worth woven into the fabric of Appalachian culture. This concept is important to consider when designing PSE interventions focused on food access in Appalachia.

The declining fiscal contribution of farming, as well as the practice itself, has been gradual yet consistent in Appalachia (17). As our findings suggest, the decline in farming could be attributed to generational shifts in industry opportunities. In Appalachia, farming practices began to deteriorate in the late 19th century, when a new economic stimulus appeared in the form of timbering and coal mining (18). Since then, the region has continued to experience agrarian decline. The 2017 Census of Agriculture for Martin County showed 30 farms and 43 total producers (60% male, 40% female); the average age of producers was 47. Ten farmers reported being younger than 35; 17 reported farming as their primary occupation, and only 3 farmers sold directly to consumers (19). Furthermore, the Kentucky Appalachian region lost a disproportionate amount of farmland from 2007 through 2012: 9.2% compared with 0.8% across the United States (17). The effect of these declines in Appalachia has yet to be fully explored. However, it begs further investigation when considering factors that have led to the persistent poverty levels, poor health status, and dissolved food access points in this community.

Health disparities in Appalachia, including those related to continued outmigration, have led to economic decline and increased poverty (20). From 2010 to 2019 alone, the population in Martin County decreased by an estimated 13.4% (12). The GTE framework further guides synergetic interventions and explores the intertwining realms that influence equity in the context of outmigration, economic decline, and increased poverty. Therefore, it is worth continuing to investigate the chasm between a community practice of food sharing and a farming decline as a mode to incorporate GTE principles to improve healthy food access in rural Appalachian communities such as Martin County.

The shift from traditional farmers markets is increasingly evident, leaving communities and food systems to envision alternative modes in which to implement healthier lifestyle behaviors, including fruit and vegetable consumption (21). Small farms and home gardens are important assets in Appalachian heritage; they have numerous social and historical implications and reflect strong local values, such as self-sufficiency and esteemed locavore practices (sourcing and consumption of locally grown or produced foods), bolstering their feasibility as effective interventions (22). The findings from our focus groups echo the role of small-scale home gardens in this Appalachian community as a mode of increasing access to fresh fruits and vegetables. Appalachian communities value these cultural customs, as evidenced by the rich history of heirloom vegetable seeds in the region (22). Future work should use culturally relevant tools and examine the existing food system infrastructure when developing novel strategies to increase access to fruits and vegetables outside traditional approaches. Although farmers markets have been viable interventions in some communities (23), they may not be suitable solutions for all, given the unique characteristics of Appalachian communities. For example, a qualitative study of 15 low-income Appalachian residents found that only 1 person regularly visited a farmers market, citing pricing and inconvenience as barriers (24). Although respondents reported generally positive attitudes toward farmers markets, the economic and cultural environmental landscapes and other barriers do not make them a plausible intervention for all Appalachian communities (25,26).

The findings from our focus groups add to the growing body of research illuminating the health inequities Appalachian communities face. It is important to note the rapid decline of the socioeconomic landscape in rural communities compared with their urban counterparts (27). Although common barriers, such as affordability and access to healthy food, exist among low-income residents of both rural and urban communities, Appalachia has unique challenges, including low population density, geographic isolation, and persistent poverty, that amplify these barriers (7,25). An increase in poverty leads to less food affordability, particularly among rural low-income populations in the Appalachian region (27). Additionally, since the completion of our focus groups, 1 of only 3 grocery stores in this community closed. This further reinforced the food access barriers in this community.

Inadequate access to healthy foods contributes to the declining health status of rural communities, including increased rates of obesity and chronic diseases (1,3). Inadequate access to healthy foods is challenging when coupled with aforementioned barriers and transportation access. Collectively, these factors make rural Appalachian communities distinctly different from impoverished urban communities when addressing improvements to food accessibility and, more broadly, the health status of populations. Despite probing feasible solutions for the multitude of barriers their food system presented, participants were not forthcoming with many solutions aside from suggested enhancement to current practices such as home gardening.

For interventions to be successful, they must be tailored to unique community needs. For example, participants in our study deemed farmers markets impractical, although they are a common intervention to mitigate problems with food systems in rural communities. However, participants identified some community assets, particularly Grow Appalachia, an initiative established to address food insecurity by working with families to grow produce at home. Through training and technical assistance, Grow Appalachia enables communities to prepare, plant, and cultivate home gardens, improving access to nutritious foods and enhancing social enterprise to sustain an equitable food system (14). In 2019, the Martin County Cooperative Extension Office partnered with Grow Appalachia to enhance food security. The partnership enables Grow Appalachia to provide home gardeners with resources and services, such as equipment and seeds, while the Cooperative Extension Service provides ongoing support and training throughout the growing season. By supporting individual gardeners, the Grow Appalachia framework may be more effective in improving access to fruits and vegetables than sustaining the farmers market in this rural community. Furthermore, because of coronavirus disease 2019 (COVID-19), interest in the victory garden toolkit on how to grow gardens — distributed by Cooperative Extension offices — has increased. The increased interest lends support for continued interventions that focus on home gardening. Food preservation and cooking classes are additional services that support home gardeners and promote healthy eating (28) and are services identified as desirable to this community.

Future initiatives must consider the deeper roots of systemic issues to implement effective and equitable solutions. One issue influencing food choice in this community is basic food security. Martin County has historically faced high rates of food insecurity. Yet, because of the COVID-19 crisis, food insecurity is projected to increase by more than 5% to 26%; 1 in 4 households will experience food insecurity in the years to come (29). The repercussions of food insecurity will be numerous for an already vulnerable population. Moreover, Appalachia experiences persistent poverty (16.3% vs. 14.6% for United States), with Appalachian Kentucky having the highest poverty rate among all states in the Appalachian region (25.6%) (26). To address food access inequities, poverty and food security status must first be addressed. Addressing only 1 quadrant of the GTE framework is likely insufficient to implement sustainable change in food access. The incorporation of additional strategies that support the 3 remaining quadrants of the GTE framework are needed to balance and enhance effectiveness and sustainability of future interventions. Furthermore, finding culturally relevant facilitators to promote healthy choices will be key to behavior change.

Our study has several limitations. We did not randomly select our sample; we used a purposive, community-engaged approach to recruiting. Participants reported higher levels of education than the general county population. Additionally, our sample included more women than men and older participants (13), limiting the external validity of our findings to other rural or Appalachian populations. In an equity perspective, this is an important limitation and suggests that the barriers identified in our study are likely not the only barriers that impede access to healthy food in the community. Finally, social desirability bias may have influenced respondents' comments. Despite these limitations, our study demonstrates the value of framing barriers to food access in a rural Appalachian population with an equity lens. Future PSE interventions to address food access in this and similar populations should consider using the GTE framework to envision new approaches that explicitly acknowledge social inequities that challenge healthy eating.

Few macro-scale approaches, such as enhancing farmers markets, have shown broad success in rural Appalachia, which speaks to the heterogeneity of these communities (24,30). Designing food access interventions in rural Appalachia that explicitly acknowledge the social inequities in the region and actively engage community members are likely to be more successful than those that do not. This study revealed a novel overarching theme: enhancing community capacity through various channels that depend on the existing resources reported by community residents. Our findings validated the importance of having community buy-in to support the small grower through multiple avenues, including Grow Appalachia and Cooperative Extension Service programming. The COVID-19 pandemic has further affected the food system in Appalachian communities. Instead of enhancing farmers markets, future investigators focused on obesity prevention work in rural Appalachia must learn about the local food system and culture. This focus will enhance community capacity for growing personal gardens, increase food access availability, and improve equity.

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Tables

Table 1. Sociodemographic Characteristics of Focus Group Participants (N = 34) and the General Population of Martin County, Kentucky, 2019

Characteristic	No. (%)	Martin County, %[a]
Age, median, y	46	39
Sex		
Female	27 (79)	45
Male	7 (21)	55
Race		
Non-Hispanic White	34 (100)	92
Non-Hispanic Black	0	7
Other races combined	0	1
Hispanic ethnicity	0	3
Education		
<High school graduate	1 (3)	26
High school graduate	4 (12)	39
Some college	12 (35)	25
College graduate	17 (50)	9
Household income, $		
<20,000	8 (24)	—[b]
21,000–59,999	13 (38)	—[b]
≥60,000	13 (38)	—[b]

[a] Data source: US Census Bureau (12).
[b] No analogous data categories available from the US Census Bureau.

Table 2. Barriers to Healthy Eating in Martin County, Kentucky, as Identified by Focus Group Participants and Organized Within the Getting to Equity Framework[a]

GTE Quadrant and Participant Narratives	Illustrative Quote[b]
GTE quadrant: Increase healthy options	
Limited food retail options	[O]ne of the main problems with [local grocery store] is not enough people in our community buy the fruits and vegetables, and so they don't keep as much on hand because it doesn't sell as quickly here.
Lack of access to produce	I know for the senior citizens, like, we will order bananas but we can't get them around here 'cause they don't have enough for us to go purchase. So we have to order them and they come frozen. And when you open it up, it's black.
	We do have a local produce, private owned produce store, but they don't keep a lot of stuff.
GTE quadrant: Reduce deterrents to healthy behaviors	
Cost of healthy food	Fresh fruits and vegetables are not cheap.
	A lot of people are on fixed income . . . and it's hard to eat healthy . . . it's the bottom line. It is way expensive to eat healthy.
Availability of fast food	It's like, say you go to McDonald's or Wendy's or somewhere, you know a salad is $4 or $5 compared to you know, chicken nuggets a dollar.
	You can go out and get a dollar hamburger versus $5 for fruit.
	You can buy a box of Little Debbie's for $1.99 and you can't buy hardly anything out of the produce case for $1.99.
	I am sure there are a lot of kids out there right now that's in high school that have very little fresh vegetables their whole life. Their parents have always went to McDonalds or a pizza place.
	I think it's just tradition, people are used to eating their fatty . . . fried foods. . . . I would agree with that. I think it's just part of the culture. That's just what we're used to.
Transportation barriers	Transportation is a very big issue . . . it's getting out there and getting them to a grocery store that's a barrier for them.
	Transportation is the biggest issue for this community. . . . It is a big obstacle. . . . It is getting them to church, it is for getting them to school, it is for getting them to the grocery store, to the doctor, it is just a major issue.
	I have people that pay people to drive them out of the hollow basically.
GTE quadrant: improve social and economic resources	
Persistent poverty	I mean, we never knew we were poor until Johnson and Kennedy came and told us we were poor.
	Because they are not going to ask. I think it is just a pride thing for some people.
	Honestly, my biggest thing is that I can take an elderly woman who lives alone and is a widow and she gets $15 a month in food stamps. And I think that is insanity. She gets no food vouchers — she living off $771 a month.
	I mean, we're, like, the most unhealthy people in the country. This part, I mean that's just honest, central Appalachia it is.
GTE quadrant: build community capacity[c]	
Lack of cooking skills	There is a whole generation just like me . . . that is something that we didn't do, so we don't even know how to teach our kids to do that. There is a whole gap there of you know.
	They are some of the younger generation that asks, "Dad, well, how do you fix corn, how do you fix green beans?" They don't know how. They don't know to put it in a pot, put some water in it and put it on boil . . . they have no clue how to fix fresh vegetables.
	When RAMP [local food pantry] gives out produce, we have suppliers that send us stuff like eggplant and squash. Stuff that I have never heard of and can't pronounce and stuff like that. And people don't want it.
Lack of interest in farming	There's no money in it . . . for the work and time and effort you put into it, if you don't just enjoy doing it, there is no money in it. . . . You can't do it and make your car payment every month. You couldn't use it as a second income. There is no way to be profitable with it.
	It is a good thing if kids get to see it made . . . or get to see it grown, or whatever. And they know where, my grandkids don't know where stuff comes from. They don't work in a garden.
	You would probably have to have someone to teach people because while there aren't any farmers in the county, they're getting old or they have already died off and heaven forbid the kids would ever have to work in a garden.

[a] The Getting to Equity framework provides a guide for implementing obesity prevention activities that gives priority to health equity principles (9,10).
[b] Selected qualifying quotes included; not all quotes included per GTE framework and qualitative methodology.
[c] Assets (Grow Appalachia, community pride, and Cooperative Extension Programming) identified by participants would be categorized into this quadrant, but they are not included here.

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Table 2. Barriers to Healthy Eating in Martin County, Kentucky, as Identified by Focus Group Participants and Organized Within the Getting to Equity Framework[a]

GTE Quadrant and Participant Narratives	Illustrative Quote[b]
	Most of my adult male relatives worked in the coal mines and they worked 6 days a week. . . . My dad left before sunrise and home after dark. Between coaching my little league and fishing.
	That whole generation of working people were worked their fingers to the bone.
	My grandpa had the garden, but then my dad's generation is the one quit gardening.

[a] The Getting to Equity framework provides a guide for implementing obesity prevention activities that gives priority to health equity principles (9,10).

[b] Selected qualifying quotes included; not all quotes included per GTE framework and qualitative methodology.

[c] Assets (Grow Appalachia, community pride, and Cooperative Extension Programming) identified by participants would be categorized into this quadrant, but they are not included here.

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ORIGINAL RESEARCH

Oral Health Behaviors in Very Young Children in Low-Income Urban Areas in Chicago, Illinois, 2018–2019

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PEER REVIEWED

Summary

What is already known on this topic?

Health disparities are well documented in the prevalence of and morbidity associated with dental caries, the most common chronic disease of childhood.

What is added by this report?

Most data on oral health risk and behaviors do not include infants and toddlers. We describe the oral health behaviors of children younger than 3 years and identify areas for intervention.

What are the implications for public health practice?

Behaviors established during early childhood set the trajectory for a lifetime. This analysis shows the importance of the family unit and social support in efforts to improve oral health outcomes for high-risk children.

Abstract

Introduction

Because most data on oral health do not include infants and toddlers, we aimed to describe the oral health behaviors of low-income children younger than 3 years and determine factors associated with child tooth brushing.

Methods

We obtained data from the Coordinated Oral Health Promotion Chicago study, which included 420 families with children aged 6 to 36 months and their caregivers in Cook County, Illinois. We assessed child frequency of brushing from caregiver reports and objectively determined child dental plaque scores. Significant factors associated with tooth brushing frequency and dental plaque score were identified using the Least Absolute Shrinkage and Selection Operator variable selection.

Results

Mean child age was 21.5 (SD, 6.9) months, and only 45% of caregivers brushed their children's teeth twice per day or more. The mean plaque score was 1.9 (SD, 0.6), indicating high levels of plaque. Child brushing frequency was higher when children were older; used the correct toothpaste amount; brushed for a longer duration; and when caregivers brushed their own teeth more frequently, had more help with the overall care of the child's teeth, and had family to help. Child brushing frequency was lower for caregivers with more interference from activities of daily life. Children whose caregivers had more adult help with child brushing had better plaque scores; worse plaque scores were seen in children with higher sugary beverage and food consumption and lower household incomes.

Conclusion

The tooth brushing behaviors of young children are strongly associated with those of their parents and with the level of family support for brushing. Interventions to improve brushing in young children should focus on the entire family.

Introduction

Dental caries is the most common chronic disease of childhood, affecting over half of US children aged 6 to 8 years (1). Although treatment of caries leads to significant direct health care costs, the true costs extend beyond the health care setting. Caries is associated with impaired cognitive development, increased school absenteeism, worse school performance, increased missed work for parents, and worse quality of life (2–4). Oral health disparities are well documented, and low-income minority children experience the highest prevalence and illness from caries (5–8).

Caries risk is influenced by many factors over the life course beginning during the prenatal period (9). Most data on oral health risk and behaviors do not include infants and toddlers, even though these formative years determine the trajectory for children's oral health (10). The largest health survey in the United States, the National Health and Nutritional Examination Survey (NHANES), captures oral health behaviors data only for children aged 3 years or older. Also lacking is a complete understanding of oral health risk factors in very young children and a reliable model to predict future caries in children. Although many of these risk factors are well documented (eg, low fluoride exposure, limited access to dental care, overconsumption of sugar-sweetened beverages) (11,12), the frequency of exposure to these risk factors in children younger than 3 years is unknown. This lack of data makes it challenging to prospectively identify children who will develop caries and become high users of tertiary oral health services such as emergency departments, urgent care clinics, and operating rooms for oral care.

In addition to limited information on oral health risk factors for children younger than 3, information on the frequency and facilitators of protective oral health behaviors in this age group is also lacking. Major health promotion efforts have been implemented to educate primary care providers and families about these protective behaviors (13,14). One of the primary recommendations is twice-daily tooth brushing with fluoridated toothpaste, shown to be a low-cost clinically effective means of reducing caries for dentate children (15). Chronic conditions such as childhood obesity and diabetes have resulted in an increased awareness of the need to reduce sugar-sweetened beverages and high-sugar foods. There is a growing emphasis on the age 1 dental visit and increased coverage for private and publicly funded dental programs (16–18). Although access to dental care theoretically has improved with expanded programs and Medicaid coverage, many barriers to accessing care persist because dental coverage does not equate to use of dental care (7). Whether increased awareness of brushing and dietary recommendations translates to more adoption of these behaviors in young children is also unknown.

To effectively implement preventive interventions to establish healthy oral care behaviors, we must first characterize the baseline oral health behaviors of young children and identify factors associated with these behaviors. The Coordinated Oral Health Promotion (CO-OP) Chicago study included 420 children aged 6 to 36 months and their primary caregivers. In this analysis we describe the children's oral health behaviors and determine factors associated with child tooth brushing, captured as caregiver-reported brushing frequency, and observed dental plaque.

Methods

Data were obtained from the baseline sample (N = 420 child/caregiver dyads) of the CO-OP Chicago study with the National Institute of Dental and Craniofacial Research's Oral Health Disparities Consortium (19). To qualify, families needed to have a child aged 36 months or younger with at least 2 fully erupted central maxillary incisors. Children also had to receive medical care or services at one of the partnering Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) centers or pediatric medical clinics serving low-income communities in Cook County, Illinois. Families were excluded if their primary language was not English or Spanish, the child did not live with the primary caregiver 5 days per week or more, or the child had medical conditions that interfered with routine tooth brushing. Participants were recruited by research assistants (RAs) in the 20 partnering clinics and WIC centers from January 2018 through February 2019. Families that met inclusion criteria were scheduled for an enrollment visit where the baseline data collection occurred (19).

Caregivers provided written informed consent and parental permission at the start of the enrollment visit. Child assent was waived because of child age. Institutional review boards at the University of Illinois at Chicago, the University of California San Francisco, and the Chicago Department of Public Health approved the study.

Data collection was conducted mainly in homes by paired RAs using standardized methods established by the research team (19). RAs first administered a verbal questionnaire using prompt cards that asked about the child's and caregiver's oral health behaviors and beliefs, other health conditions, access to care, psychosocial factors, and demographics. Child and caregiver oral health quality of life was captured using the Early Childhood Oral Health Impact Scale (ECOHIS) and Oral Health Impact Profile, respectively. Caregiver quality of life (referred to as "social functioning"), depression, anxiety, and social support were measured using Patient-Reported Outcomes Measurement Information System (PROMIS) measures. Family functioning was assessed using the Confusion, Hubbub, and Order Scale (CHAOS). RAs took photographs of the child's teeth before and after the application of plaque disclosing solution using a standardized protocol. At the end of the visit, caregivers were asked to demonstrate how the child's teeth are typically brushed. RAs used checklists to systematically capture duration of brushing, supplies used (eg, toothbrushes, mouthwash, floss), and parent involvement. Data were entered directly into the study's Research Electronic Data Capture (REDCap) database. Calibrated dental clinicians, including a board-certified pediatric dentist and a registered dental hygienist, later reviewed images in the research office and scored them for plaque using the Oral Hygiene Index–Maxillary Incisor Simplified (OHI-MIS) scale. The OHI-MIS scale is a modification of the Simplified Oral Hygiene Index; the adaptions allow for plaque scoring using photographs in children with an incomplete primary dentition (20). Plaque scores of less than 0.7 are considered “good,” 0.7–1.8 are “fair,” and 1.9–3.0 are “poor” (21).

Analyses

Demographic characteristics of children and caregivers, as well as the frequency of tooth brushing and plaque scores, were reported using counts (percentages) or mean and SD for categorical variables and median and interquartile range for continuous variables. Frequency of brushing was recoded as a continuous variable, and variables with 5 or more ordinal categories were also recoded as continuous measures. Thirty-two variables were considered in the analyses based on a priori–determined potential for influence on the primary outcomes. Pair-wise correlations for most covariates were low, with few correlations being in the moderate range, specifically among the PROMIS measures ($\rho < 0.80$). The 2 primary outcome measures, child frequency of brushing and plaque score, were correlated at −0.11, $P = .02$. Some variables had missing values. Of 420 participant records, 369 (87.9%) had complete observational data. Variables describing observed toothpaste amount, type of toothpaste, and length of observed brushing had the most missing data points (47–48 cases, 11.2%–11.4%) due mainly to parent or child refusal of the brushing demonstration. Responses were coded as “not applicable” for some variables. For example, if a child had not yet started brushing, toothpaste use would be coded as not applicable. Those responses were then recoded as no for analysis. Household income was reported as unknown by 52% of participants, which was expected for the population. Consequently, income was used as a categorical variable, with “unknown” as a category.

The selection of significant factors associated with the 2 outcomes (frequency of tooth brushing and plaque score) was performed using the Least Absolute Shrinkage and Selection Operator (LASSO) variable selection. The LASSO is a shrinkage estimator with a variable selection. The estimator shrinks regression coefficients of some of the variables to zero, hence selecting essential variables. The penalty parameter lambda determining feature selection was chosen by tenfold cross-validation to minimize predicted mean-squared error. Model averaging is a technique based on the empirical distribution of the statistics resulting from the resampling of the original population with a replacement. We used 2-step model averaging. In the first step, the model selection using LASSO shrinkage was repeated for 1,000 samples. The procedure allowed for ranking of variable importance by reporting the percentage of time that a variable was selected into the model. This first step of model averaging produced a model that contained a large number of effects. The second step of the model averaging (ie, refitting) was used to obtain a more parsimonious model by specifying the percentage of cut-point of effects retained in the final model. After a more parsimonious model was identified, a least-squares model was fit with no effect selection on 1,000 samples with replacement, which produced an empirical distribution of the regression coefficients on which the importance of the variables was based. Because standard inference does not properly consider the model selection process in LASSO, model averaging is the preferred method to interpret the standard error of the model estimates (22). The list of essential factors for both outcomes is reported using 20% and 40% frequency selection. The lower percentage was less restrictive and allowed more variables into the model. Based on the empirical distribution, the mean value of regression coefficients with a 90% confidence interval was reported as the final model results. All statistical analyses were done by using SAS 9.4 (SAS Institute).

We also tested a full linear model, allowing all 32 variables to be present, which represented the least-biased parameter estimates. All models controlled for partnering site using a set of indicator variables. The caregiver, child, and household demographic characteristics and children’s brushing behaviors are described elsewhere (19).

Results

The mean child age was 21.5 (SD 6.9) months, and 50.7% of children were female. Almost all children had health insurance (95.5%), which was mainly Medicaid (89.3%). Most caregivers were female (96.4%) and the biological parent (96.4%); the rest were other relatives or foster parents. Parents described themselves primarily as Black race (41.9%) or Hispanic ethnicity (52.1%). More than half reported some education after high school (52.4%), 31.4% had a high school degree or GED, and 16.2% had less than a high school education. Sixty-one percent of caregivers lived with a partner or spouse. Caregivers reported their overall health as “excellent/very good” (40.5%), “good” (39.8%), or “fair/poor” (19.8%). Caregivers reported much worse social functioning (mean *t*-score, 32.0 [SD, 6.9]) than the reference population (mean *t*-score, 50 [SD, 10]). Caregiver anxiety and depression symptoms were slightly lower than the reference population means (mean *t*-score, 46.6 [SD, 8.1] and mean *t*-score, 46.2 [SD, 6.9], respectively).

Only 25 (6.0%) caregivers had not started brushing or wiping their children’s teeth. For the rest, 45.0% brushed their children’s teeth twice per day or more, 33.8% once per day, and 15.2% brushed sometimes but not every day. The mean OHI-MIS plaque score was in the range of “poor” at 1.9 (SD 0.6); 54.9% scored 1.9 or higher. Most caregivers did all the brushing during observations without active child participation (6.2%). Most children (74.3%) had a child-sized toothbrush, and 52.3% used toothpaste with fluoride. Some children rinsed with water (36.0%) and/or spit (25.3%) after brushing.

Caregivers reported high oral health knowledge (mean, 4.2 [SD 0.8]), and social support was comparable to reference population means (Table 1). Half of the caregivers reported that the activities of daily life never made it difficult to care for their child's teeth, although 26.0% of caregivers never or rarely had help caring for their children's teeth. More than half of children (59.7%) had never been to the dentist. Exclusively drinking purchased bottled water was the most common response for drinking water source (54.6%). Exposure to sugary beverages was common, with 28.8% saying their children consumed sugary beverages once per day and 37.2% consuming sugary beverages twice per day or more. Caregivers reported major oral health challenges of their own; 56.4% said their mouth and teeth were in "fair" or "poor" condition. One quarter (25.7%) brushed less than twice per day, and 43.2% had not been to a dentist in over a year. The main reasons for caregivers not getting needed dental care in the past year were related to cost and insurance coverage.

Tables 2 and 3 present the results of multiple linear models without selection (full models) and the variables selected using LASSO regularization from the 32 potential associated factors, controlling for partner sites. The overlap in variables identified as important between the full models and LASSO regularization indicates low confounding and multicollinearity between variables. The LASSO 20% frequency selection shows the less restricted model, which allowed more variables to remain. The important factors for frequency of child tooth brushing identified by the more restrictive LASSO regularization with a 40% threshold to be retained in the final model included 8 variables, 7 of which met significance at the 10% level. Child brushing frequency (Table 2) was higher when children were older (mean $\beta = 0.014$; 90% CI, 0.006 to 0.022); used the correct toothpaste amount (mean $\beta = 0.115$; 90% CI, 0.004 to 0.221); brushed for a longer duration (mean $\beta = 0.001$; 90% CI, 0.000 to 0.002); and when caregivers brushed their own teeth more frequently (mean $\beta = 0.397$; 90% CI, 0.299 to 0.490), had more help with the overall care of the child's teeth and child brushing (mean $\beta = 0.058$; 90% CI, 0.021 to 0.096), and had family or a partner to help care for the child's teeth (mean $\beta = 0.292$; 90% CI, 0.229 to 0.354). Child brushing frequency was lower for caregivers with more brushing interference from activities of daily life (mean $\beta = -0.105$; 10% CI, −0.161 to −0.048).

With regard to plaque score, children whose caregivers had more help from other adults with brushing their child's teeth had better plaque scores (mean $\beta = -0.092$; 90% CI, −0.156 to −0.028) (Table 3). Higher plaque scores were seen in children with higher sugary beverage consumption (mean $\beta = 0.014$; 10% CI, 0.006 to 0.022), higher sweet or sugary food consumption (mean $\beta = 0.009$; 90% CI, 0.001 to 0.017), and lower household incomes (mean $\beta = 0.153$; 90% CI, 0.036 to 0.268).

Discussion

We identified multiple factors associated with tooth brushing behaviors and dental plaque in low-income children aged 36 months or younger, and these findings are relevant because dental caries begins early. The consistency in selecting the same set of factors between the full and LASSO regularization models highlights the robustness of the selection procedure in identifying meaningful factors associated with the frequency of tooth brushing and plaque score for this population.

Data from 2011–2016 reported a caries prevalence of 23% in US children aged 2 to 5 years, and this prevalence doubled by elementary school (1). In Illinois, overall caries and untreated caries prevalence have repeatedly surpassed national rates and disproportionately impact low-income, non-Hispanic Black, and Hispanic children (23). The participants in our analyses represent this high-risk demographic category. Identification of early risk and protective factors is essential to reduce oral health disparities and prevent or slow caries development in children.

The most influential factors associated with child brushing frequency in our analyses were the caregiver's own brushing frequency and caregivers having assistance with brushing from others. These associations are consistent with findings from other studies (24–26). Caregivers that brush their own teeth are more likely to brush their children's teeth as well (26). This association may be driven by caregiver oral health literacy, an overall value on oral hygiene within the family, established household routines, or by the fundamental principle that children learn from imitating adults (27). Having additional caregivers assist with child tooth brushing was associated with both higher brushing frequency and lower plaque scores. This points to the critical need for more family support for child brushing at this young age, mainly because children do not have the knowledge or manual dexterity to brush their teeth independently until they are much older. Caregivers have a fixed amount of time to complete necessary tasks, such as those conducted as part of morning or evening routines. When additional caregivers are available to assist with these tasks, children are more likely to receive assistance or supervision with an oral health regimen. Our findings emphasize the importance of the family unit or household, as everyone plays an important role in encouraging and directly supervising a child's tooth brushing.

The frequency of consumption of sugary foods and beverages was associated with worse plaque scores. This finding may be because parents that give more sugary beverages may demonstrate other unhealthy behaviors such as brushing less frequently or effectively. Households that rely on calorie-dense, readily available foods may do so out of necessity and not have the capacity or support to implement regular brushing routines. This finding is concerning because the frequency of exposure to sugar-sweetened foods and beverages is a significant risk factor for dental caries via acidogenic bacteria in plaque (28).

Finally, children in the lowest income category had the highest levels of plaque. Although most of our sample was low-income, worse outcomes in the lowest income level are not surprising. Low-income caregivers have repeatedly reported significant barriers to accessing dental care for their children (29), and these results are compounded by the lack of providers that accept Medicaid, as well as limited case management resources. The overall rate of providers enrolled with Medicaid in the Chicago area is high compared with the rest of the state, mirroring the geographic density of Illinois's population. Unfortunately, enrollment as a Medicaid provider does not mean these dentists serve a significant number of patients on Medicaid. The reality is that many of these providers take only a small number of Medicaid patients and may not perform restorative procedures.

What was surprising were the many factors not associated with brushing behaviors, including access to dental care, caregiver quality of life, social functioning, and caregiver oral health knowledge. Research indicates that children's dental care usage behaviors were associated with their caregivers' behaviors in these areas; children were more likely to have used dental care within the past year when their parents also used dental services (23,25). A possible explanation for the lack of association between dental care use and child brushing behaviors is that most of our sample had the same insurance, limiting variability. Research shows that the overall physical and psychological health and functioning of caregivers influences how they care for the health of their children; poor health, adversity, and inequality accumulate over the life course and across generations (30). Our study did not show differences in behaviors associated with caregiver quality of life and mental health, which may have been because of a lack of variability in the sample, instrument limitations, or perhaps not-yet-identified resilience factors. Finally, uncooperative child behavior is common in toddlers and poses a barrier to tooth brushing, even when caregiver knowledge and intent are good.

Our study has limitations. Because the data were cross-sectional, causation and potential directionality of effects cannot be established. We also did not measure all modifiable factors that influence oral health behaviors. The sample was limited to 1 densely populated urban county in the Midwest, and families had similar economic and races/ethnicities, which limits generalizability. Tooth brushing frequency was caregiver-reported because of the challenges of objectively measuring this behavior in young children, raising the potential for social desirability bias and data inaccuracy. However, we compared our self-reported data to data from other studies, including NHANES, and our results were similar (19). We also added a second measure of brushing — plaque score — to objectively capture the adequacy of brushing behaviors.

Our results indicate the necessity of interventions that target adult assistance with child brushing and reduction of sugary beverages and snack consumption among very young children. Similar to results in older children, our results demonstrate that brushing behaviors of young children are strongly associated with those of their parents and the level of family support for brushing. Interventions to improve brushing in young children should focus on the entire family, encouraging healthy oral health behaviors for parents as well as children. Clinicians and educators should also consider asking about family routines and supports parents have for brushing their children's teeth and offering appropriate interventions when problems are identified. Because low-income urban children are at high risk for developing caries beginning at a very early age, research is needed to determine whether these risk factors are also associated with caries development over time. We should also continue to develop and test interventions that will translate into improved oral health behaviors and outcomes for children.

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Tables

Table 1. Oral Health Risk Factors of Children Aged 6 to 36 Months (N = 420),[a] Coordinated Oral Health Promotion Chicago Study, Chicago, Illinois, 2018–2019

Risk Factor	Value
Caregiver Oral Health	
Condition of mouth and teeth (n = 419)	
Very good	30 (7.2)
Good	153 (36.5)
Fair	175 (41.8)
Poor	61 (14.6)
Frequency of brushing	
Sometimes, but not every day	6 (1.4)
Once per day	102 (24.3)
Twice per day	254 (60.5)
More than twice per day	58 (13.8)
Time since last dentist visit (n = 419)	
Never have been	4 (1.0)
≤6 months	157 (37.5)
>6 months but ≤1 year	77 (18.4)
>1 year but ≤2 years	83 (19.8)
>2 years	98 (23.4)
Main reason for last dentist visit (n = 416)	
Went in on own	218 (52.4)
Something was wrong	138 (33.2)
Other	60 (14.4)
Could not get dental care in the past 12 months (n = 137)	
Could not afford	23 (16.8)
No insurance	32 (23.4)
Insurance did not cover	45 (32.8)
Pregnant	16 (11.7)
Other	21 (15.3)
Child Risk Factors	
Caregiver's/adult's help with brushing	
Child does not brush	25 (6.0)
Child brushes alone	11 (2.6)
Sometimes/most of the time	151 (36.0)
Always	233 (55.5)
Length of time since child's last dental visit (n = 419)	
Never has been	250 (59.7)

[a] Values are no. (%), unless otherwise indicated; N = 420 unless otherwise indicated.
[b] The Oral Health Knowledge Scale was developed by the Knowledge and Behavior Workgroup of the Early Childhood Caries Collaborating Centers (31).

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(continued)

Table 1. Oral Health Risk Factors of Children Aged 6 to 36 Months (N = 420),[a] Coordinated Oral Health Promotion Chicago Study, Chicago, Illinois, 2018–2019

Risk Factor	Value
≤6 months	139 (33.2)
>6 months but ≤2 years	30 (7.2)
Child needed dental care but could not get, past 12 months	31 (7.4)
Type of drinking water (n = 416)	
Purchased only	227 (54.6)
Tap only	73 (17.5)
Both purchased and tap	116 (27.9)
Frequency of sugary beverage consumption	
Rarely or never	74 (17.6)
Once per week, not daily	69 (16.4)
Once per day	121 (28.8)
Twice per day	83 (19.8)
Three times per day or more	73 (17.4)
Child 15 months or older and still drinks from bottle (n = 341)	137 (40.2)
Caregiver Knowledge, Support, and Barriers	
Caregiver knowledge, mean (SD)[b]	4.2 (0.8)
Family/partner help care for child's teeth	
All the time	144 (34.3)
Most of the time	83 (19.8)
Some of the time	84 (20.0)
Rarely	42 (10.0)
Never	67 (16.0)
Social support, *t*-score, mean (SD) (n = 419)	
Emotional	55.9 (8.9)
Instrumental	54.8 (9.3)
Informational	57.7 (9.8)
Activities of daily life make it difficult to care for child's teeth	
All the time	7 (1.7)
Most of the time	29 (6.9)
Some of the time	84 (20.0)
Rarely	88 (21.0)
Never	212 (50.5)

[a] Values are no. (%), unless otherwise indicated; N = 420 unless otherwise indicated.
[b] The Oral Health Knowledge Scale was developed by the Knowledge and Behavior Workgroup of the Early Childhood Caries Collaborating Centers (31).

Table 2. Factors Associated with Frequency of Child Tooth Brushing Among Children Aged 6 to 36 Months (N = 420), Coordinated Oral Health Promotion Chicago Study, Chicago, Illinois, 2018–2019[a]

Variable	Full Model			LASSO 20% Frequency Selection			LASSO 40% Frequency Selection		
	β	SD	10% CI	Mean β	SD	90% CI	Mean β	SD	90% CI
Intercept	0.423	0.649	−0.644 to 1.489	−0.610[b]	0.253	−1.02 to −0.164	−0.613[b]	0.139	−0.835 to −0.381
Activities of daily life make it difficult to care for child’s teeth	−0.127[b]	0.033	−0.182 to −0.072	−0.102[b]	0.035	−0.158 to −0.043	−0.105[b]	0.034	−0.161 to −0.048
Caregiver age in years	0.002	0.006	−0.007 to 0.012	0.003	0.005	−0.005 to 0.012	—	—	—
Caregiver/adults help with brushing	0.282[b]	0.041	0.214 to 0.349	0.273[b]	0.040	0.206 to 0.339	0.292[b]	0.037	0.229 to 0.354
Caregiver frequency of brushing	0.378[b]	0.055	0.287 to 0.468	0.386[b]	0.055	0.294 to 0.474	0.397[b]	0.058	0.299 to 0.490
Child age in months	0.015[b]	0.006	0.006 to 0.025	0.014[b]	0.006	0.005 to 0.023	0.014[b]	0.005	0.006 to 0.022
Correct toothpaste amount	0.098	0.071	−0.019 to 0.214	0.082	0.072	−0.031 to 0.206	0.115[b]	0.068	0.004 to 0.221
Family/partner help care for child’s teeth	0.078[b]	0.025	0.037 to 0.118	0.058[b]	0.023	0.019 to 0.096	0.058[b]	0.023	0.021 to 0.096
Fluoride toothpaste used	0.004	0.071	−0.113 to 0.122	0.032	0.068	−0.082 to 0.145	—	—	—
Frequency of sweet or sugary foods	−0.004	0.005	−0.012 to 0.005	−0.005	0.004	−0.012 to 0.003	—	—	—
Household chaos	−0.089	0.064	−0.194 to 0.016	−0.042	0.062	−0.147 to 0.059	—	—	—
Household income in last year, $									
<30,000	0.091	0.081	−0.042 to 0.223	0.107	0.080	−0.026 to 0.238	0.100	0.078	−0.029 to 0.236
30,000–60,000	−0.057	0.093	−0.210 to 0.095	—	—	—	—	—	—
>60,000	−0.144	0.144	−0.381 to 0.093	—	—	—	—	—	—
Unknown/refused	1 [Reference]			—	—	—	—	—	—
Length of time since child’s last dental visit	0.065	0.056	−0.028 to 0.158	0.047	0.054	−0.043 to 0.136	—	—	—
Observed brushing time in seconds	0.001[b]	0.001	0.000 to 0.002	0.001[b]	0.001	0.000 to 0.002	0.001[b]	0.001	0.000 to 0.002
Total ECOHIS Score	0.008	0.008	−0.005 to 0.021	0.012[b]	0.007	0.000 to 0.024	—	—	—

Abbreviations: —, not applicable; ECOHIS, Early Childhood Oral Health Impact Scale; LASSO, Least Absolute Shrinkage and Selection Operator.

[a] Models include 32 variables; only significant variables are reported in the table. All models also control for a partner site. The full model uses categorical variables as a single construct, whereas LASSO treats the set of indicator variables from the same categorical variables as independent variables. The coefficients for the household income variable represent differences from the reference category in the full model, but in the LASSO models the coefficients represent differences from all categories not selected into the model.

[b] Significant at $P < .10$.

Table 3. Factors Associated with Higher Child Plaque Score Among Children Aged 6 to 36 Months (N = 420), Coordinated Oral Health Promotion Chicago Study, Chicago, Illinois, 2018–2019[a]

Factor	Full Model			LASSO 20% Frequency Selection			LASSO 40% Frequency Selection		
	β	SD	10% CI	Mean β	SD	90% CI	Mean β	SD	90% CI
Intercept	1.717[b]	0.628	0.684 to 2.749	1.939[b]	0.204	1.593 to 2.276	2.010[b]	0.107	1.833 to 2.181
Caregiver/adults help with brushing	−0.094[b]	0.040	−0.159 to −0.028	−0.102[b]	0.040	−0.167 to −0.034	−0.092[b]	0.040	−0.156 to −0.028
Caregiver age in years	−0.005	0.005	−0.013 to 0.004	−0.004	0.005	−0.012 to 0.004	—	—	—
Caregiver relationship status									
Single	0.261	0.147	0.019 to 0.503	0.114	0.071	−0.007 to 0.225	—	—	—
Living with partner/spouse	0.134	0.140	−0.096 to 0.365	—	—	—			—
Separated/divorced	1 [Reference]			—	—	—	—	—	—
Child race/ethnicity									
Black	0.066	0.155	−0.189 to 0.322	—	—	—	—	—	—
Hispanic	0.198	0.154	−0.056 to 0.450	0.127[b]	0.073	0.008 to 0.252			—
Other	0.372	0.254	−0.046 to 0.791	0.347[b]	0.181	0.040 to 0.628			—
White	1 [Reference]			—	—	—	—	—	—
Observed brushing time in seconds	−0.001[b]	0.001	−0.002 to −0.000	−0.001[b]	0.001	−0.002 to −0.000	−0.001	0.001	−0.002 to 0.000
Fluoride toothpaste used	0.093	0.069	−0.021 to 0.207	0.109[b]	0.065	0.002 to 0.218	—	—	—
Frequency of sugary beverage consumption	0.014[b]	0.005	0.006 to 0.023	0.014[b]	0.005	0.005 to 0.022	0.014[b]	0.005	0.006 to 0.022
Frequency of sweet/sugary foods	0.008	0.005	−0.000 to 0.016	0.007	0.005	−0.001 to 0.015	0.009[b]	0.005	0.001 to 0.017
Household income in last year, $									
<30,000	0.187[b]	0.078	0.058 to 0.315	0.175[b]	0.074	0.049 to 0.292	0.153[b]	0.071	0.036 to 0.268
30,000–60,000	−0.004	0.090	−0.152 to 0.144	—	—	—	—	—	—
>60,000	0.007	0.139	−0.222 to 0.236	—	—	—	—	—	—
Unknown/refused	1 [Reference]			—	—	—	—	—	—
Total ECOHIS Score	0.007	0.007	−0.005 to 0.019	0.005	0.007	−0.006 to 0.017	—	—	—

Abbreviations: —, not applicable; ECOHIS, Early Childhood Oral Health Impact Scale; LASSO, Least Absolute Shrinkage and Selection Operator.

[a] Models include 32 factors; only significant variables are reported in the table. All models also control for a partner site. The full model uses categorical variables as a single construct, whereas LASSO treats the set of indicator variables from the same categorical variables as independent variables. In this model, for caregiver race/ethnicity, caregiver relationship status, and household income, the coefficients in the full model represent differences from the reference category but in the LASSO models, the coefficients represent differences from all categories not selected into the model.

[b] Significant at $P < .10$.

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ORIGINAL RESEARCH

A Randomized Trial to Improve Adherence to Follow-up Eye Examinations Among People With Glaucoma

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PEER REVIEWED

Summary

What is already known on this topic?

Nonadherence to follow-up eye care is common among people with glaucoma and other eye diseases. Use of patient navigators and social workers can increase adherence to eye care appointments.

What is added by this report?

The results of a randomized, controlled trial of patients with glaucoma and other eye diseases showed that a patient navigation and social work intervention doubled the rate of follow-up adherence in community settings.

What are the implications for public health practice?

Involving patient navigators and social workers in ophthalmic care could improve care and reduce disease progression.

Abstract

Introduction

Appointment nonadherence is common among people with glaucoma, making it difficult for eye care providers to monitor glaucoma progression. Our objective was to determine whether the use of patient navigators, in conjunction with social worker support, could increase adherence to recommended follow-up eye appointments.

Methods

A randomized, controlled trial evaluated the effectiveness of an intervention that used patient navigators and social workers to improve patient adherence to follow-up eye care compared with usual care. Participants with glaucoma and other eye diseases (N = 344) were identified at primary care clinics in community settings through telemedicine screening of imaging and then randomized to enhanced intervention (EI) or usual care (UC). Data on participants' visits with local ophthalmologists were collected for up to 3 years from randomization. Groups were compared for timely attendance at the first visit with the local ophthalmologist and adherence to recommended follow-up visits.

Results

Timely attendance at the first visit was higher for EI than UC (74.4% vs 39.0%; average relative risk [aRR] = 1.85; 95% CI, 1.51–2.28; $P < .001$). Rates of adherence to recommended annual follow-up during year 1 were 18.6% in the EI group and 8.1% in the usual care group (aRR = 2.08; 95% CI, 1.14–3.76; $P = .02$). The aRR across years 2 and 3 was 3.92 (95% CI, 1.24–12.43; $P = .02$).

Conclusion

An intervention using patient navigators and social workers doubled the rate of adherence to annual recommended follow-up eye care compared with usual care in community settings, and was effective at increasing connections with local ophthalmologists. Interventions to further improve long-term adherence are needed.

Introduction

Glaucoma is a chronic eye disease resulting in visual field defects and progressive vision loss and is the leading cause of irreversible blindness worldwide (1). Among other chronic diseases, diabetes in particular is associated with increased likelihood of developing glaucoma (2,3). Because glaucoma is asymptomatic in early stages, early detection and timely intervention are critical to prevent vision loss (4). Nonadherence to recommended follow-up eye examinations reduces care and worsens outcomes (5). Fifty-four percent of people diagnosed with glaucoma fail to attend follow-up eye-related appointments (6). Barriers to nonadherence include health care costs, lack of transportation, and emotional distress (7,8). These barriers most often affect people of color, who have lower attendance rates at follow-up eye care appointments than White patients (9–11).

Patient navigators and social workers can help address barriers to appointment adherence. Patient navigators direct patients to appropriate health care resources, coordinate and schedule appointments, verify insurance status, and arrange transportation (12,13). Patient navigation programs have been used in other medical fields to promote adherence to medication and treatment (14–16). Few studies have looked at using patient navigators to improve appointment adherence among glaucoma patients, particularly among previously undiagnosed people with risk factors for glaucoma and eye disease (12,17).

Social workers assess, track, and lessen psychosocial barriers to care to improve quality of life and patient well-being (7,18). Social workers not only help patients navigate the health care system; they also provide emotional support, which has been shown to increase appointment adherence (18–20). In one study, a medical social worker in a pediatric ophthalmology setting increased appointment adherence by 45% (19,20). In several observational studies, glaucoma patients reported that a social worker resolved their issues and supported their keeping appointments with their ophthalmologist (7,21).

The combined use of social workers and patient navigators to improve appointment adherence among glaucoma patients has not been investigated previously in a controlled, prospective adult study. Our objective was to determine whether the use of patient navigators and social workers could increase adherence to recommended follow-up eye appointments among a high-risk population with glaucoma or other eye diseases.

Methods

Study design

The Philadelphia Telemedicine Glaucoma Detection and Follow-up Study was a prospective, randomized clinical trial that aimed to address the issue of poor adherence to follow-up eye examinations by providing patient navigator and social worker support to directly guide participants through the eye care process (22). The 5-year study was conducted by Wills Eye Hospital, funded by the Centers for Disease Control and Prevention, and registered with ClinicalTrials.gov (NCT02390245). As described previously (22), the study's 2 phases 1) conducted a practice-based telemedicine screening program for glaucoma and other eye diseases among underserved populations with risk factors for eye disease and 2) evaluated whether a community intervention with patient navigation and social worker support improved access to and use of eye care. The study was approved by the Wills Eye Hospital Institutional Review Board and was conducted in accordance with the Declaration of Helsinki. Written informed consent was obtained from all participants before each phase of the study.

In Phase 1, the study aimed to identify people with undiagnosed glaucoma and other eye diseases and facilitate their referral to local ophthalmologists. A targeted sample at high risk for eye disease was recruited from 12 community partner organizations and consisted of African American, Hispanic, and Asian adults over age 40; adults over age 65 of any race/ethnicity; and people over age 40 with a family history of glaucoma or currently diagnosed with diabetes. We enrolled only people who had not seen an ophthalmologist in the previous 12 months (N = 906). After informed consent was obtained, participants underwent a brief vision screening in their primary care provider's (PCP's) office (Visit 1), which included measuring visual acuity and intraocular pressure (IOP), and using fundus (retina) photography. Both retina and glaucoma specialists used telemedicine to read the images at Wills Eye Hospital. If the IOP was greater than 30 mm Hg, participants were immediately referred to a local ophthalmologist (fast-tracked). Otherwise, participants with findings suggestive of sight-threatening disease, such as glaucoma, diabetic retinopathy, or hypertensive complications, or with unclear screening results were invited to return to the same location for a comprehensive eye examination by an ophthalmologist (Visit 2). At Visit 2, visual acuity and IOP were assessed again in addition to an ophthalmologic examination. Visual field tests were also performed, and vision-related quality of life was assessed by using the National Eye Institute Vision Function Questionnaire (NEI-VFQ). Previous publications (22) report extensively on this first phase, including detailed methods and recruitment summary and concordance of the telemedicine eye screening findings and comprehensive examination diagnosis (23).

All participants who completed Visit 2 or who were fast-tracked were invited to participate in Phase 2 of the study. Phase 2 was a randomized controlled clinical trial designed to evaluate whether an enhanced intervention (EI) using patient navigation and social worker support improved patient adherence to follow-up eye care over usual care (UC) among those with newly diagnosed or suspected glaucoma or other ocular conditions.

Recruitment and randomization. Participants consenting to participate in Phase 2 were randomized to either the UC group or the EI group at a fixed 1:1 allocation ratio by using a masked method of random permuted blocks. Study coordinators retrieved the randomization and allowed participants to select an ophthalmologist they would like to follow up with over the next several years from a list of 20 participating offices located within 5 miles of the screening site.

Usual care. Participants randomized to UC were given their selected ophthalmologist's contact information and a copy of their eye examination results. UC participants were instructed to schedule an initial appointment with the ophthalmologist (Visit 3). Once connected to that ophthalmologist, services provided by each local ophthalmology practice generally included telephone calls and/or text message reminders before appointments. No practices provided patient navigator or social worker assistance as part of their usual care during the study period.

Enhanced intervention. Participants randomized to EI received a team-based intervention that included comprehensive assessment by a licensed social worker and assistance from patient navigators. The social worker called EI participants up to 3 times within 2 weeks to conduct an initial assessment, explain the EI process, assess participants' understanding of their new or existing ocular diagnosis, and document current and past barriers to obtaining eye care. The social worker provided community resources for participants in need of food and medications at no cost or at a reduced cost and discussed options for transportation to the local ophthalmologist. The social worker also assessed the participant's ability to complete their activities of daily living and provided emotional support. EI participants interacted by telephone with the social worker at least 3 times per year over 2 years.

Wills Eye Hospital study managers, ocular technicians, and research assistants served as patient navigators for EI participants. Their responsibilities included calling participants to schedule appointments; confirming appointments by mail, email, and/or text messaging; arranging transportation through Customized Community Transportation and Philadelphia Paratransit Service; and scheduling language interpreters with medical training to participate in eye examinations as needed. Patient navigators were able to identify cultural and language differences and were aware of health literacy issues. When possible, navigators were race and language concordant with the patient population.

Management and follow-up examinations. At Visit 3 and each follow-up visit, the local ophthalmologist assessed the participant's ocular, medical, and family history and conducted a comprehensive eye examination based on their clinical practice. The ophthalmologist would reconfirm ocular diagnoses, perform testing, adjust treatment recommendations as needed, and recommend follow-up intervals for the participant.

Final study visit. All randomized participants were invited to a final visit at their PCP's office at the end of the follow-up period. At this visit, the NEI-VFQ was re-administered, visual acuity and IOP were measured, and overall participant satisfaction with the study was assessed.

Outcome assessment. The research staff visited local ophthalmologists' offices to record visit dates, indications, findings, and treatments for up to 3 years from Visit 2. Data collection closed in March 2019.

Annual adherence. The primary outcome measure was adherence to recommended follow-up eye care appointments after Visit 3. Adherence was assessed annually on the basis of the expected follow-up schedule defined at the index visit for that year. In the first year, the follow-up recommendation given at Visit 3 by the ophthalmologist was classified into 1 of 4 categories: return within 2 months, return in 3 to 4 months, return in 6 months, or return in 12 months. This follow-up recommendation was then translated into the corresponding expected number of visits per year: 6, 3, 2, or 1. Participants were classified as adherent if the number of visits made within 13 months of Visit 3 (395 days) met or exceeded this expected number. Those who attended fewer visits or did not attend the initial visit with the local ophthalmologist within 12 months were deemed nonadherent for the first year. Adherence in the second and third years of follow-up was similarly defined; however, the follow-up recommendation used to define the required number of visits was based on the patient's most recent visit with the ophthalmologist before the start of that follow-up year. That is, the last visit that occurred during the first year of follow-up determined the follow-up schedule applied to the second year; similarly, the last visit that occurred during the second year of follow-up determined the follow-up schedule for the third year. When no visit occurred during a given year, the previous follow-up recommendation was carried forward. Additional measures of intervention effectiveness were explored, as detailed below.

Visit 3 attendance — initial visit with local ophthalmologist. The study evaluated the intervention's effectiveness in achieving the initial connection with the local ophthalmologist through timely attendance at Visit 3. Timely attendance was defined as having a first visit within 12 months of randomization.

Visit 4 attendance — first follow-up visit with local ophthalmologist. Adherence to the first follow-up visit (Visit 4) was assessed on the basis of the follow-up recommendation of the local ophthalmologist at Visit 3. Participants with follow-up recommended within 2 months were deemed adherent to the first follow-up visit if they returned within 3 months; for recommended follow-up of 3 to 4 months, 6 months, or 12 months, patients were considered adherent to Visit 4 within 6, 12, or 15 months, respectively.

Total number of visits with local ophthalmologist. The total number of visits included all visits on distinct days occurring after randomization, including Visit 3.

Satisfaction. A brief questionnaire was administered at the final study visit to assess overall satisfaction. By using a 4-point Likert-type scale, participants were asked to state their satisfaction with the study and the local ophthalmologist, perceived helpfulness of the study toward understanding their recommended eye-care, and likeliness to continue with follow-up care at the local ophthalmologist.

Statistical analysis

The study was designed to detect a 20% difference in adherence rates between groups during the first year of follow-up by using a 2-tailed test with $\alpha = 0.025$. With a final sample size of at least 135 participants per group, power to detect such a difference was 86% when the overall adherence across both study arms was 50%.

Participant characteristics at Visits 1 and 2 were summarized by randomization arm by using means and SDs or number and percentages. Adjusted estimates of the relative risk (aRR) of timely attendance at Visit 3 were calculated by using Poisson regression in a generalized estimating equation framework (24). An extension of this model for longitudinal data was used to jointly model repeated annual measures of follow-up adherence (25). The longitudinal model included time (year 1, 2, or 3), randomization assignment, and randomization by time interaction. Both models adjusted for baseline characteristics believed to be associated with adherence to follow-up: Visit 2 recommended follow-up (as a surrogate for disease severity), age at screening, sex, insurance type, and baseline NEI-VFQ composite score.

In the longitudinal model, 2 relative risks were calculated and 2 hypotheses were tested: 1) comparing randomization groups at year 1 to assess differences in early adherence and 2) calculating the average effect of randomization group across years 2 and 3 to test the long-term efficacy of the intervention. Each test was performed with $\alpha = 0.025$. Supporting analyses compared groups with respect to the percentage of participants who attended any visits with the local ophthalmologist, the percentage of participants who were adherent to their first post-Visit 3 visit, and the total number of visits after randomization. Analyses of dichotomous end points used the same approach as Visit 3 analysis. Number of visits was modeled by Poisson regression with follow-up time from randomization as the offset. An exploratory subset analysis was performed for participants with glaucoma-related diagnoses (those diagnosed with glaucoma, glaucoma suspect, or ocular hypertension). All analyses were performed by using SAS 9.4 and SAS/STAT 14.3 (SAS Institute).

Results

Participant characteristics

From April 2015 through February 2017, 906 participants completed the telemedicine eye vision screening (Visit 1) with their PCP as part of Phase 1 of this 5-year study (Figure 1) (22). On telemedicine reading, 355 participants (39%) were classified as having normal fundus images. The remaining 551 participants had abnormal or suspicious fundus images (334, 37%), unreadable fundus images (155, 17%), or IOP exceeding 21 mm Hg (62, 7%). Fifteen participants had IOP >30 mm Hg that required fast-track referral to the local ophthalmologist. The other 536 participants were invited to have a comprehensive eye examination by their PCP; 347 participants (65%) attended this Visit 2. These 347 patients and the 15 fast-tracked patients were invited to participate in Phase 2. A total of 344 participants consented and were randomized to either EU (n = 172) or UC (n = 172). Participants were followed up for a minimum of 22 months post-randomization.

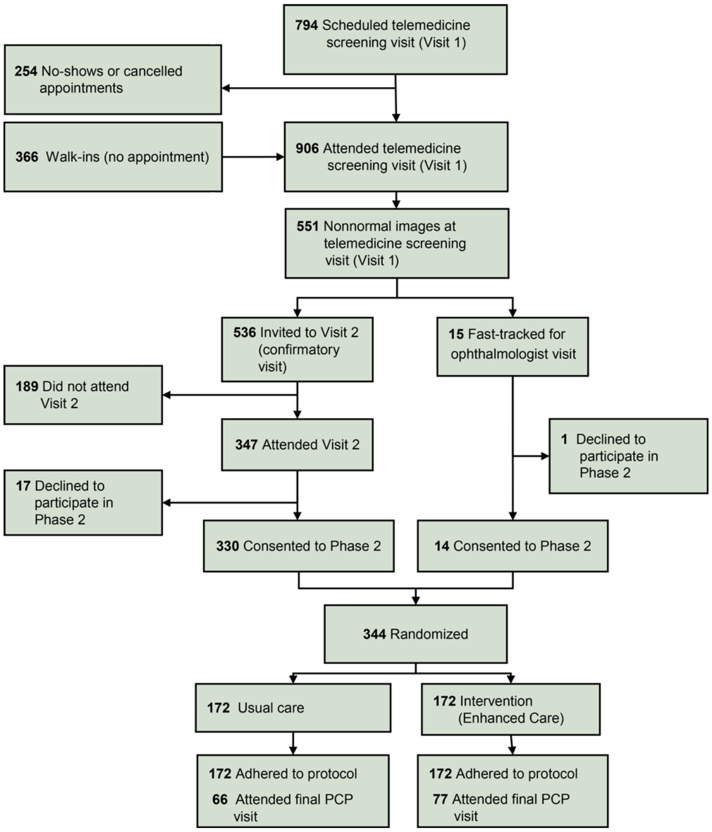

Figure 1. Flow chart describing the Philadelphia Telemedicine Glaucoma Detection and Follow-up Study, indicating participant inclusion, exclusion, and randomization to the usual care group or enhanced intervention group.

The mean age of participants was 59.9 years at screening; most (59%) were women and 66% were African American (Table 1). Roughly two-thirds (n = 230, 66.9%) had a glaucoma-related diagnosis at Visit 2 or were fast-tracked to visit an ophthalmologist because of high IOP. An NEI-VFQ average composite score of 82 indicated somewhat diminished vision-related quality of life. We saw no large differences in randomization groups with respect to baseline characteristics, although the EI group had a slightly higher percentage of women and a lower percentage of participants with diabetes (Table 1).

Timely Visit 3 attendance. About half of participants (56.7% [74.4% EI, 39.0% UC]) attended the initial visit with the local ophthalmologist within 12 months of randomization (Table 2). In adjusted analysis (Table 2), the EI group showed an 85% relative increase in timely Visit 3 attendance (adjusted relative risk [aRR] = 1.85; 95% CI, 1.51–2.28; $P < .001$). The effect was similar in the subset of participants with glaucoma-related diagnoses (aRR = 1.73; 95% CI, 1.37–2.19; $P < .001$). Among those who made timely contact with the local ophthalmologist, the median time to first visit was 57 days (interquartile range [IQR]: 39–92) in EI and 47 days (IQR: 27–82) in UC. Rates of any attendance at the local ophthalmologist were also higher in EI (77.9% vs 41.3%; aRR = 1.83; 95% CI, 1.51–2.22; Table 2) although only 6 EI and 4 UC participants ever attended a later visit after failing to make contact with the ophthalmologist in the first 12 months.

Adherence to follow-up after Visit 3. In year 1, the adherence rate was 18.6% in the EI group and 8.1% in UC with an aRR of 2.08 (95% CI, 1.14–3.76; $P = .016$) indicating that the intervention significantly increased the rate of adherence (Figure 2) (Table 3). Adherence was relatively stable in years 2 and 3 for EI, while declining over time in UC. The average aRR of adherence across years 2 and 3 was 3.92 (95% CI, 1.24–12.43; $P = .02$). Results were similar in an exploratory analysis of the glaucoma-related diagnosis subset with an aRR of 2.30 for year 1 adherence (95% CI, 1.10–4.82) and 3.44 across years 2 and 3 (95% CI, 1.11–10.63) (Table 3).

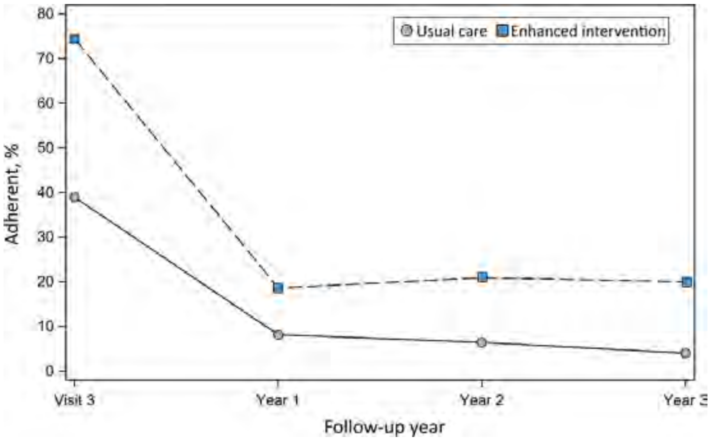

Figure 2. Adherence to recommended follow-up schedule over time by intervention group. Visit 3 was the initial visit with the community ophthalmologist. Timely adherence to Visit 3 was defined as attendance within 12 months of randomization. Annual adherence in Years 1–3 was defined as having attended all recommended follow-up visits within 13 months based on the recommended follow-up at the visit closest to the beginning of the year.

For adherence to the first follow-up visit recommended by the local ophthalmologist (Visit 4), the rate was 56.4% for EI group and 22.7% for UC (aRR = 2.39; 95% CI, 1.78–3.22) (Table 2). The average number of visits per year of follow-up was 0.9 in EI and 0.4 in UC (aRR = 2.07; 95% CI, 1.54–2.78) (Table 2). The proportion of participants who attended at least 1 visit in the first year of follow-up was 41.3% in EI and 18.0% in UC (aRR = 2.18; 95% CI, 1.52–3.12) (Table 2).

Final study visit and satisfaction survey. One-hundred forty-three participants attended the final study visit at the PCP office (EI, 77;

UC, 66). Both groups were satisfied or very satisfied with participation in the study (EI, 98.7%; UC, 93.9%), and most participants in both groups found the study very helpful in understanding and taking care of their eyes (EI, 64.9%; UC, 54.5%).

Discussion

In analysis of our primary outcome, we found that an intervention combining the support of patient navigators and social workers doubled adherence to recommendations for follow-up with a local ophthalmologist during the first year. These effects were similar for participants with or without glaucoma-related diagnoses. Much of this effect was likely due to an 85% relative increase in timely attendance at the initial visit with the ophthalmologist (Visit 3) for those randomized to the intervention arm (EI). After the first year, adherence rates dropped, but were still higher in the EI group.

Our results are similar to previous studies. The UC group in our study had only 39% attendance at the initial ophthalmologist visit, similar to results from the Hoffberger program, which provided free community-based eye screenings to residents of Baltimore, Maryland, at high risk for eye disease (6). In another prospective study, after 1 year, participants with glaucoma-related diagnoses had 82.5% follow-up adherence rates with the help of only patient navigators in office-based settings, compared with 73.3% in the usual care group; however, differences were not significant (12). Adherence in this study was defined as 1 or more visits within 1 year of diagnosis, and these rates were similar to what we observed for the same outcome in our intervention group (74.4%). Although the UC rate was much lower in our study, it is consistent with low rates seen in another recent study (26).

Patients with glaucoma may face barriers to receiving follow-up eye care, which should be recognized and addressed. A questionnaire presented to patients in a glaucoma clinic who were referred to a medical social worker found that the most frequent barrier to receiving eye care was emotional distress; additional barriers were cost of visits, lack of insurance, transportation, impairment of daily activities, and language (7). Another study reported forgetfulness as a major barrier to adherence to follow-up care (27). Degree of depression was also correlated with level of nonadherence to eye care recommendations (28). The results of our study suggest that combining support of patient navigators and social workers may be effective in reducing these barriers and thereby improving outcomes.

Our low annual adherence rates may be because adherence for the year was defined on the basis of the follow-up recommendation at the beginning of the year. For example, if a participant was given a recommendation during Visit 3 to follow up in 2 months, this was considered the desired follow-up interval throughout the following year. However, recommendations for follow-up could have varied during the year, and this may have affected our annual adherence results.

Our study had several limitations. First, in spite of the improved adherence in the EI, annual adherence was still unacceptably low compared to what is necessary for adequate treatment. Second, our sample size for year 3 limited our ability to assess the long-term benefit of the intervention. Lastly, different ophthalmologists' offices used diverse measures to remind patients to return for follow-up eye examinations, which were not controlled and could have affected our results.

This study targeted a diverse, urban population at risk for glaucoma but not receiving regular eye care. Study results would likely be generalizable to similar settings, although access to care, insurance rates, and existing support systems are likely to differ in other geographic areas and may affect the benefit of the intervention.

Future studies could consider combining additional interventions to further increase rates of adherence to follow-up eye care. Other interventions that may show promise include providing incentives such as free eyeglass prescriptions or free eyeglasses (26) and providing other financial incentives to encourage at-risk participants to return for follow-up eye examinations (12). The costs of the screening phase have been previously reported (22); the cost-effectiveness of our adherence intervention is being evaluated. In conclusion, our study addresses a critical gap in ophthalmic care by improving adherence to follow-up recommendations by using patient navigators and social workers. Addressing this gap is important because adherence to eye care contributes to a better prognosis for patients with chronic eye disease. We believe that use of social workers and patient navigators could be scaled on a national level to decrease the growing burden associated with glaucoma and other sight-threatening eye diseases.

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Tables

Table 1. Demographic and Clinical Characteristics of Subjects (N = 344) Randomized to Usual Care and Intervention Groups, the Philadelphia Telemedicine Glaucoma Detection and Follow-up Study

Characteristic	All (N = 344)	Usual Care (n = 172)	Intervention (n = 172)
Age, y, mean (SD)	59.9 (11.0)	59.0 (10.6)	60.8 (11.4)
Sex, n (%)			
Female	202 (58.7)	94 (54.7)	108 (62.8)
Male	142 (41.3)	78 (45.3)	64 (37.2)
Race/ethnicity[a], n (%)			
African American	223 (66.2)	111 (66.1)	112 (66.3)
White	52 (15.4)	25 (14.9)	27 (16.0)
Asian	16 (4.8)	7 (4.2)	9 (5.3)
Hispanic	37 (11.0)	20 (11.9)	17 (10.1)
More than one race	9 (2.7)	5 (3.0)	4 (2.4)
Family of history glaucoma, n (%)	87 (25.3)	49 (28.5)	38 (22.1)
Current smoker, n (%)	95 (27.6)	45 (26.2)	50 (29.1)
Hypertension, n (%)	237 (68.9)	122 (70.9)	115 (66.9)
Diabetes, n (%)	198 (57.6)	108 (62.8)	90 (52.3)
Insurance type, n (%)			
Medicaid	130 (37.8)	64 (37.2)	66 (38.4)
Medicare	91 (26.5)	40 (23.3)	51 (29.7)
Private	99 (28.8)	54 (31.4)	45 (26.2)
None	24 (7.0)	14 (8.1)	10 (5.8)
Screening outcome, n (%)			
Abnormal	218 (63.4)	112 (65.1)	106 (61.6)
Unreadable	85 (24.7)	38 (22.1)	47 (27.3)
Ocular hypertension	41 (11.9)	22 (12.8)	19 (11.0)
Visit 2 recommended follow-up, n (%)			
Every 3–4 months	54 (15.7)	26 (15.1)	28 (16.3)
Every 6 months	115 (33.4)	59 (34.3)	56 (32.6)
Every 12 months	175 (50.9)	87 (50.6)	88 (51.2)
logMAR visual, mean (SD)			
Lower (better)	0.2 (0.2)	0.2 (0.2)	0.2 (0.2)
Higher (worse)	0.3 (0.4)	0.3 (0.5)	0.3 (0.3)

Abbreviations: C/D ratio, cup-to-disc ratio; dB, decibel; IOP, intraocular pressure; logMAR, logarithm of the minimum angle of resolution; NEI-VFQ, National Eye Institute Visual Function Questionnaire.

[a] Race was unknown for 7 subjects.

[b] IOP was carried forward from visit 1 for 17 subjects (including 14 fast-tracked subjects).

[c] C/D ratio was not available for 22 subjects (including 14 fast-tracked subjects).

[d] Mean deviation was not available for 19 subjects (including 14 fast-tracked subjects).

[e] One subject did not complete the questionnaire; samples sizes vary across subscales.

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Table 1. Demographic and Clinical Characteristics of Subjects (N = 344) Randomized to Usual Care and Intervention Groups, the Philadelphia Telemedicine Glaucoma Detection and Follow-up Study

Characteristic	All (N = 344)	Usual Care (n = 172)	Intervention (n = 172)
IOP[b], mmHg, mean (SD)			
Lower (better)	14.9 (4.4)	15.3 (4.7)	14.5 (4.0)
Higher (worse)	16.6 (5.2)	16.9 (5.3)	16.2 (5.0)
C/D Ratio[c], mean (SD)			
Lower	0.4 (0.2)	0.4 (0.2)	0.4 (0.2)
Higher	0.5 (0.2)	0.5 (0.2)	0.5 (0.2)
Mean deviation[d], dB, mean (SD)			
Lower	4.7 (5.2)	4.8 (5.5)	4.7 (4.9)
Higher	7.8 (6.3)	8.0 (6.6)	7.5 (5.9)
Glaucoma-related diagnosis, n (%)			
None	114 (33.1)	52 (30.2)	62 (36.0)
Glaucoma	38 (11.0)	17 (9.9)	21 (12.2)
Glaucoma suspect	153 (44.5)	80 (46.5)	73 (42.4)
Ocular hypertension	25 (7.3)	14 (8.1)	11 (6.4)
Fast-tracked at screening (IOP >30 mm Hg)	14 (4.1)	9 (5.2)	5 (2.9)
NEI-VFQ composite score[e], mean (SD)	82.2 (15.7)	82.1 (16.0)	82.3 (15.5)

Abbreviations: C/D ratio, cup-to-disc ratio; dB, decibel; IOP, intraocular pressure; logMAR, logarithm of the minimum angle of resolution; NEI-VFQ, National Eye Institute Visual Function Questionnaire.

[a] Race was unknown for 7 subjects.

[b] IOP was carried forward from visit 1 for 17 subjects (including 14 fast-tracked subjects).

[c] C/D ratio was not available for 22 subjects (including 14 fast-tracked subjects).

[d] Mean deviation was not available for 19 subjects (including 14 fast-tracked subjects).

[e] One subject did not complete the questionnaire; samples sizes vary across subscales.

Table 2. Summary of Adherence Outcomes, the Philadelphia Telemedicine Glaucoma Detection and Follow-up Study

Outcome	Usual Care (n = 172) n (%)	Intervention (n = 172) n (%)	All (n = 344) RR (95% CI)	Glaucoma (n = 230) RR (95% CI)
Attended Visit 3 within 12 months	67 (39.0)	128 (74.4)	1.85 (1.51–2.28)	1.73 (1.37–2.19)
Attended any visit at local ophthalmologist	71 (41.3)	134 (77.9)	1.83 (1.51–2.22)	1.69 (1.36–2.09)
Adherent in Year 1	14 (8.1)	32 (18.6)	2.08 (1.14–3.76)	2.30 (1.10–4.82)
Adherent to first follow-up visit (Visit 4)	39 (22.7)	97 (56.4)	2.39 (1.78–3.22)	2.55 (1.79–3.63)
At least 1 visit in Year 1	31 (18.0)	71 (41.3)	2.18 (1.52–3.12)	2.31 (1.48–3.62)
Total visits attended per year	0.4 (0.7)[a]	0.9 (0.8)[a]	2.07 (1.54–2.78)	1.99 (1.44–2.74)

Abbreviation: RR, relative risk.
[a] Values are mean (SD).

Table 3. Intervention Effect on Adherence to Follow-up Schedule, by Year of Follow-up, the Philadelphia Telemedicine Glaucoma Detection and Follow-up Study

Variable	Total	Adherent to Follow-Up, n (%)	Adjusted Relative Risk (95% CI)	*P* Value[a]
Year 1				
Usual care	172	14 (8.1)	Reference	NA
Intervention	172	32 (18.6)	2.08 (1.14–3.76)	.02
Year 2				
Usual care	140	9 (6.4)	Reference	NA
Intervention	129	27 (20.9)	2.90 (1.39–6.02)	.004
Year 3				
Usual care	25	1 (4.0)	Reference	NA
Intervention	25	5 (20.0)	5.30 (0.56–49.95)	.15
Average, year 1–year 2				
Usual care	NA	NA	Reference	NA
Intervention	NA	NA	3.92 (1.24–12.43)	.02
Glaucoma Subset				
Year 1				
Usual care	120	9 (7.5)	Reference	NA
Intervention	110	21 (19.1)	2.30 (1.10–4.82)	.03
Year 2				
Usual care	98	7 (7.1)	Reference	NA
Intervention	79	16 (20.3)	2.47 (1.05–5.80)	.04
Year 3				
Usual care	19	1 (5.3)	Reference	NA
Intervention	18	4 (22.2)	4.80 (0.56–41.17)	.15
Average, year 2–year 3				
Usual care	NA	NA	Reference	NA
Intervention	NA	NA	3.44 (1.11–10.63)	.03

Abbreviation: NA, not applicable.

[a] *P* values were calculated by using GEE (generalized estimating equation) Poisson regression models adjusted for Visit 2 recommended follow-up (as a surrogate of disease severity), age at screening, sex, insurance type, and baseline National Eye Institute Visual Function Questionnaire composite score.

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