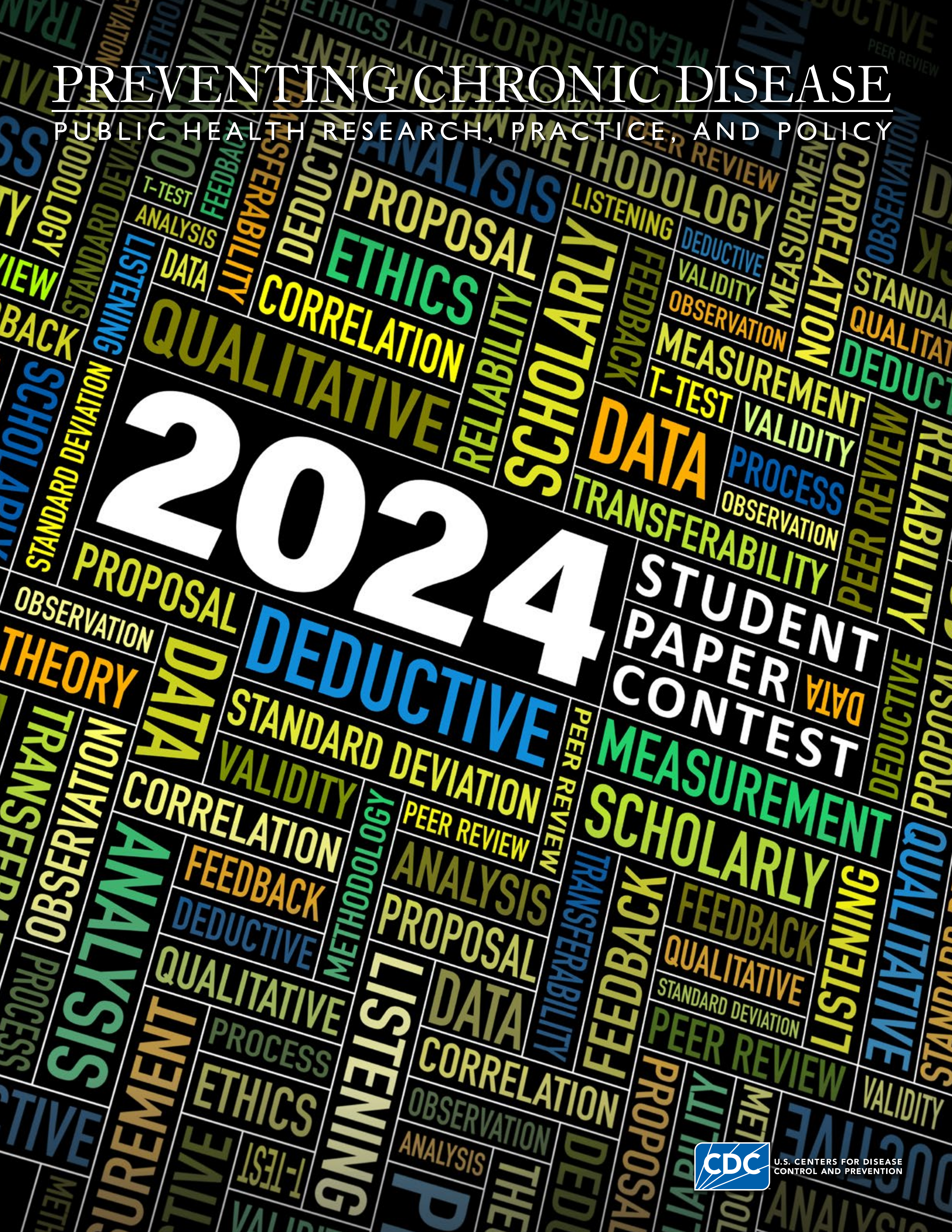
PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY



2024 STUDENT PAPER CONTEST

CDC
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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 peer-reviewed public health findings, innovations, and practices with editorial content respected for its integrity and relevance to chronic disease prevention.

PCD Staff

Associate Editors

Positioning Students for Success: 2024 Student Paper Contest Winners, Student Committee Research Skills-Building, and Release of 2025 Call for Papers

Leonard Jack Jr, PhD, MSc1

Preventing Chronic Disease celebrated its 20th anniversary this year. In 2011, the journal initiated its first Student Paper Contest in which students from around the world submit research papers to the journal for consideration. In our ongoing commitment to mentoring future public health professionals, the journal has guided students in developing their scholarly writing skills, with the goal of helping them become established contributors to the public health literature. We are tremendously proud to have served over the past decade as a place for students to consistently develop their expertise in peer-reviewed publication. The journal offers rare opportunities for students to learn from our leadership and its rich pool of scholarly volunteers — associate editors, peer reviewers, and others — as well as from mentors at their respective institutions. Since launching the Student Paper Contest 13 years ago, the journal has welcomed submissions at all levels, ranging from high school and undergraduate students to masters, doctoral, and postdoctoral candidates. Regardless of whether papers are accepted for publication, PCD provides students with extensive feedback helpful in identifying areas for improvement that can facilitate conversations between students and their mentors and assist them in future publishing efforts.

Goals and Submission Requirements

Eligibility requirements for the journal's Student Paper Contest are refined annually but in general remain consistent to their original charge (1). Students submitting papers for consideration are currently enrolled in or have in the last 12 months completed their degrees and programs, high school diplomas, undergraduate and graduate degrees, medical residencies, or postdoctoral fellowships. For the contest, PCD considers only one of two types of papers: original research and GIS (Geographic Information Systems) Snapshots. The primary goals of the Student Paper Contest are in the following 5 areas:

- Provide students with an opportunity to become familiar with a journal's manuscript submission requirements and peer-review process

- Assist students in connecting their knowledge and training on conducting quality research according to a journal's publication expectations

- Develop students' research and scientific writing skills to become producers of knowledge rather than just consumers of knowledge

- Provide students with an opportunity to become a first author on a peer-reviewed article

- Promote supportive, respectful, and mutually beneficial student–mentor relationships that strengthen students' ability to generate and submit scholarly manuscripts through their professional careers

2024 Winners and Submissions

PCD received 20 student research papers for our 2024 contest. After careful internal review, 15 of these underwent peer review. Nine of the 15 were accepted for publication and appear in the 2024 Student Research Paper Collection. Student authors continue to demonstrate their expanding interest in timely public health topics that include the cost barrier of medications in a student-run free clinic, WIC (Special Supplemental Nutrition Program for Women, Infants, and Children) benefits for purchase of fruits and vegetables and food security, colorectal cancer knowledge and screening among men, the use of geospatial hot spots and cold spots in cancer-related disparities in the US, factors associated with access to mental health services among children in the US, lifestyle intervention program for Spanish-speaking immigrants without health insurance, trends in gestational weight gain andprepregnancy obesity, and exploring the evidence of outpatient follow-up visits to reduce readmissions for cardiovascular health conditions.

After careful review, PCD did not select winners in the undergraduate, master's, and postdoctoral categories this year. We are, however, pleased to announce the winners of the 2024 Student Paper Contest in the high school and doctoral categories.

In the journal's high school category, Meng and Wiznitzer, authors of "Factors Associated With Not Receiving Mental Health Services Among Children With a Mental Disorder in Early Childhood in the United States, 2021–2022," reported findings about a strong link between health care factors and not receiving mental health services among children with a mental disorder in early childhood (2). The authors concluded that without timely treatment in early childhood, mental health disorders can impair children's learning abilities and relationships with others and may contribute to lifelong complications.

Guo and colleagues produced the winning paper in the doctoral category: "Geospatial Hot Spots and Cold Spots in US Cancer Disparities and Associated Risk Factors, 2004–2008 and 2014–2018" (3). This paper identified factors with the strongest influence on creating hot spots and cold spots, including unemployment, preventable hospital stays, mammography screening, and high school education. Authors highlighted the need for targeted interventions and policies that address limited access to health care and its associated risk factors.

We congratulate all student winners and students of papers that were not accepted for publication. Over the years, PCD has heard from mentors that their students have benefited from this realworld scholarly writing opportunity. Our commitment to increasing the capacity of students to generate quality peer-reviewed submissions will continue to expand over the coming years.

2025 Call for Student Papers

Moving forward, PCD will offer 2 student paper opportunities. First, we will continue to welcome students' interest in submitting research papers for the Student Paper Contest. We are interested in publishing research papers on the prevention, screening, and surveillance of chronic diseases and related population-based interventions, including but not limited to arthritis, asthma, cancer, depression, diabetes, obesity, cardiovascular disease, and COVID-19. Students are also invited to submit papers in response to our new essay submission call for papers, "Students Have Their Say: Novel Approaches and Solutions to Current and Emerging Public Health Problems." This essay submission opportunity allows students to identify and discuss new approaches to persistent or emerging public health challenges. We believe that students are in a unique position to offer novel ideas and share fresh perspectives, and we want them to have their say. To obtain detailed information about submission requirements for both opportunities, students, mentors, and readers are encouraged to visit our Calls for Papers page. Interested students are also encouraged to visit our Author's Corner for important information on how to develop a manuscript and associated tables or figures. Both of our Student Paper contest (original research or GIS Snapshots only) and student essay contest (essay only) are due by 5:00 PM EST on Monday, March 24, 2025.

Student Scientific Writing and Review Committee

Last year, PCD expanded its commitment to building the next generation of public health researchers by establishing its inaugural Student Scientific Writing and Review Training Committee. Last year's students completed an extensive training course and received our certificate of completion. Training is well under way for the second round of student appointees from across the country. Students appointed to the 2024 student committee, upon completion of their near year-long appointment, will get exposure to the following skills and abilities:

- Understanding the purpose and function of a respected peer-reviewed journal
- Understanding submission requirements for specific article types offered by a peer-reviewed journal (eg, format, word count, headings, manuscript style)
- Using the journal's electronic management tracking system to submit an article
- Becoming familiar with the peer-review process and how to appropriately respond to comments and suggestions from the journal
- Recognizing key components of a scientific research publication (qualitative, or mixed methods)

- Understanding how to appraise the quality of each component of a publication
- Assessing strengths and weaknesses of an article's methods, statistical analyses, data reporting, findings, and conclusions
- Applying skills developed from critiquing articles as a reviewer to generate quality papers as an author
- Writing strong introductions (ie, rationale), research questions, methods, findings, and conclusions
- Conducting literature reviews and creating bibliographies on topics of interests
- Working collaboratively with others within and outside one's area(s) of interest and expertise to address complex public health challenges and opportunities
- Learning to distinguish between the lay writing and scholarly writing necessary for consideration by a peer-reviewed journal

We look forward to hearing great things about students benefiting from the many learning opportunities the journal offers. Please join us in congratulating students who are seeking these opportunities and using lessons learned in their future academic preparation and real-world work experiences.

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PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E79 OCTOBER 2024

ORIGINAL RESEARCH

Factors Associated With Not Receiving Mental Health Services Among Children With A Mental Disorder in Early Childhood in the United States, 2021–2022

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0126.htm

Suggested citation for this article: Meng JF, Wiznitzer E. Factors Associated With Not Receiving Mental Health Services Among Children With A Mental Disorder in Early Childhood in the United States, 2021–2022. Prev Chronic Dis 2024;21:240126. DOI: https://doi.org/10.5888/pcd21.240126.

PEER REVIEWED

Summary

What is already known on this topic?

Many mental disorders begin in early childhood. Without timely treatment, mental disorders experienced by young children can impair their learning ability and relationships with others, causing lifelong complications.

What is added by this report?

Using data collected in 2021 and 2022 from a large, nationally representative sample of US children, we estimated that 19.0% of children aged 2 to 8 years had 1 or more mental disorders. Poor experiences with health care providers were consistently associated with not receiving mental health services when needed among young children with mental disorders.

What are the implications for public health practice?

Future public health efforts should prioritize enhancing patients' experiences with mental health care providers.

Abstract

Introduction

Many mental disorders begin in early childhood. Without timely treatment, mental disorders experienced by young children can impair their learning ability and relationships with others, causing lifelong complications. However, not all children with a mental disorder in early childhood receive treatment.

Methods

Using data collected from 46,424 children aged 2 to 8 years in the 2 most recent cycles of the National Survey of Children's Health (2021 and 2022), we estimated the prevalence of having a mental disorder and investigated factors associated with young children not receiving mental health care when needed. All analyses were adjusted for survey weights to account for the complex sampling design and nonresponse biases in generating nationally representative estimates.

Results

In 2021 and 2022, 19.0% of US children aged 2 to 8 years had 1 or more mental disorders. Of these children, 9.1% reported not receiving any needed health care in the previous 12 months, and of these, 45.8% reported not receiving mental health services when needed. The primary reasons for not receiving needed health care were problems getting an appointment (72.1%), issues related to cost (39.3%), and services needed not being available in the area (38.5%). Poor experiences with health care providers were consistently associated with not receiving needed mental health services among children with mental disorders.

Conclusion

Our findings suggest a strong link between health care factors and not receiving needed mental health services among US children with a mental disorder in early childhood. In addition to increasing the availability of mental health services and expanding health insurance coverage, future public health efforts should prioritize enhancing patients' experiences with health care providers.

Introduction

One in 5 children aged 3 to 17 years in the US has a mental disorder (1). Mental disorders in children are characterized by a clinically significant disturbance in a child's cognition, emotion, or behavior and often include mental, behavioral, and developmental disorders (2). According to national surveys, the most common mental disorders affecting children in the US are anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), and behavioral disorders (3). A previous study reported a substantial increase in the number of children diagnosed with mental disorders in the US before the onset of the COVID-19 pandemic (4), and the pandemic exacerbated the mental health conditions experienced by children due to factors such as social isolation, disruptions of routines and support systems, and limited access to mental health services (5).

Early childhood is a pivotal stage of child development (6). During this period, a child's brain undergoes rapid growth and development (7). Positive experiences in early childhood contribute to emotional resilience, self-esteem, and development of crucial coping skills, whereas negative experiences can impair learning ability and relationships with others, causing lifelong complications (8). Because a child's brain is highly adaptable and responsive to environmental influences during early childhood, it is imperative for young children with mental disorders to receive timely treatment, which can prevent more severe mental health problems or other chronic diseases in later life (9).

Many children with a mental disorder are untreated. The unmet needs for treatment among children with mental disorders likely reflect the complex interplay of individual, family, community, and societal factors (10), but the multilevel factors associated with not receiving needed mental health services among young children have not been identified. Addressing this gap in knowledge is essential to guide priority areas for strategies designed to improve the mental well-being of children in the US. The objective of this study was to assess the prevalence of early childhood mental disorders among US children after the COVID-19 pandemic and the proportion of these children not receiving mental health services when needed. An additional objective was to identify factors at the child, parental, household, neighborhood, and health care levels associated with not receiving needed mental health services among children with mental disorders in early childhood.

Methods

We used nationally representative data for US children from the National Survey of Children's Health (NSCH). The NSCH is a series of national surveys conducted by the US Census Bureau to assess the health and well-being of US children aged 0 to 17 years (11); the survey collects a wide range of data related to children's mental health through online or mailed surveys. A parent or caregiver (referred to as "parent" hereinafter) familiar with the child's health status and health care is the survey respondent. The 2 most recent cycles of NSCH (2021 and 2022) consisted of 104,995 children representative of noninstitutionalized children aged 0 to 17 years. The weighted percentage of children in age groups 0 to less than 2 years (infant to toddler), 2 to 8 years (early childhood), more than 8 to less than 12 years (middle childhood), and 12 to less than 18 years (adolescence) was 9.9%, 37.8%, 17.1%, and 35.2%, respectively. For this study, we included 46,424 children who were in early childhood at the time of the survey.

Mental disorders

Parents were asked whether they had ever been told by a doctor or other health care provider that their child had any of 22 health conditions. A child was considered to ever have had a mental disorder if their parent responded yes to 1 or more of the following 10 conditions: depression, anxiety, behavioral and conduct problems, ADHD, autism spectrum disorder, Tourette syndrome, learning disability, intellectual disability, development delay, or language disorder. Parents who responded yes to any of these conditions were further asked whether this child currently had the condition.

Not receiving health care or mental health services when needed

All parents were asked whether at any time in the previous 12 months their child needed health care but did not receive it. The child whose parent responded yes to this question was categorized as not receiving any needed health care in the previous 12 months, and these parents were further asked which type of health care (medical, dental, vision, hearing, mental health services, or others) was not received. The child whose parent marked "mental health services" was categorized as not receiving needed mental health services in the previous 12 months. In addition, these parents were asked whether any of the following 6 reasons contributed to this child not receiving needed health services: child not eligible for the services, services needed not available in the area, problems getting appointments, problems getting transportation or childcare, doctor's office was not open, and issues related to cost.

Child, parental, household, neighborhood, and health care factors

The NSCH Screener Questionnaire and Topical Questionnaire asked parents about various demographic, parental, household, neighborhood, and health care factors. For the children, we included the following variables: the child's age, sex, race, ethnicity, nativity (born in US or outside US), and general health. For parental characteristics, we included parent's age, education, nativity (first-, second, third-generation household or more, and other), and place of birth (born in US or outside US). For household characteristics, we included family structure, primary household language, and whether the household received cash assistance from government, food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits, free or reduced-cost meals, or WIC (Special Supplemental Nutrition Program for Women, Infants, and Children) program benefits in the previous 12 months.

Neighborhood characteristics included the physical environment of the neighborhoods, such as whether there were sidewalks or walking paths, a park or playground, a recreation or community center, a library or book mobile, litter or garbage on street, poorly kept or rundown housing, and vandalism such as broken windows or graffiti in the neighborhood. Parents were also asked to what extent they agreed with the statement about the neighborhood offering a supportive or safe environment, such as people in the neighborhood helped each other out, watched out for each other's children in the neighborhood, felt this child is safe in the neighborhood, or knew where to go for help in the community when encountering difficulties.

For children who had a health care visit in the previous 12 months, parents were asked how often the child's doctors or other health care providers 1) spent enough time with this child, 2) listened carefully to parents, 3) showed sensitivity to the family's values and customs, 4) provided the specific information parents needed concerning this child, and 5) helped parents feel like a partner in this child's care. Response options were always, usually, sometimes, or never. For children who needed decisions to be made about their health care, such as whether to get prescriptions, referrals, or procedures, parents were asked how often the child's health care providers 1) discussed with them the range of options to consider for this child's health care or treatment, 2) made it easy for parents to raise concerns or disagree with recommendations for this child's health care, and 3) worked with parents to decide which healthcare and treatment choices would be best for this child. Response options were always, usually, sometimes, or never.

For health insurance coverage, parents were asked whether their child was currently (in the previous 12 months) covered by health insurance. Parents who indicated having current insurance coverage were further asked about the type of insurance, and how often the child's health insurance benefits met the child's overall health needs and mental or behavioral health needs. For the 2 latter questions response options were always, usually, sometimes, or never. In addition, parents were asked whether the family had problems paying the child's health care bills in the previous 12 months.

Statistical analysis

We first examined the characteristics of US children in early childhood. We then estimated the weighted prevalence and 95% CIs of having 1 or more mental disorders among these children. We further estimated the proportion and associated 95% CIs of not receiving health care when needed, the type of health care services not received, and reasons for not receiving any needed health services, among all US children aged 2 to 8 years and separately for those with a current mental disorder. Among children with a current mental disorder, we compared the child, parental, household, neighborhood, and health care factors between those who did not receive needed mental health services and those who did; we used analysis of variance or χ^2 tests for these comparisons. We used the Bonferroni correction to adjust for multiple comparisons (12).

We used survey weights to account for the complex sampling design of NSCH and nonresponse biases in generating nationally representative estimates. A 2-sided P value of $\leq .05$ denoted significance. We used SAS version 9.4 (SAS Institute, Inc) to conduct all analyses.

Results

Among US children aged 2 to 8 years whose parents participated in the NSCH, the mean age was 5.0 years (Table 1). Of these children, 51.2% were boys, 12.7% were non-Hispanic Black, 25.5% were Hispanic, and 49.5% were non-Hispanic White; 96.5% were born in the US. Among those born outside the US, the mean length of time living in the US was 3.1 years. More than two-thirds (69.7%) of parents reported excellent general health for their child. Almost three-quarters (73.8%) of children were from households with 2 parents, and 84.5% of households spoke English as the primary language. Approximately one-fifth (21.0%) of households had received SNAP benefits and 14.0% had received WIC benefits in the previous 12 months.

The prevalence of having ever received a diagnosis of an early childhood mental disorder was 19.0% (weighted n = 5,239,089), and the prevalence of currently having an early childhood mental disorder was 16.0% (weighted n = 4,405,414). The prevalence of having ever been diagnosed with a mental disorder was 11.2% for language disorder, 7.7% for development delay, 6.3% for behavioral and conduct disorder, 4.9% for learning disability, 4.6% for ADHD, 4.0% for anxiety, 3.3% for autism spectrum disorder, 0.8% for intellectual disability, 0.5% for depression, and 0.1% for Tourette syndrome (Table 2). The prevalence of currently having a mental disorder was 9.0% for language disorder, 6.2% for development delay, 5.4% for behavioral and conduct disorder, 4.4% for learning disability, 4.3% for ADHD, 3.4% for anxiety, 3.1% for autism spectrum disorder, 0.8% for intellectual disability, 0.5% for depression, and 0.1% for Tourette syndrome.

Among US children in early childhood, 3.0% (weighted n = 814,794) reported not receiving any needed health care in the previous 12 months (Table 3); of these children, 29.0% (weighted n = 230,315) reported not receiving mental health services when needed. Among children with a current mental disorder, 9.1% (weighted n = 400,095) reported not receiving any needed health care in the previous 12 months; of these children 45.8% (weighted n = 178,119) reported not receiving mental health services when needed. Overall, the prevalence of not receiving mental health services when needed was 0.8% among all US children in early childhood, and 4.0% among US children with a current early childhood mental disorder. The top reasons for not receiving any needed health care among children with a current early childhood mental disorder were problems getting appointment (72.1%), issues related to cost (39.3%), and needed services not being available in the area (38.5%).

Among US children in early childhood with a current mental disorder, those who received and did not receive the mental health services when needed did not differ by any child, household, or neighborhood characteristic (Table 4). However, the parents of children who did not receive mental health services when needed, compared with the parents of children who received services, were significantly more likely to report worse experiences with health care providers in all 5 domains. For example, the percentage of parents who indicated that health care providers never spend enough time with their child was 11.5% among parents of children who did not receive needed mental health services and 2.1% among parents of children who received services (Table 4). In addition, parents of children who did not receive needed mental health services, compared with parents of children who received services, were significantly more likely to indicate that their child's doctor or other health care provider never discussed the range of options for treatment (6.1% vs 2.9%), never made it easy to raise concerns or disagreements (5.1% vs 3.1%), or never worked with caregivers to decide together best treatment choices (12.7% vs 1.6%).

Children with an early childhood mental disorder who received needed mental health services did not differ from children who did not receive services by current health insurance coverage or type of insurance coverage. However, parents of children who did not receive needed mental health services, compared with parents of children who received services, were significantly more likely to indicate that their health insurance never offered benefits or covered services that meet needs (5.9% vs 1.3%) and that their health insurance never offered benefits or covered services that meet their mental or behavioral health needs (19.8% vs 4.6%).

Discussion

In this nationally representative sample of US children, we found that 19.0% of US children in early childhood had ever received a diagnosis of a mental disorder and 16.0% had a current mental disorder. Among children with current early childhood mental disorders, 9.1% did not receive any needed health services and 4.0% did not receive needed mental health services in the previous 12 months. The lack of access to health care services, negative experiences with health care provides, and health insurance not covering the needed services were the factors most strongly associated with not receiving needed mental health services among these children.

The prevalence of ever having a mental health disorder among children aged 2 to 8 years in our study (19.0%) is a 9% relative increase and a 1.6 percentage-point absolute increase in the prevalence of mental disorders in children of this age since 2016, which was 17.4% (13). Mental disorders in early childhood can affect a child's development and well-being, potentially resulting in long-term cognitive, emotional, and social challenges (14–18). The high and increasing prevalence of mental disorders among young children underscores the urgency of providing timely treatment during the critical period of child development. Among children aged 2 to 8 years, the difference in the prevalence of receiving any health care services when needed between children with current mental disorders in early childhood and all children (9.1% vs 3.0%) was largely driven by a high proportion of children with mental disorders who reported that they did not receive the needed mental health services in the previous 12 months. Despite the rapid advancements in evidence-based treatment of children with mental disorders (19,20), children with early childhood mental disorders may encounter more barriers to receiving health care when needed, particularly mental health services, compared with children without mental disorders.

The top reasons for not receiving any needed health care services among children with early childhood mental disorders were similar to reasons among all children aged 2 to 8 years. However, the percentage of children with mental disorders in early childhood who had problems related to appointment availability and service accessibility was higher than the percentage of all children aged 2 to 8 years, suggesting that poor access to health care services may be a systemic barrier. Our findings indicated that 72.1% of children with mental disorders who did not receive any needed health care reported difficulties in getting appointments, and nearly 40% did not have needed services available in their areas. Future strategies need to focus on bridging the gap between the demand and availability in mental health services for young children with mental disorders.

In our effort to identify factors associated with unmet needs, we assessed a wide range of factors, following the social-ecological model for health (21). Despite previously reported disparities by child and family socioeconomic position and household (22) or neighborhood conditions (23), we did not find significant differences in receiving needed mental health services by child, household, or neighborhood factors. Instead, we found that poor experiences with health care providers were strongly associated with not receiving needed mental health services. In particular, parents of children who received needed mental health services, compared with parents of children who did not, were 5 times more likely to report that their health care providers never spent enough time, never listened carefully, or never helped them feel like a partner in their child's health care. Our findings align with previous research that assessed barriers to seeking and receiving mental health services, including the feeling of not being listened to or being dismissed by health care professionals (24). Together, these findings suggest that trust and confidence in health service providers could play a crucial role in parents seeking mental health services for children in need (25).

Lack of insurance coverage has been reported as a barrier to accessing mental health services in previous studies (26). However, we found that young children with mental disorders who received health care services and young children with mental disorders who did not receive health care services had similar rates of health insurance coverage, regardless of insurance type. However, children who did not receive needed mental health services were more likely than children who did to report that their insurance did not allow them to see the health care providers they needed or offer mental health benefits. Thus, despite the overall similar rates in insurance coverage, certain insurance plans may not provide adequate benefits to meet the child's mental health service needs. The cost of mental health services may also be a barrier to receiving them. Although we did not find significant differences between those who received or did not receive needed mental health services, 20% to 30% of parents of children with mental disorders in early childhood reported having difficulties paying the child's health care bills.

Strengths

Our study has several strengths. It provides updated evidence on the prevalence of mental disorders among US children after the COVID-19 pandemic. The analyses used data from a nationally representative sample of US children. Our findings, therefore, are generalizable to all noninstitutionalized children in the US. The focus on children in early childhood has important implications, because many mental disorders start in early childhood, and early interventions can substantially reduce the risk of future long-term complications. In addition, our study analyzed data from NSCH, one of the few national surveys that provide comprehensive surveillance data on a wide range of mental disorders among young children, such as those in early childhood.

Limitations

Our study has some limitations. First, the cross-sectional design of this study prevents us from establishing causal relationships. Second, the assessment of mental disorders was based on parental self-report, which is subject to recall bias or social desirability bias. In addition, the parent's self-reported need for mental health services may not reflect the need assessed by health care providers. Third, the NSCH lacks adequate representation of children from racial and ethnic groups other than non-Hispanic White, non-Hispanic Black, and Hispanic groups, and does not include a sufficient number of children who speak languages other than English or Spanish. These factors limit our ability to assess whether language or culture acts as a barrier to seeking and receiving mental health services among children with mental disorders.

Conclusion

Our study provides updated evidence on the prevalence of early childhood mental disorders among US children after the COVID-19 pandemic. With the high and increasing prevalence of mental disorders among young children, it is imperative to improve the provision of mental health services for those in need. In addition to increasing the availability of mental health services and expanding health insurance coverage, future public health efforts should prioritize enhancing patients' experiences with health care providers and establishing patient-centered communications on children's mental health needs and treatment options.

Acknowledgments

The authors received no external financial support for the research. The authors declared no potential conflicts of interest with respect to the research. No copyright materials were used in this article.

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Tables

Table 1. Child, Household, and Neighborhood Characteristics of Children Aged 2–8 Years in the United States (N = 46,424) Whose Parents Participated in the National Survey of Children's Health, 2021–2022

Characteristic	% (95% CI)[a]
Child	
Age, mean (95% CI), y	5.0 (4.97–5.06)
Sex	
Male	51.2 (50.2–52.0)
Female	48.8 (47.8–49.8)
Race and ethnicity	
Hispanic	25.5 (24.5–26.6)
Non-Hispanic Black	12.7 (12.0–13.5)
Non-Hispanic White	49.5 (48.5–50.5)
Other[b]	12.2 (11.7–12.8)
Child place of birth	
In US	96.5 (95.9–97.0)
Outside US	3.5 (3.0–4.1)
Length of time in the US among children born outside US, mean (95% CI), y	3.1 (2.8–3.3)
General health	
Excellent	69.7 (68.7–70.6)
Very good	22.8 (22.0–23.7)
Good	6.2 (5.7–6.8)
Fair	1.2 (0.8–1.5)
Poor	0.05 (0.03–0.12)
Parent	
Age, mean (95% CI), y	38.6 (38.4–38.8)
Education	
Less than high school	10.3 (9.5–11.2)
High school or GED	19.0 (18.1–20.0)
Some college or technical school	25.8 (24.8–26.7)
College degree or higher	44.8 (43.8–45.9)
Place of birth	
In US	76.1 (75.0–77.2)
Outside US	23.9 (22.8–25.0)

Abbreviations: GED, General Educational Development; SNAP, Supplemental Nutrition Assistance Program; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] All values are percentage (95% CI) unless otherwise indicated; percentages and 95% CIs were adjusted for survey weights.

[b] Participants who were not Hispanic, non-Hispanic Black, or non-Hispanic White were grouped into the "Other" group.

[c] First-generation households are households where ≥1 parent was born outside the US and child was born outside the US; second-generation households are households where ≥1 parent is born outside the US and the child is born in the US; third-generation households or more are households where both parents were born in US; other households are households where child is born in the US and parents are not listed.

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Table 1. Child, Household, and Neighborhood Characteristics of Children Aged 2–8 Years in the United States (N = 46,424) Whose Parents Participated in the National Survey of Children's Health, 2021–2022

Characteristic	% (95% CI)[a]
Nativity[c]	
First-generation household	2.6 (2.1–3.1)
Second-generation household	23.9 (22.9–24.8)
Third-generation household or more	66.6 (65.6–67.6)
Other	6.9 (6.3–7.5)
Household	
Family structure	
Two parents	73.8 (72.8–74.8)
Single parent	21.8 (20.9–22.8)
Grandparent household	3.2 (2.9–3.6)
Other	1.1 (0.9–1.3)
Primary household language	
English	84.5 (83.5–85.4)
Spanish	10.0 (9.1–10.9)
Other	5.6 (5.1–6.1)
In the past 12 months, family has ever received:	
Cash assistance from government	5.2 (4.7–5.7)
Food stamps or SNAP benefits	21.0 (20.0–21.9)
Free or reduced-cost meals	37.1 (36.0–38.1)
WIC benefits	14.0 (13.2–14.9)

Abbreviations: GED, General Educational Development; SNAP, Supplemental Nutrition Assistance Program; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] All values are percentage (95% CI) unless otherwise indicated; percentages and 95% CIs were adjusted for survey weights.

[b] Participants who were not Hispanic, non-Hispanic Black, or non-Hispanic White were grouped into the "Other" group.

[c] First-generation households are households where ≥1 parent was born outside the US and child was born outside the US; second-generation households are households where ≥1 parent is born outside the US and the child is born in the US; third-generation households or more are households where both parents were born in US; other households are households where child is born in the US and parents are not listed.

Table 2. Prevalence of Mental Disorders Among Children in Early Childhood (Aged 2–8 Years) in the US, National Survey of Children's Health, 2021–2022

Disorder	N (weighted n)[a]	Weighted % (95% CI)[b]
At least 1 mental disorder		
Ever	8,714 (5,239,089)	19.0 (18.2–19.8)
Current	7,047 (4,405,414)	16.0 (15.2–16.7)
Language disorder		
Ever	4,975 (3,074,499)	11.2 (10.5–11.8)
Current	4,029 (2,486,755)	9.0 (8.4–9.6)
Developmental delay		
Ever	3,686 (2,116,305)	7.7 (7.2–8.2)
Current	2,912 (1,697,624)	6.2 (5.7–6.6)
Behavioral or conduct problems		
Ever	2,927 (1,743,197)	6.3 (5.9–6.8)
Current	2,582 (1,497,935)	5.4 (5.0–5.9)
Learning disability		
Ever	1,859 (1,344,023)	4.9 (4.4–5.4)
Current	1,776 (1,212,369)	4.4 (4.0–4.8)
Attention deficit/hyperactivity disorder		
Ever	1,942 (1,246,007)	4.6 (4.2–5.0)
Current	1,846 (1,193,736)	4.3 (4.0–4.7)
Anxiety		
Ever	1,933 (1,090,934)	4.0 (3.6–4.3)
Current	1,733 (950,394)	3.4 (3.1–3.8)
Autism spectrum disorder		
Ever	1,396 (899,389)	3.3 (2.9–3.6)
Current	1,334 (849,498)	3.1 (2.7–3.4)
Intellectual disability		
Ever	345 (218,759)	0.8 (0.6–1.0)
Current	329 (213,157)	0.8 (0.6–0.9)
Depression		
Ever	236 (169,285)	0.6 (0.5–0.8)
Current	197 (127,181)	0.5 (0.4–0.6)
Tourette syndrome		
Ever	58 (35,389)	0.13 (0.07–0.19)
Current	50 (26,672)	0.10 (0.05–0.15)

[a] N is the number of children whose parents participated in the National Survey of Children's Health; weighted n is the number of US children represented by parents.
[b] Percentages and 95% CIs were adjusted for survey weights.

Table 3. Prevalence of and Reasons for Children Aged 2–8 Years Not Receiving Health Services When Needed in the United States, National Survey of Children's Health, 2021–2022[a]

Category	% (95% CI)	
	All children aged 2–8 years (n = 46,424)	Children aged 2–8 years with current mental disorders (n = 7,407)
Not receiving any health care services when needed	3.0 (2.6–3.3)	9.1 (7.8–10.5)
Type of needed health services not received		
Medical care	33.9 (28.0–39.9)	27.1 (18.9–35.3)
Dental care	45.7 (39.8–51.5)	33.7 (26.2–41.2)
Vision care	10.2 (7.1–13.4)	9.1 (4.9–13.3)
Hearing care	6.5 (3.7–9.3)	4.4 (2.0–6.8)
Mental health services	29.0 (24.3–33.6)	45.8 (38.2–53.5)
Other	13.5 (10.1–16.9)	18.5 (13.2–23.9)
Not receiving mental health services when needed	0.8 (0.7–1.0)	4.0 (3.3–4.8)
Reasons for not receiving any needed health services		
Problems getting appointment	60.1 (54.1–66.1)	72.1 (65.1–79.0)
Issues related to cost	37.6 (31.7–43.4)	39.3 (31.4–47.2)
Services needed not available in the area	29.4 (24.5–34.2)	38.5 (31.1–45.9)
Doctor's office wasn't open	21.1 (16.2–26.0)	21.8 (13.8–29.8)
Child not eligible for the services	18.8 (14.2–23.4)	18.5 (12.8–24.3)
Problems getting transportation or childcare	13.5 (9.9–17.1)	16.9 (11.0–22.8)

[a] Percentages and 95% CIs were adjusted for survey weights.

Table 4. Child, Household, Neighborhood, and Health Care Factors Associated With Not Receiving Mental Health Services When Needed Among US. Children with Mental Disorders in Early Childhood, National Survey of Children's Health, 2021–2022

	Receipt of mental health services when needed, % (95% CI)[a]		
Characteristics	**Yes (n = 7,077)**	**No (n = 330)**	***P* value[b]**
Child			
Age, mean (95% CI), y	5.9 (5.6–6.2)	5.5 (5.4–5.6)	.39
Sex			
Male	64.5 (62.2–66.8)	68.7 (60.2–77.3)	>.99
Female	35.5 (33.2–37.8)	31.3 (22.7–39.8)	
Race and ethnicity			
Hispanic	24.5 (22.1–27.0)	22.5 (14.9–30.1)	>.99
Non-Hispanic Black	15.1 (13.1–17.2)	14.0 (5.1–22.9)	
Non-Hispanic White	50.2 (47.8–52.6)	52.0 (42.7–61.4)	
Other	10.1 (8.8–11.4)	11.5 (6.1–16.8)	
Place of birth			
In US	97.5 (96.6–98.4)	98.7 (97.2–100)	>.99
Outside US	2.5 (1.6–3.4)	1.3 (0–2.8)	
Household			
Hard to cover basic needs such as food or housing			
Never	47.3 (44.9–49.7)	43.5 (34.3–52.7)	>.99
Rarely	32.7 (30.4–45.0)	30.4 (21.5–39.3)	
Somewhat often	15.7 (13.8–17.5)	19.0 (11.0–27.0)	
Very often	4.3 (3.4–5.2)	7.0 (3.3–10.8)	
In the past 12 months, family has ever received			
Cash assistance from government	6.7 (5.3–8.0)	4.9 (1.9–7.9)	>.99
Food stamps or Supplemental Nutrition Assistance Program benefits	29.5 (27.1–32.0)	28.0 (18.7–37.3)	>.99
Free or reduced-cost meals	48.4 (45.9–50.9)	48.9 (39.5–58.3)	>.99
Women, Infant, and Children (WIC) benefits	15.2 (13.3–17.1)	12.6 (6.5–18.8)	>.99
Neighborhood			
Physical environment			
Sidewalks/walking paths	73.7 (71.6–75.8)	71.1 (63.3–78.9)	>.99
Park/playground	73.9 (71.6–76.1)	74.6 (66.9–82.4)	>.99
Recreation center	45.8 (43.3–48.3)	43.1 (33.7–52.5)	>.99
Library/bookmobile	64.9 (62.5–67.3)	61.6 (52.4–70.7)	>.99
Litter/garbage	23.8 (21.6–26.0)	28.0 (19.3–36.7)	>.99
Rundown housing	16.7 (14.7–18.8)	18.1 (10.6–25.6)	>.99
Vandalism	9.3 (7.6–11.0)	9.2 (4.4–13.9)	>.99
Supportive/safe environment			
Help each other out	80.0 (77.5–81.9)	78.1 (69.6–86.6)	>.99

[a] Percentages and 95% CIs were adjusted for survey weights.
[b] *P* values were generated from analysis of variance for continuous variables (age) and χ^2 test for categorical variables (all others) and were adjusted for multiple comparisons using Bonferroni correction.

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Table 4. Child, Household, Neighborhood, and Health Care Factors Associated With Not Receiving Mental Health Services When Needed Among US. Children with Mental Disorders in Early Childhood, National Survey of Children's Health, 2021–2022

Characteristics	Receipt of mental health services when needed, % (95% CI)[a]		*P* value[b]
	Yes (n = 7,077)	No (n = 330)	
Watch out for other's children	79.3 (77.2–81.3)	74.2 (65.3–83.1)	>.99
Know where to go for help	86.0 (84.2–87.8)	74.6 (65.6–83.5)	>.99
Child safe in neighborhood	91.5 (90.1–93.0)	87.0 (79.7–94.3)	>.99
Health care factors			
Experience with health care providers			
Spending enough time			
Always	55.0 (52.4–57.5)	38.2 (28.6–47.8)	.004
Usually	31.6 (29.1–34.0)	32.7 (24.3–41.1)	
Sometimes	11.3 (9.7–13.0)	17.6 (10.7–24.5)	
Never	2.1 (1.5–2.7)	11.5 (5.2–17.9)	
Listen carefully			
Always	64.9 (62.4–67.4)	45.9 (36.3–55.4)	.004
Usually	27.3 (24.9–29.7)	29.6 (21.4–37.8)	
Sometimes	6.8 (5.5–8.1)	19.6 (12.2–27.0)	
Never	1.0 (0.6–1.6)	4.9 (0.6–9.2)	
Show sensitivity to family values/customs			
Always	68.0 (65.5–70.5)	56.5 (47.1–65.8)	.004
Usually	24.1 (21.8–26.4)	23.8 (16.1–31.4)	
Sometimes	6.4 (5.2–7.6)	14.7 (8.2–21.1)	
Never	1.5 (0.8–2.1)	5.1 (0.7–9.5)	
Provide specific information needed			
Always	65.0 (62.5–67.5)	38.7 (29.3–48.2)	.008
Usually	27.0 (24.6–29.4)	34.5 (25.7–43.3)	
Sometimes	6.9 (5.5–8.2)	21.8 (14.1–29.5)	
Never	1.2 (0.7–1.6)	5.0 (0.9–9.1)	
Helped parents feel like partners in child's care			
Always	66.2 (63.7–68.7)	45.4 (35.8–54.9)	.004
Usually	24.4 (22.1–26.8)	30.4 (21.8–39.0)	
Sometimes	7.5 (6.1–9.0)	14.9 (8.7–21.1)	
Never	1.8 (1.1–2.6)	9.3 (3.9–14.7)	
Discuss range of options			
Always	59.7 (55.8–63.7)	37.7 (27.3–48.1)	.004
Usually	26.8 (22.9–30.7)	25.0 (16.4–33.6)	
Sometimes	10.6 (8.3–12.9)	31.2 (20.6–41.8)	

[a] Percentages and 95% CIs were adjusted for survey weights.

[b] *P* values were generated from analysis of variance for continuous variables (age) and χ^2 test for categorical variables (all others) and were adjusted for multiple comparisons using Bonferroni correction.

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Table 4. Child, Household, Neighborhood, and Health Care Factors Associated With Not Receiving Mental Health Services When Needed Among US. Children with Mental Disorders in Early Childhood, National Survey of Children's Health, 2021–2022

	Receipt of mental health services when needed, % (95% CI)[a]		
Characteristics	**Yes (n = 7,077)**	**No (n = 330)**	***P* value[b]**
Never	2.9 (1.7–4.0)	6.1 (1.1–11.1)	
Make easy to raise concerns			
Always	62.3 (58.5–66.2)	42.0 (31.2–52.8)	.004
Usually	25.3 (21.7–29.0)	24.2 (15.8–32.6)	
Sometimes	9.3 (7.5–11.0)	28.7 (18.6–38.9)	
Never	3.1 (1.8–4.3)	5.1 (0.7–9.4)	
Work together to decide best treatment			
Always	64.1 (60.2–68.0)	42.1 (31.5–52.6)	.004
Usually	24.9 (21.2–28.6)	23.6 (14.9–32.4)	
Sometimes	9.4 (7.3–11.5)	21.6 (12.8–30.3)	
Never	1.6 (1.0–2.2)	12.7 (4.7–20.8)	
Health insurance and payment			
Current covered by health insurance			
Yes	96.6 (95.6–97.7)	97.6 (95.1–100)	>.99
No	3.4 (2.3–4.4)	2.4 (0–4.9)	
Current insurance type			
Through employer	53.0 (50.5–55.5)	57.6 (28.0–67.2)	>.99
Purchased directly from insurance company	4.2 (3.4–5.0)	4.0 (1.4–6.7)	>.99
Medicaid/Medicaid Assistance/government assistance plan	49.5 (47.1–52.0)	50.2 (40.7–59.7)	>.99
Indian Health Service	0.8 (0.4–1.2)	0.3 (0–0.5)	>.99
TRICARE/other military	2.8 (2.1–3.5)	3.9 (1.4–6.3)	>.99
Other	2.2 (1.4–2.9)	2.1 (0.4–3.7)	>.99
Health insurance offers benefits or cover services that meet needs			
Always	58.8 (56.4–61.2)	33.9 (24.5–43.2)	<.004
Usually	31.2 (29.0–33.5)	38.7 (29.8–47.6)	
Sometimes	8.6 (7.3–10.0)	21.5 (14.4–28.7)	
Never	1.3 (0.9–1.8)	5.9 (0–11.8)	
Health insurance offers benefits or cover services that meet the mental or behavioral health needs			
Always	53.1 (50.2–56.0)	17.5 (9.5–25.4)	<.004
Usually	28.2 (25.6–30.7)	24.7 (16.2–47.3)	
Sometimes	14.2 (12.1–16.2)	38.0 (28.7–47.3)	
Never	4.6 (3.2–5.9)	19.8 (12.1–27.6)	
Problems paying health care bills in the past 12 months			
Yes	21.3 (18.7–23.8)	32.0 (22.8–41.3)	.55
No	78.7 (76.2–81.3)	68.0 (58.7–77.2)	

[a] Percentages and 95% CIs were adjusted for survey weights.

[b] *P* values were generated from analysis of variance for continuous variables (age) and χ^2 test for categorical variables (all others) and were adjusted for multiple comparisons using Bonferroni correction.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E84 OCTOBER 2024

ORIGINAL RESEARCH

Geospatial Hot Spots and Cold Spots in US Cancer Disparities and Associated Risk Factors, 2004–2008 to 2014–2018

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0046.htm

Suggested citation for this article: Guo LR, Hughes MC, Wright ME, Harris AH, Osias MC. Geospatial Hot Spots and Cold Spots in US Cancer Disparities and Associated Risk Factors, 2004–2008 to 2014–2018. Prev Chronic Dis 2024;21:240046. DOI: https://doi.org/10.5888/pcd21.240046.

PEER REVIEWED

Summary

What is already known on this topic?

Disparities in cancer death rates exist across the social gradient, with lower socioeconomic groups and racial and ethnic minority populations experiencing higher death rates.

What is added by this report?

We used geospatial analysis to identify hot spots and cold spots of disparities in cancer death rates across US counties. We identified factors associated with these disparities, including access to care, health behaviors, and social determinants of health.

What are the implications for public health practice?

Policy and interventions should address geospatial disparities, focusing on social determinants of health, health care access, and healthy behaviors to achieve equitable cancer outcomes.

Abstract

Introduction

Despite declining cancer death rates in the US, cancer remains the second deadliest disease and disparities persist. Although research has focused on identifying risk factors for cancer deaths and associated disparities, few studies have examined how these relationships vary over time and space. The primary objective of this study was to identify cancer mortality hot spots and cold spots — areas where cancer death rates decreased less than or more than neighboring areas over time. A secondary objective was to identify risk factors of cancer mortality hot spots and cold spots.

Methods

We analyzed county-level cancer death rates from 2004 through 2008 and 2014 through 2018, exploring disparities in changes over time for socioeconomic and demographic variables. We used hot spot analysis to identify areas with larger decreases (cold spots) and smaller decreases (hot spots) in cancer death rates and random forest machine learning analysis to assess the relative importance of risk factors associated with hot spots and cold spots. We mapped spatial clustering areas.

Results

Geospatial analysis showed hot spots predominantly in the Plains states and Midwest and cold spots in the Southeast, Northeast, 2 Mountain West states (Utah and Idaho), and a portion of Texas. Factors with the strongest influence on hot spots and cold spots were unemployment, preventable hospital stays, mammography screening, and high school education.

Conclusion

Geospatial disparities in changes in cancer death rates point out the critical role of access to care, socioeconomic position, and health behaviors in persistent cancer mortality disparities. Study results provide insights for interventions and policies that focus on addressing health care access and social determinants of health.

Introduction

Despite declines in cancer death rates during the past 3 decades, cancer remains the second leading cause of death in the US (1,2). Disparities in cancer death rates also persist across many groups in the US (1). For example, the decline in cancer death rates has been slower for groups with lower socioeconomic position and for racial and ethnic minority populations, particularly Black Americans. Cancer death rates also vary geographically: Southern states and rural areas of the country have the highest cancer death rates and slower rates of decline (3).

Social determinants of health (SDOH), defined as the conditions in which people live, work, and age (4,5), contribute to cancer death and persistent cancer-related disparities. SDOH domains include economic stability (eg, poverty, food insecurity), education access and quality, health care access and quality, neighborhood and built environment (eg, violence, air pollution), and social and community context (eg, social support) (4). SDOH can be beneficial or adverse, and they affect health outcomes through influence on health behaviors, environmental exposures, stress levels, and access to care.

Several studies have linked unfavorable SDOH, particularly lower education and income, to higher cancer death rates (3,6,7) and positive SDOH, such as access to cancer care (8), private health insurance (9), and access to healthy diets (10), to better cancer outcomes. Like cancer death rates, SDOH and downstream risk factors (eg, smoking, physical activity, and diet) vary by geography.

Few studies have examined how relationships among SDOH and cancer death rates vary over time and by geography (11). Understanding these dynamic relationships is crucial for adequately and accurately addressing persistent cancer disparities and identifying targets for intervention and resource allocation. The primary objective of this study was to identify cancer mortality hot spots and cold spots — areas where cancer death rates decreased less than or more than neighboring areas over time. A secondary objective was to identify risk factors of cancer mortality hot spots and cold spots.

Methods

We obtained age-adjusted total cancer death rates at the county level, available in 5-year aggregates from 2004 through 2018, from CDC WONDER (Centers for Disease Control and Prevention Wide-ranging ONline Data for Epidemiologic Research) (12). National mortality data available on CDC WONDER are publicly available; data are collected by state registries and provided to the National Vital Statistics System. Data are based on death certificates for US residents; each death certificate specifies a single underlying cause of death and includes demographic data. The number of deaths and death rates can be obtained at multiple geographic levels (national, state, and county, when available), and by age group, race, Hispanic ethnicity, sex, and cause of death (4-digit ICD-10 [*International Classification of Diseases, Tenth Revision*] codes [13]). We collected the data from the US 1999–2018: Underlying Cause of Death data file in CDC WONDER and used ICD-10 codes C00–C97 to identify death rates for malignant neoplasms.

Next, we identified risk factors for total cancer death rates by conducting a comprehensive review of the published literature in PubMed. We used the search terms “cancer mortality” AND (“risk factor” OR “determinants” OR “predictors”) for the period 2000 to 2022. Two reviewers (L.R.G., M.C.O.) conducted the PubMed search, ensuring that the search and selection of studies were comprehensive and unbiased. Risk factors were identified through a qualitative meta-review or second-order review of the evidence associated with SDOH and cancer burden, focusing on systematic reviews and meta-analyses to synthesize and evaluate the literature comprehensively. This approach ensured that the collected data could be used for complex analysis methods, such as random forest or other machine learning models. We then obtained county-level data for identified risk factors from CDC (14), the US Census Bureau (15), and County Health Rankings & Roadmaps (16). These data allowed us to explore how risk factors might influence cancer deaths at the same geographic level as the CDC WONDER mortality data. Final data included age-adjusted total cancer death rates and aggregated individual risk factors, such as demographic factors, health behaviors, and SDOH and were used for both geospatial analysis and machine learning analysis (Table).

Ethics approval and consent to participate were not applicable in this study as decided by Northern Illinois University Institutional Review Board. This secondary analysis used publicly available datasets.

Study variables

Our study was designed to identify hot spots and cold spots of county-level cancer mortality changes between 2004–2008 and 2014–2018 based on available data. We used these periods to focus on longer trends and examined negative SDOH and demographic risk factors linked to persistent disparities over time (Table). Total cancer mortality was the dependent variable, while demographic characteristics, health behaviors, access to care, health literacy, health conditions, and economic stability were categorized as independent variables.

Geospatial hot spot analysis

We calculated changes in total cancer death rates as the difference in the rate between 2004–2008 and 2014–2018 by subtracting the 2014–2018 rate from the 2004–2008 rate. We applied imputation to the counties that had missing data by taking the average of the surrounding counties. We then applied Getis-Ord Gi* analysis with the Euclidean distance as fixed distance in ArcGIS Pro 2.7 (Esri) (17). Euclidean distance measures the direct distance between 2 nearest counties to ensure each feature has at least 1 neighbor. We identified hot spots and cold spots on the changes in total cancer death rates. We linked CDC WONDER data with the data file "USA Counties, August 4, 2022 updated" in ArcGIS Pro 2.7 by the Federal Information Processing Standard (FIPS) code at the county-level GIS layer. The hot spot analysis examines each geographical feature in the context of neighboring features. It calculates *z* scores and *P* values to identify where features with either high or low values cluster spatially compared with neighboring areas. We set the significance level at .10 to capture more potential hot spots with a high prevalence of cancer. This significance level can help to find weak clustering patterns that may have some significance. For this study, we defined hot spots as counties with a significantly smaller decrease ($P < .10$) in cancer mortality rates between 2004–2008 and 2014–2018 compared with the averages of the cluster of surrounding counties. In contrast, cold spots refer to counties with a significantly larger decrease in total cancer mortality rates during the same period compared with the averages of the cluster of surrounding counties. Positive *z* scores indicate the clustering of high values, signifying a hot spot, while negative *z* scores indicate the clustering of low values, signifying a cold spot. A *z* score near zero suggests no apparent spatial clustering and can be considered an average area. We then mapped spatial clustering areas and identified hot spots and cold spots (18).

Analysis of associated SDOH and downstream risk factors

First, we applied random forest analysis to address our second study objective to identify SDOH and downstream risk factors associated with hot spots and cold spots. Data on SDOH, demographic characteristics, and health behavior were available for 1,614 of all 3,143 US counties from 2004 to 2018. We used the variables as presented in the datasets. Previous studies with a comparable scope also faced challenges related to missing data and analyzed only a subset of the 3,143 counties (19–21).

Next, as part of random forest analysis, we selected variables by using a bagging technique that generated multiple bootstrap samples from the original dataset. Bagging is an ensemble learning technique that combines multiple models trained on bootstrapped subsets of the original dataset to improve predictive performance and reduce variance (22). We then used these bootstrap samples to train a multitude of decision trees, where each tree randomly selects features at each split point, creating a "forest" that votes on the final prediction. Each decision tree acts like a flowchart, splitting the data based on features (risk factors). We then calculated the importance of each predictor in making those predictions. This approach helped identify which predictor had the strongest influence on the outcome. By averaging importance scores from multiple decision trees, random forest analysis captures individual variable influence and interactions while reducing overfitting, enabling a more robust understanding of variables that have the most effect on changes in total cancer death rates at the county level (22). This ensemble approach strengthens the analysis by addressing variance in single-tree predictions, leading to a more robust understanding of which variables are truly important.

We applied the random forest algorithm to all 1,614 counties and the hot spot and cold spot clusters between 2004–2008 and 2014–2018 using 22 SDOH and other factors (Table) to determine their effect on changes in cancer death rates. The random forest model ranked the most important variable at 100% and scaled all other variables in relation to it. In this analysis, the more important the factor, the greater the effect on the model's ability to predict cancer death rates. We used the "randomForest" package in R 4.2 (R Core Team, 2023) for these analyses.

Results

The hot spot analysis (Figure 1) showed a large cluster on the US mainland (primarily in the Plains states and the Midwest) and a few counties in Hawaii. Cold spots were located in the Southeast, a portion of the Northeast, 2 states in the Mountain West (Utah and Idaho), and portions of Texas, Louisiana, and Alaska. The mean (SD) change in total cancer death rates in the US was −21.23 (18.75) deaths per 100,000 people. The mean (SD) change in death rate per 100,000 people was −16.6 (18.8) deaths for hot spots and −25.5 (18.4) deaths for cold spots. The mean percentage change was −7.7% for hot spots and −12.8% for cold spots. Additionally, the CDC WONDER dataset has an average 18.7% missing death rate data for all counties and states each year. A few states have an average missing data rate higher than 35%: Texas (86.2%), Nebraska (56.2%), Kansas (51.1%), and South Dakota (39.7%). Other states that have missing data are Alaska (22.3%), Idaho (18.7%), Minnesota (11.8%), Missouri (13.9%), Oklahoma (12.9%), Utah (12.9%), and Virginia (13.3%).

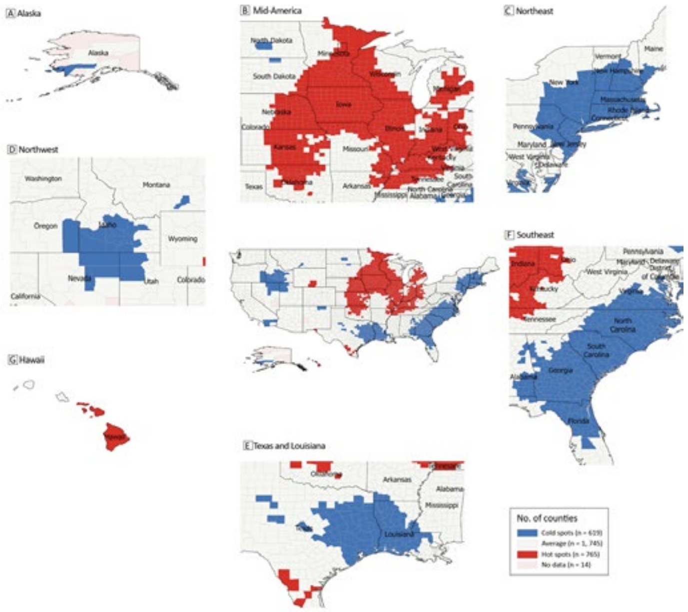

Figure 1. Changes in total cancer death rates at the county level between 2004–2008 and 2014–2018 in the US.

Risk factors for cancer mortality hot spots and cold spots

The random forest analysis included 765 hot spot counties and 619 cold spot counties. Less than a high school education, preventable hospital stay, Asian race, and low income were the top 4 risk factors for change in total cancer mortality from 2004 through 2018 (Figure 2). For hot spots, the top 5 risk factors for changes in cancer mortality were preventable hospital stays, being aged 65 years or older, poor mental health, transportation issues, and low income (Figure 3). For cold spots, the top 5 risk factors were no mammography screening, preventable hospital stays, no mental health provider, Hispanic ethnicity, and Black race. For average regions, the top 5 risk factors were drinking, being aged 65 years or older, obesity, preventable hospital stays, and no primary care provider.

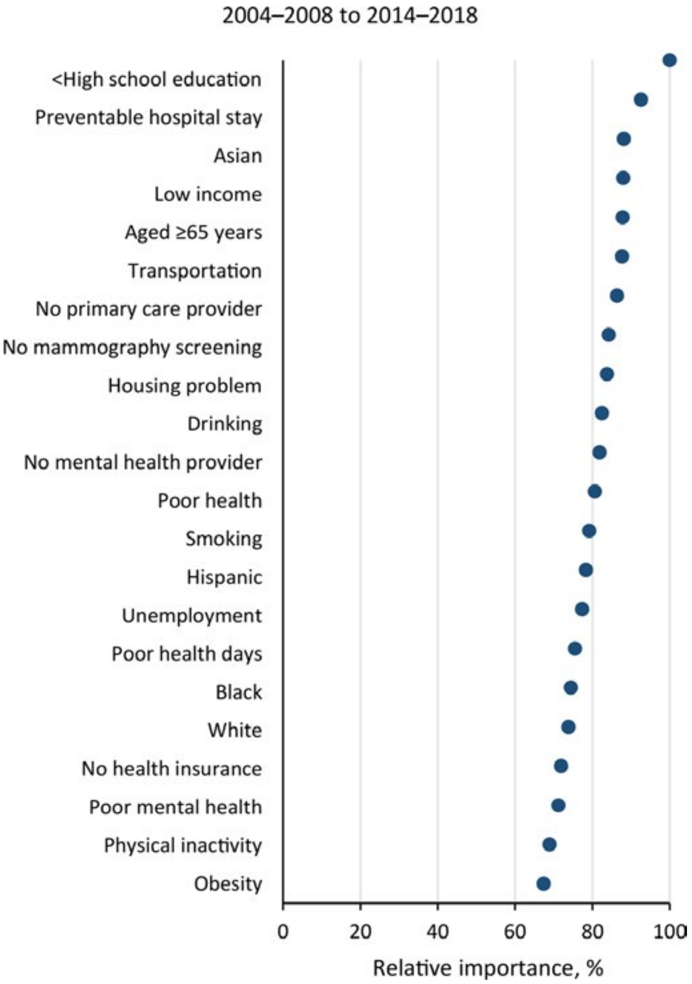

Figure 2. Relative importance of predictors of changes in total cancer mortality rates between 2004 and 2018 in US counties.

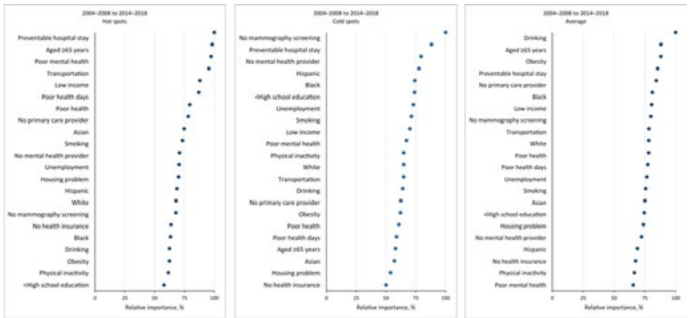

Figure 3. Relative importance of predictors of changes in total cancer mortality rates in hot spots and cold spots from geospatial analysis of US counties, 2004–2008 to 2014–2018.

The patterns of risk factor importance in hot spots and cold spots (Figure 3) were similar to the patterns for all US counties. However, areas with the greatest increase in cancer death rates were associated with an older population and higher levels of alcohol consumption, and the greatest decreases in cancer death rates were associated with higher rates of mammography screening.

Discussion

Although overall cancer death rates in the US are decreasing, disparities exist in how quickly they are decreasing across time and geographic areas. Our findings highlight similarities and differences in the hierarchy of risk factors for cancer death rates according to geographic hot spots and cold spots. Preventable hospital stays and mental health–related factors were top risks for cancer mortality risks in both hot spots and cold spots. These findings align with prior research showing that limited access to health care worsens outcomes, including preventable hospital stays and higher cancer death rates (23). Our study used a novel approach — machine learning (random forest analysis) — to analyze geospatial and temporal patterns in cancer death rates.

Cancer mortality hot spots and cold spots

Using geospatial hot spot analysis, we found significant geospatial disparities in changes in total US cancer death rates between 2004–2008 and 2014–2018. The hot spots identified in our study have higher persistent cancer death rates compared with the national trend (rates decreased less than expected), while cold spots reflect areas with alleviated cancer death rates (rates decreased more than expected). Hot spots were predominantly concentrated in the Midwest, while cold spots were prevalent in the Southeast, Northeast, and 2 Mountain West states.

Risk factors for cancer mortality hot spots and cold spots

We found various associations between negative socioeconomic position, access to health care services, and health behaviors. SDOH can positively or negatively influence health. We focused on negative SDOH and their influence on cancer mortality and how top risk factors of cancer mortality disparities differed in hot spots and cold spots. Some risk factors identified in our study were related to lower socioeconomic position, which can substantially affect access to cancer care. In general, people with low socioeconomic position have a heightened risk of various adverse health conditions, including cancer, due to factors such as unemployment, lower education levels, and poverty (23).

Risk factors in hot spots

Preventable hospital stays are admissions that could have been avoided with adequate ambulatory care or health care coordination. Often caused by delayed or inadequate access, they can worsen health outcomes and increase mortality rates (24). Preventable hospitalization is common among cancer patients (25). Preventable hospitalizations are more prevalent in advanced-stage cancer than earlier-stage cancer, highlighting how inadequate health care access can worsen overall health outcomes, including death rates (26).

Our finding that being aged 65 years or older is a risk factor for cancer aligns with prior research linking age to preventable chronic conditions and cancer risk factors (27). The third top risk factor, poor mental health, mirrored research showing that mental health investment improves health outcomes, including lowering cancer death rates (28). In contrast, patients who develop mood, anxiety, or substance use disorders for the first time after a cancer diagnosis may be at an increased risk of cancer-related death (29).

Transportation availability, the fourth top risk factor in hot spots, is another factor that influences access to health care. Transportation problems can hinder health care in the US, especially for cancer patients, who have frequent health care visits, long treatment periods, and financial obligations (30). Transportation barriers can cause delays in follow-up care after abnormal screening test results and limit access to specialized oncology care (31). Overcoming transportation barriers is crucial for improving cancer care access and outcomes, particularly in areas with persistently high cancer death rates.

Risk factors in cold spots

Preventable hospital stays and having no mental health provider were among the top 5 risk factors for changes in cancer mortality in cold spots. Having no mammography screening, being unemployed, and having less than a high school education were also in the top 5 risk factors. Our findings are consistent with a study across 79 countries that linked unemployment to higher mortality rates for cancers with available screening tests, suggesting the effect of economic instability on cancer outcomes (32).

Two other top risk factors for changes in cancer mortality in cold spots were Hispanic ethnicity and Black race. This finding demonstrates the effect of racial and ethnic health disparities on cancer mortality rates. Disparities in 5-year cancer survival persist between Black patients (67%) and White patients (72%), even among patients with similar income (27). Moreover, a study found that later-stage lung cancer was diagnosed more often in Black patients than in White patients even though Black patients had higher socioeconomic position (27). Lower overall cancer death rates among the Hispanic population might explain why Hispanic populations align with cold spots, but not hot spots. However, in a study that used data from 1950–2014, stomach and liver cancer death rates were higher in the Hispanic population than in the US general population; additionally, after adjustment for deprivation and other covariates, cancer death rates were significantly higher in the Hispanic and Black populations than in the non-Hispanic White population (33).

Risk factors in average regions

Hot spots and cold spots depict extreme cancer disparities, while average regions reflect typical mortality trends. The study of average regions offers valuable insight into cancer disparities. Two of the top 3 risk factors associated with average regions were related to health behaviors (alcohol consumption and obesity), and the third was being aged 65 years or older, also a top risk factor in hot spots. Alcohol consumption, the top risk factor in average regions, increases cancer mortality risk in a dose-dependent manner (34). Older adults who are heavy drinkers have higher cancer death and incidence rates than nonheavy drinkers (35). Poor diet and low levels of physical activity are often associated with obesity. Excessive weight is linked to increased risk of various cancers (36). While the exact mechanisms for this connection are not known, it highlights the importance of healthy lifestyle habits in cancer prevention. Our findings underscore the need for interventions that promote healthy behaviors, particularly among older adults, to make strides in reducing cancer mortality (37).

The availability of cancer health care resources, which we did not examine due to data limitations, can also play a role in reducing cancer disparities. Cancer death rates in early Medicaid expansion states significantly decreased between 2007–2009 and 2012–2016 (25), highlighting the effect of policy on health care access. However, simply increasing access to health care is insufficient to eliminate disparities. Despite advancements in cancer treatment, cancer control at the population level requires resources to address SDOH and other risk factors. Our study used a machine learning algorithm, random forest analysis, to identify a set of SDOH and other factors that reflect the intricate interplay of individual, community, and societal influences on cancer disparities (7) and underscores the need for multilevel interventions, including comprehensive health policies, to address disparities effectively.

Limitations and strengths

Our study has several limitations. First, our analysis focused on changes in total cancer death rates, which may not account for the various contributions of cancer types, such as lung cancer, a more prevalent cancer type with a strong modifiable risk factor of smoking. Second, our hot spot analysis identified areas with relatively high or low values, but it may not have fully considered the complex contextual factors influencing these patterns. Third, the missing county-level cancer death data and imputation to account for missing values may have affected the accuracy of our spatial analysis and are subject to interpretation. Fourth, aggregated cancer registry data protect patient privacy and can suppress differences and details in analysis, which may have affected our results. Nevertheless, hot spot analysis on imputed data provides a nuanced view of spatial patterns by incorporating estimated values for missing data. This approach can reveal potential clusters of extreme mortality rates that might be hidden by relying solely on cut points. Fifth, the study period predates the COVID-19 pandemic. Although future studies will include pandemic-era data, this study provides a valid framework for the utility of geospatial methods to study changes in cancer death rates. Lastly, while valuable, the application of random forest modeling is subject to its inherent limitations in providing insights into causality or the precise magnitude of variable effects on disparities in changes in total cancer death rates.

Despite these limitations, our study has several strengths. First, our geospatial analysis of total cancer death rates revealed areas with substantial disparities, highlighting the utility of geospatial methods in studying changes in cancer death rates. Geospatial analysis enabled a localized understanding of cancer mortality trends by visualizing and analyzing data across geographic space, revealing patterns and disparities that may not be evident from traditional statistical methods. Second, we used a machine learning algorithm to examine associated risk factors. This method excels in handling high-dimensional datasets and allowed us to capture intricate interactions among variables and mitigate overfitting, thus enhancing the robustness and generalization of our analysis.

Conclusions

This study identified cancer mortality hot spots and cold spots and associated risk factors of cancer mortality between 2004–2008 and 2014–2018 at the US county level. Our findings emphasize the critical role of access to care, socioeconomic position, and health behaviors in reducing disparities in cancer death rates. Acknowledging these complexities and the various negative SDOH and demographic risk factors of cancer mortality by region, a comprehensive but localized approach that addresses both access to health care and the underlying SDOH is essential for achieving meaningful reductions in cancer disparities. This evidence informs public health practitioners and policymakers as they develop targeted interventions and policies. By understanding geospatial disparities in cancer and their underlying risk factors, public health can focus much-needed cancer treatment and prevention on the counties and populations most vulnerable to cancer-related death.

Acknowledgments

The authors express their gratitude to Dr Mahdi Vaezi from the Northern Illinois University Department of Engineering Technology for his thoughtful consultation on the study design and implementation of geospatial analysis.

The study is supported by Northern Illinois University's Health Sciences Doctoral–Faculty Dyad Grant and Northern Illinois University's Research & Artistry Opportunity Grant. The authors declare that they have no competing interests. No copyrighted material, surveys, instruments, or tools were used in the research described in this article.

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Table

Table. Variables and definitions for Study of Cancer Disparities and Associated Risk Factors, United States, 2004–2018

Variable[a]	Definition[b]	Sources
Total cancer mortality rate	The number of deaths, with all types of cancer as the underlying cause of death, occurring in a specified population during a time frame.	CDC Wide-ranging ONline Data for Epidemiologic Research (WONDER) (12)
Demographic characteristics		
Age	Age of respondent, grouped as ≥65 or <65 years.	American Community Survey (15)
Race and ethnicity		
Non-Hispanic American Indian or Alaska Native	A person having origins in any of the original peoples of North and South America (including Central America) and who maintains tribal affiliation or community attachment.	American Community Survey (15)
Non-Hispanic Asian	A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.	American Community Survey (15)
Non-Hispanic Black or African American	A person having origins in any of the Black racial groups of Africa.	American Community Survey (15)
Hispanic	A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.	American Community Survey (15)
Non-Hispanic Native Hawaiian and Other Pacific Islander	A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. This includes people who reported detailed Pacific Islander responses such as Native Hawaiian or Other Pacific Islander; Fijian; Chamorro; Marshallese; Native Hawaiian; Other Micronesian; Other Pacific Islander; not Specified; Other Polynesian; Samoan; and Tonga.	American Community Survey (15)
Non-Hispanic White	A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.	American Community Survey (15)
Sex	Respondents mark either male or female to indicate their biological sex.	American Community Survey (15)
Health behaviors		
Smoking	Percentage of adults that reported currently smoking.	Behavioral Risk Factor Surveillance System (14)
Obesity	Percentage of adults that report having a body mass index ≥30.	Behavioral Risk Factor Surveillance System (14)
Physical inactivity	Percentage of adults that report no leisure-time physical activity.	County Health Rankings & Roadmaps (16)
Drinking	Percentage of adults that report excessive drinking.	Behavioral Risk Factor Surveillance System (14)
Access to care, health literacy, health conditions		
Lacks health insurance	Respondents who do not have health insurance coverage as from private health insurance or public coverage	County Health Rankings & Roadmaps (16)
High school education	Respondents who received at least a regular high school diploma and did not attend college were instructed to report “regular high school diploma.”	County Health Rankings & Roadmaps (16)
Unemployment	Respondents aged ≥16 years who were neither “at work” nor “with a job but not at work” during the reference week and were actively looking for work during the last 4 weeks, and were available to start a job.	County Health Rankings & Roadmaps (16)
Mammography screening	Percentage of female Medicare enrollees having ≥1 mammogram in 2 years.	County Health Rankings & Roadmaps (16)
Preventable hospital stay	Discharges for ambulatory care sensitive conditions per 1,000 Medicare enrollees.	County Health Rankings & Roadmaps (16)
Primary care physicians	Primary care physicians per 100,000 population.	County Health Rankings & Roadmaps (16)
Poor health	Percentage of adults that report fair or poor health.	County Health Rankings & Roadmaps (16)
Poor health days	Average number of reported physically unhealthy days per month.	County Health Rankings & Roadmaps (16)

[a] Total cancer death rate is the dependent variable; all others are independent variables.
[b] Definitions are from original data sources.

(continued on next page)

(continued)

Table. Variables and definitions for Study of Cancer Disparities and Associated Risk Factors, United States, 2004–2018

Variable[a]	Definition[b]	Sources
Poor mental health days	Average number of reported mentally unhealthy days per month.	County Health Rankings & Roadmaps (16)
Mental health providers	Mental health providers per 100,000 population.	County Health Rankings & Roadmaps (16)
Economic stability		
Housing problem	Percentage of households with at least 1 of 4 housing problems: overcrowding, high housing costs, lack of kitchen, lack of plumbing facilities.	County Health Rankings & Roadmaps (16)
Household without vehicle	Percentage of households that do not own ≥1 vehicle.	County Health Rankings & Roadmaps (16)
Median household income	A measure that divides the selected monthly owner costs as a percentage of household income distribution into 2 equal parts: one-half of the cases falling below the median selected monthly owner costs as a percentage of household income and one-half above the median	County Health Rankings & Roadmaps (16)
Transportation	Percentage of housing units with no vehicle available.	County Health Rankings & Roadmaps (16)

[a] Total cancer death rate is the dependent variable; all others are independent variables.
[b] Definitions are from original data sources.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E34 MAY 2024

ORIGINAL RESEARCH

The Cost of Medications at a Student-Run Free Clinic in New Haven, Connecticut, 2021–2023

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Accessible Version: www.cdc.gov/pcd/issues/2024/23_0277.htm

Suggested citation for this article: See C, Hegde K, Reid L, Shi R, Luthra R, Dong W, et al. The Cost of Medications at a Student-Run Free Clinic in New Haven, Connecticut, 2021–2023. Prev Chronic Dis 2024;21:230277. DOI: https://doi.org/10.5888/pcd21.230277.

PEER REVIEWED

Summary

What is already known on this topic?

People who lack health insurance also often lack access to medical services and cannot afford prescription medications. Inability to pay for prescription medications can lead to medication nonadherence.

What is added by this report?

Among patients at a free clinic, 64% required financial assistance to obtain prescribed medications, and 22% were prescribed an expensive medication, defined as medication costing more than $20.

What are the implications for public health practice?

Prescription assistance programs, discount coupons, transportation to pharmacies, and home delivery are ways to make medications more affordable. Student volunteer patient navigators demonstrate the positive effect of student-run clinics on improving access to medications among low-income groups.

Abstract

Introduction

Haven is a student-run free clinic in New Haven, Connecticut, that serves more than 500 patients annually. Haven's pharmacy department helps patients obtain medications by providing discount coupons or medications from the clinic's in-house pharmacy, directly paying for medications at local pharmacies, and delivering medications to patients' homes. This study aimed to identify prescriptions that have the highest cost among Haven patients.

Methods

Our sample consisted of all Haven patients who attended the clinic from March 2021 through March 2023. Patients were eligible to be seen at Haven if they were aged 18 to 65 years, lacked health insurance, and lived in New Haven. We determined the lowest cost of each medication prescribed to Haven patients by comparing prices among local pharmacies after applying a GoodRx discount. We defined expensive medication as more than $20 per prescription. We excluded medical supplies.

Results

Of the 594 Haven patients in our sample, 64% (n = 378) required financial assistance and 22% (n = 129) were prescribed at least 1 expensive medication. Among 129 patients prescribed an expensive medication, the mean (SD) age was 45.0 (12.3) years; 65% were women, and 87% were Hispanic or Latino. Median (IQR) household annual income was $14,400 [$0–$24,000]. We identified 246 expensive medications; the median (IQR) price per prescription was $31.43 ($24.00–$52.02). The most frequently prescribed expensive medications were fluticasone propionate/salmeterol (accounting for 6% of all expensive medications), medroxyprogesterone acetate (6%), albuterol sulfate (5%), and rosuvastatin (5%).

Conclusion

The average Haven patient has an income well below the federal poverty level, and many have chronic cardiovascular and respiratory conditions that require expensive medications. Future research should work toward making medications universally affordable.

Introduction

Solutions are needed to address the financial cost of medications among people without health insurance. Lack of health insurance is a cause of medication nonadherence and a barrier to improved health. Haven Free Clinic is a student-run primary care clinic that serves more than 500 unique patients annually in 20 departments ranging from pharmacy to social services. Haven's catchment area is the greater New Haven area in Connecticut. The Haven pharmacy department assists patients in obtaining affordable medication by providing discount coupons, distributing over-the-counter medications from Haven's basic in-house pharmacy, paying for medication at local pharmacies, and delivering medications to patients' homes.

Medication nonadherence is common among patients with low socioeconomic status (1). In 2022, adults without health insurance were more than 2 times as likely as adults with private health insurance to report delaying or not getting a medication due to cost (12.3% vs 5.4%) (2). In 2019, 12.5% of adults aged 19 to 64 years in New Haven had no health insurance (Mark Abraham, executive director, DataHaven, email communication, January 2024), slightly lower than the national rate of 12.9% (2). This comparatively lower rate was in part due to the Affordable Care Act (ACA) (3), which expanded Medicaid insurance for people with low incomes (<138% of the federal poverty level [FPL]) in 31 states, including Connecticut. Among New Haven residents covered by health insurance as a result of the ACA, 77% are members of racial and ethnic minority populations, 73% have no education beyond high school, and 64% live in working families (4). In New Haven in 2019, 26% of the Latino population, 8% of the Black population, and 6% of the non-Hispanic White population had no health insurance (5). New Haven is a town of 134,023 residents (5) and approximately 21 neighborhoods (6); the median income ranges from $31,250 to $87,384 (7). To date, no studies have described the medications and their associated medical conditions that impose the greatest financial burden on people without health insurance. This study investigates this question by using data from the single-center Haven database.

Methods

This study is a retrospective review of the Haven pharmacy departments' internal medication database and patient electronic medical records. We included data on all patients seeking care at Haven's weekly Saturday clinic during a 2-year period, from March 6, 2021, to March 4, 2023. People are eligible to receive care at Haven if they are aged 18 to 65 years, have no health insurance, and live in New Haven County. Patients who have diabetes and require insulin, have HIV/AIDs, need prenatal care, or are receiving active chemotherapy are referred to other health centers and thus were not included in our analyses. Patients who opted out of research were also excluded from our analyses.

The Haven clinic

A student-run clinic is a health care delivery program in which students take primary responsibility for the logistics and operational management of services under the supervision of faculty advisors. Frequently, a student-run clinic serves low-income patients who may not have health insurance, are experiencing homelessness, or are at high risk of inadequate management of serious medical problems ranging from hypertension to substance use disorder and violence. Often, student-run clinics provide free access to various services — including blood pressure screening, vaccinations, medications, and laboratory work — and provide low-cost acute care and chronic case management (8).

The Haven Free Clinic (www.havenfreeclinic.com) is a student-run clinic founded in 2005 that partners with Yale University to provide the New Haven community access to comprehensive, high-quality health care free of charge. Haven is run by a group of students from the Yale School of Medicine, Yale School of Nursing, Yale School of Public Health, Yale Physician Associate Program, and Yale University. All health care services are provided by Yale students, under the supervision of licensed physicians, nurse practitioners, and physician associates from the Yale community.

Haven's existing patient population is predominantly Latino (90%) and Spanish-speaking (85%). The average age of Haven patients is 35 years. However, the clinic serves a diverse population of patients who cannot afford medical care. Many Haven patients have not received medical care for at least 2 to 3 years before coming to Haven (9).

The Haven pharmacy department is made up of graduate and undergraduate students and is typically run by 4 student codirectors assisted by 20 volunteers. The codirectors maintain the in-house inventory of medications, distribute in-house medications at clinic, coordinate pharmacy donation deliveries from nonprofit organizations, assist in the purchase of over-the-counter and prescribed medications (often via telephone), help patients enroll in prescription assistance programs, and coordinate delivery of medications to patient homes. At the clinic, volunteers assist codirectors to perform these tasks. Their main responsibilities are to help distribute medications and identify the most affordable medication options for patients by using GoodRx coupons.

Study population

The largest proportion (45%) of Haven's patient population resides in Fair Haven (one of the poorest neighborhoods in New Haven), where the median annual household income was $45,966 in 2021 (10). The Hill, where 17% of the Haven patient population resides, had a median annual household income of $45,416 in 2021 (11). For comparison, in 2021, the median annual US household income was $70,784 (12), $83,572 in Connecticut (13), and $48,973 in New Haven (14). The unemployment rates in Connecticut and in New Haven in 2021 were both 6% (13, 14). The only retail pharmacy that accepts payment over the telephone in New Haven is located in Amity, which poses transportation problems for patients who live 3 to 6 miles away in Fair Haven and the Hill and lack a mode of transportation (Figure 1). Amity is more affluent than the neighborhoods in which our patients live, with a median income of $81,809 in 2021 (16). Neighborhoods in New Haven such as Fair Haven and the Hill may be "pharmacy deserts" — areas with inadequate access to retail pharmacies that disproportionately affect low-income people (17–19).

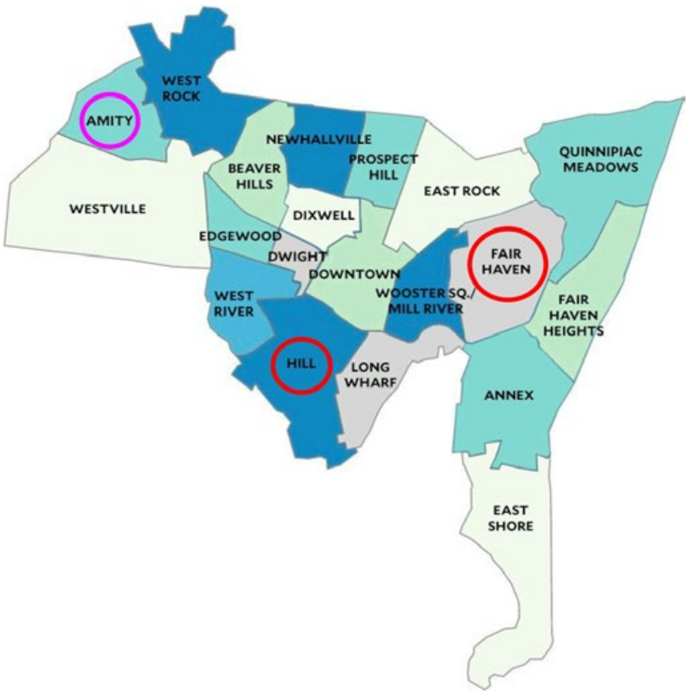

Figure 1. Location of neighborhoods in New Haven, Connecticut. A large proportion (62%) of Haven's patients live in either the Hill or Fair Haven, 3 to 6 miles from Amity, which has the only retail pharmacy in New Haven that accepts payment over the telephone. Map tiles by Stamen Design, under CC BY 4.0 (15). Data by OpenStreetMap, under ODbL, adapted by the Yale MacMillan Center, which added static neighborhood labels to the image, and used with permission. In addition, 2 red circles were added to highlight low-income neighborhoods (Fair Haven and Hill), and a purple circle was added to highlight a high-income neighborhood (Amity).

Data collection

We extracted the following demographic and health data for each patient from Haven's electronic medical records: age (in years), sex (male or female), ethnicity (Hispanic or Latino or not), employment (employed or not employed), annual individual income (calculated as weekly income multiplied by 48 weeks or biweekly income multiplied by 24 weeks), annual household income (annual individual income combined for each patient and their legally married spouse if applicable), neighborhood residence within New Haven (21 choices), *International Classification of Diseases, 10th Revision, Clinical Modification* (20) diagnosis or diagnoses for which each expensive medication was prescribed, and comorbidities (all other medical conditions each patient has, excluding diagnoses). The electronic medical records do not include information on race.

Haven's pharmacy department maintains a database of all medications prescribed by Haven physicians, regardless of where they are dispensed or distributed. The database includes information on medications for which the pharmacy department made external payments to retail pharmacies or for which patients were given the lowest-priced GoodRx coupon to purchase the medication on their own. GoodRx is a free mobile app and website that finds the lowest prescription prices in a person's neighborhood (21). We excluded medications if 1) data components (eg, price or pharmacy) were not recorded in the database, 2) they were distributed at the clinic rather than paid for at another pharmacy, 3) they were obtained via pharmaceutical company prescription assistance programs, or 4) they were blood pressure cuffs, orthotic braces, or diabetic test supplies. We excluded these medical supplies so that we could focus on medications that directly treat medical conditions. We also excluded insulin because Haven refers patients requiring insulin to other clinics for specialized care.

The medication prices listed in our study are the prices listed on the GoodRx website (www.goodrx.com), which ranges by pharmacy and its location. Haven pharmacy codirectors chose the dispensing pharmacy on the basis of patient preference and the lowest possible price indicated by a GoodRx coupon. We defined expensive medication as medication that cost more than $20 per prescription, regardless of filled amount. We used this $20 cutoff because it is the amount that Haven asks patients to contribute toward prescriptions if they are able. Generally, patients are prescribed enough medication to last them 2 or 3 months, usually until their next visit. Thus, although doses and routes of administration (eg, oral vs topical) may differ, the period of use for each prescription should be similar. We extracted data on the following characteristics of the expensive medications: route of administration (oral, topical, intramuscular, inhalation, otic, suppository, ophthalmic, or vaginal), price per prescription, and type of pharmacy where prescription was filled. We grouped pharmacies into the following categories: retail pharmacy (CVS, Rite Aid, Stop & Shop, Walgreens, and Walmart), mail order pharmacy (Blink Health and Amazon), and hospital pharmacy (Yale New Haven Health Apothecary). We determined the top 10 most commonly prescribed medications and summarized their characteristics (generic name, brand name, number of patients prescribed the medication, the medication count per patient, the range of prices paid, the mean price, the dose, the route of delivery, the type of pharmacy that filled the prescription, and the quantity prescribed).

We determined that 594 unique patients attended medical visits at Haven during our study period. We used Epic's Department Appointment Report data from electronic medical records and an internal Haven database stored on Microsoft Teams (Microsoft Corp) to count the total number of unique patients. Medical visits were defined as medical, reproductive health, or tuberculosis therapy appointments.

For data analysis, we calculated percentages for categorical variables and mean (SD) or median (IQR) for continuous variables. We used R version 4.2.3 (R Project for Statistical Computing) to conduct analyses. This study received approval from the Yale Institutional Review Board (no. 2000033657). Data generated during or analyzed for this study are not publicly available because of privacy and ethical restrictions.

Results

Of 594 unique patients attending Haven for medical visits, 64% (n = 378) required financial assistance from Haven's pharmacy department and 22% (n = 129) were prescribed an expensive medication. The mean (SD) age of patients receiving an expensive medication was 45.0 (12.3) years; 65% were female and 87% were Hispanic or Latino (Table 1). Forty-five percent lived in Fair Haven, followed by 17% in the Hill and 10% in the Annex. Sixty percent of these patients were employed. Median (IQR) individual and household annual incomes were $11,350 ($0–$19,200) and $14,400 ($0–$24,000), respectively. Of the 263 unique diagnoses associated with the expensive medications, the most common were contraceptive management (9%; n = 24), hyperlipidemia (8%; n = 21), and asthma (8%; n = 21).

The 129 patients were prescribed 113 unique expensive medications encompassing 246 total prescriptions for 263 unique medical diagnoses, totaling $10,967.78 in costs and averaging $42.51 per patient per year. The median (IQR) price per prescription (n = 246 prescriptions), regardless of amount filled was $31.43 ($24.00–$52.02) (Table 2). Of the 113 unique expensive medications, most (82%; n = 93) were purchased from retail pharmacies, followed by mail order pharmacy (8%; n = 9) and a combination of retail pharmacy and mail order pharmacy (4%; n = 5).

Among the 246 prescribed medications, the most frequently prescribed were fluticasone propionate/salmeterol (6%; n = 14), medroxyprogesterone acetate (6%; n = 14), albuterol sulfate (5%; n = 12), and rosuvastatin (5%; n = 12) (Table 2 and Table 3). The most expensive medications were budesonide ($170.00 for 60 doses of a 90 µg/actuation inhaler), ciprofloxacin–dexamethasone ($146.10 for 7.5 mL of a 0.3%–0.1% otic solution), budesonide–formoterol ($139.43 for 120 doses of an 80/4.5µg actuation inhaler), and fluticasone propionate/salmeterol ($135.00 for 60 doses of a 113–114 µg/actuation inhaler). Three of these 4 most expensive medications were inhalers prescribed for asthma, while the fourth medication — ciprofloxacin–dexamethasone — was prescribed for tympanic rupture. Of the total cost for the 246 prescriptions, 19% of the cost was for a pulmonary condition (n = 31 prescriptions), 11% was for a neurologic condition (n = 27 prescriptions), and another 11% was for a cardiovascular condition (n = 41 prescriptions) (Figure 2). Several patients accounted for substantial medication costs: 1 patient received 3 prescriptions of acetazolamide for idiopathic intracranial hypertension ($239.95 total), another received 3 testosterone gels for hypogonadism ($184.98 total), and 2 patients received 2 prescriptions each of tretinoin for acne vulgaris ($171.94 and $101.03 total).

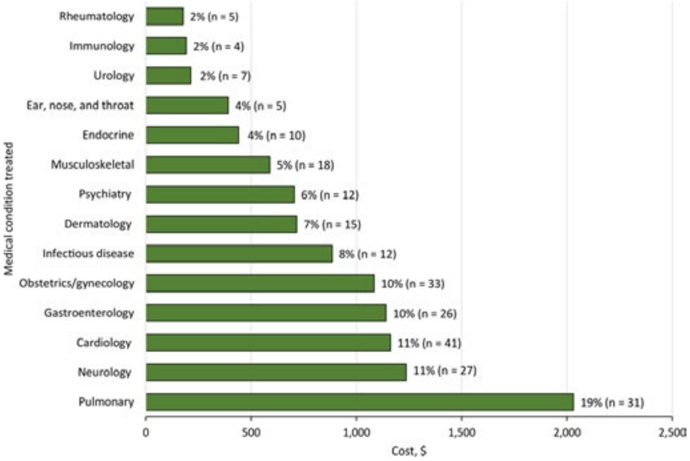

Figure 2. The costs of the 246 expensive prescriptions by type of medical condition treated, Haven Free Clinic, New Haven, Connecticut, March 2021–March 2023. At the top of each bar, the percentage indicates the percentage of the total costs of the expensive medications ($10,967.78) during the study period, and the n's indicate the number of prescriptions. An expensive medication was defined as one that cost more than $20.

Discussion

Our study is among the first to describe the financial burden of prescription medications among people without health insurance at a student-run free clinic. Our patient population lives well below the federal poverty level: the median individual annual income was $11,350 and the median annual household income was $14,400, whereas the Connecticut federal poverty level thresholds in 2023 were $14,580, $19,720, and $24,860 for a 1-, 2-, and 3-

member household, respectively (22). Some common conditions, such as type 2 diabetes and hypertension, can usually be treated with low-cost first-line agents. However, our study showed that other conditions require costly treatments, namely hyperlipidemia, treated with a daily statin for the patient's lifetime; chronic asthma, treated indefinitely with inhalers; and contraceptive management, requiring oral or injected contraceptive medication for years. The pattern in the most common comorbidities of our patient population is similar to the pattern found in a 2019 cross-sectional study of patients (n = 150) at 2 community health centers in Georgia: endocrine and metabolic disorders (86.0% vs 64.3% in our study), circulatory system diseases (79.3% vs 48.8% in our study), and mental disorders (25.3% vs 20.9% in our study) (1).

Our patients' location of residence also validates existing literature on neighborhood-based disparities in medical access. One 2012 study described a lack of community pharmacies in low-income communities, segregated Black communities, and federally designated Medically Underserved Areas in Chicago (23). Another 2012 study found that pharmacies in low-income neighborhoods in New York City had significantly higher odds of having out-of-stock medications than pharmacies in higher-income neighborhoods (odds ratio = 1.24; 95% CI, 1.02–1.52) (24). A third study, in 2015, found increased medication prices and decreased access to home delivery services in socioeconomically disadvantaged neighborhoods in Tennessee (25). In our contemporary study, we observed a similar lack of accessible pharmacies in the low-income neighborhoods where our patients reside. As hundreds of retail pharmacies nationwide closed in 2023 due to increasing competition, opioid lawsuits, and other forces, pharmacy deserts are likely to increase in number (26).

Health insurance would help our patients receive partial or full coverage for prescription medications. However, in our patient population, many cannot afford private health insurance, many are not provided health insurance by their employers, and many do not qualify for low-income health insurance through Husky Health (Connecticut's Medicaid). These factors account for the health insurance coverage gap described in the literature (27). We speculate that some patients at Haven — with no insurance, low health literacy, and language barriers (87% of our patients speak primarily Spanish) — may never obtain their medications or resort to paying retail price.

Haven's policy is to provide every patient with the medication they need while doing its best to keep within an annual pharmacy budget of $10,000. To accomplish this goal, Haven seeks financial support from external programs to cover medication costs for patients at retail pharmacies. In particular, during the study period, the clinic received a 1-time $2,500 donation and up to $2,100 in monthly cash aid debit cards from the GoodRx Helps Medication Assistance Program (28). These funds were distributed directly to patients for medication purchases.

The clinic also applied to patient assistance programs on behalf of patients, such as the program administered by the Boehringer Ingelheim Cares Foundation (29) that provides free sodium-glucose cotransporter-2 inhibitors to patients with type 2 diabetes, and the program administered by the US Department of Health and Human Services that provides free access to daily oral HIV pre-exposure prophylaxis medication for people at risk of acquiring HIV. Although three 120-day rifampin medications (4-month rifampin monotherapy) were prescribed and paid for at $128.94 each during our study period, the Connecticut Department of Public Health now provides rifampin at no cost through a tuberculosis control program it implemented (30). In 2022 and 2023, Haven treated at least 12 patients annually with rifampin for latent tuberculosis through this program.

Because of the positive effect of patient assistance programs on medication access and affordability, Haven identified a list of patient assistance programs in which patients can be enrolled. The most frequently prescribed expensive medication in our study — fluticasone propionate/salmeterol (an inhaler prescribed to treat asthma) — was offered by GSK's prescription assistance program as Advair Diskus/HFA. However, this program was not widely used by Haven's patients because they often needed medication urgently and could not wait for program approval, which often took longer than anticipated and sometimes ended with a rejection or request for further documentation. Another common reason for not using GSK's program was that patients preferred a newer inhaler with the same ingredients — AirDuo RespiClick. An additional hurdle associated with prescription assistance programs is that they often discontinue medications without much advance notice. For example, in summer 2023, GSK removed Advair Diskus/HFA from the list of medications available in its program (31), and AstraZeneca announced that Pulmicort Flexhaler (budesonide) and Symbicort (budesonide/formoterol) — also inhalers to treat asthma — would be phased out by the end of 2023 (32).

Currently, only 1 retail pharmacy in the New Haven area accepts payment over the telephone from the Haven pharmacy, which is likely the reason it is the most common pharmacy used by Haven's patients. Paying for medications over the telephone on behalf of patients increases the speed, convenience, and likelihood of patients obtaining their prescription medication. Retail pharmacies offer some of the most affordable medication prices; however, some patients lack transportation to go to one of these pharmacies. Many pharmacies have declined accepting telephone payments because of company policy and to prevent fraud, but expanding the number of pharmacies where third parties can pay for patient medications via telephone would increase the options Haven can provide to patients to alleviate their financial burden. Additionally, expanding Haven's options to deliver medications directly to patient homes would benefit patients. So far, these home delivery services have not been widely used at Haven because these medications tend to be more expensive and delivery can take 7 to 10 business days. Furthermore, not all of Haven's patients have an address where they can receive mailed medications securely.

Limitations

Our study has several limitations. First, our study is a single-center retrospective review and should be followed by a multicenter study that spans multiple states to capture data on differences in financial burden related to Medicaid expansion. Second, our study did not account for internal decisions made by health care providers to choose less expensive, alternative medications due to price, such as prescribing an AirDuo RespiClick (fluticasone propionate/salmeterol) asthma inhaler over the more expensive Pulmicort Flexhaler (budesonide) inhaler. Thus, the financial and medical effect of these decisions on patients may be greater than captured in our study. Lastly, our database did not include information on the use of prescription assistance programs and the associated cost savings. The Haven pharmacy department hopes to incorporate this into its future workflow.

Conclusion

This study from the Haven free clinic demonstrates that patients without health insurance have a financial burden resulting from having to buy prescription medications for common chronic medical conditions, including hyperlipidemia and asthma. Although Haven is often able to provide patients with affordable treatment through the efforts of 24 student volunteers and codirectors who research and apply for medication assistance programs, seek the lowest-priced options, and many times even deliver medications to patients' homes, student-run clinics cannot be easily scaled to all 7.7 million uninsured people in the US (33). Future research should seek ways to make medications, especially medications considered expensive (>$20), affordable. Removing financial barriers would improve medication adherence among patients that lack health insurance and may contribute to improved overall health.

Acknowledgments

Krupa Hegde, Lucy Reid, and Ryan Shi contributed equally to this study. The authors received no external financial support for the research, authorship, or publication of this article. The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article. No copyrighted materials, surveys, instruments, or tools were used.

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Tables

Table 1. Baseline Characteristics of 129 Patients and Their 263 Medical Diagnoses for Which Expensive Medications[a] Were Prescribed at Haven Free Clinic, New Haven, Connecticut, March 2021–March 2023[b]

Characteristic	Value
Age, mean (SD), y	45.0 (12.3)
Female, no./total (%)[c]	82/127 (65)
Hispanic or Latino, no./total (%)	112/129 (87)
Employed, no./total (%)[d]	65/108 (60)
Annual income, median (IQR), $[d]	
Individual	11,350 (0–19,200)
Household	14,400 (0–24,000)
Neighborhood residence in New Haven (n = 77), no. (%)[e]	
Fair Haven	35 (45)
Hill	13 (17)
Annex	8 (10)
Fair Haven Heights	5 (6)
Newhallville	4 (5)
East Rock	3 (4)
Edgewood	3 (4)
Quinnipiac Meadows	2 (3)
Prospect Hill	1 (1)
Downtown	1 (1)
Wooster Square/Mill River	1 (1)
Top 10 ICD-10-CM diagnoses, no. (%)[f]	
Encounter for contraceptive management, unspecified (Z30.9)	24 (9)
Hyperlipidemia, unspecified (E78.5)	21 (8)
Unspecified asthma, uncomplicated (J45.909)	21 (8)
Primary hypertension (I10)	13 (5)
Gastresophageal reflux disease without esophagitis (K21.9)	7 (3)
Migraine with aura and without status migrainosus, not intractable (G43.109)	6 (2)

Abbreviation: ICD-10-CM, *International Classification of Diseases, 10th Revision, Clinical Modification*.

[a] Expensive medication was defined as >$20 per prescription.

[b] Data source: patient electronic medical records.

[c] Denominator excludes 2 patients who identified as transgender female.

[d] Data on employment and income were available for only 108 patients.

[e] Excludes 52 patients whose residence could not be confirmed during the study period.

[f] Denominator is the number of unique diagnoses (n = 263) for which 246 expensive medications were prescribed. A patient's electronic medical record sometimes listed 2 related ICD-10-CM code diagnoses (20) for which the same medication was prescribed. One example is seasonal allergies (J30.2) and mild intermittent asthma with acute exacerbation (J45.21) for a $29.82 montelukast prescription.

[g] Denominator is the number of patients (n = 129). Comorbidities are all medical conditions other than the diagnosis for the condition that called for a prescription for an expensive medication.

[h] Patients who had diabetes and required insulin were excluded from analysis.

(continued on next page)

(continued)

Table 1. Baseline Characteristics of 129 Patients and Their 263 Medical Diagnoses for Which Expensive Medications[a] Were Prescribed at Haven Free Clinic, New Haven, Connecticut, March 2021–March 2023[b]

Characteristic	Value
H. pylori infection (B96.81)	5 (2)
Migraine without aura, not intractable, without status migrainosus (G43.009)	5 (2)
Other chronic pain (G89.29)	5 (2)
Acne vulgaris (L70.0)	5 (2)
Top 10 comorbidities, no. (%)[g]	
Hyperlipidemia	46 (36)
Hypertension	42 (33)
Obesity	25 (19)
Type 2 diabetes[h]	22 (17)
Migraine or headache	20 (16)
Gastresophageal reflux disease	18 (14)
Depression	17 (13)
Hypothyroidism	14 (11)
Latent tuberculosis	14 (11)
Anemia	10 (8)

Abbreviation: ICD-10-CM, *International Classification of Diseases, 10th Revision, Clinical Modification*.

[a] Expensive medication was defined as >$20 per prescription.

[b] Data source: patient electronic medical records.

[c] Denominator excludes 2 patients who identified as transgender female.

[d] Data on employment and income were available for only 108 patients.

[e] Excludes 52 patients whose residence could not be confirmed during the study period.

[f] Denominator is the number of unique diagnoses (n = 263) for which 246 expensive medications were prescribed. A patient's electronic medical record sometimes listed 2 related ICD-10-CM code diagnoses (20) for which the same medication was prescribed. One example is seasonal allergies (J30.2) and mild intermittent asthma with acute exacerbation (J45.21) for a $29.82 montelukast prescription.

[g] Denominator is the number of patients (n = 129). Comorbidities are all medical conditions other than the diagnosis for the condition that called for a prescription for an expensive medication.

[h] Patients who had diabetes and required insulin were excluded from analysis.

Table 2. Characteristics of 113 Expensive Medications[a] Prescribed at Haven Free Clinic, New Haven, Connecticut, March 2021–March 2023[b]

Characteristic	Value
Route of administration, no./113 (%)	
Oral	80 (71)
Topical	15 (13)
Intramuscular	7 (6)
Inhalation	6 (5)
Otic	2 (2)
Suppository	1 (1)
Ophthalmic	1 (1)
Vaginal	1 (1)
Price per prescription, regardless of filled amount (n = 246), median (IQR), $[a]	31.43 (24.00–52.02)
Type of pharmacy, no./113 (%)	
Retail	93 (82)
Mail order	9 (8)
Retail and mail order	5 (4)
Retail and hospital	4 (4)
Hospital	1 (1)
Retail, mail order, and hospital	1 (1)
Top 10 most commonly prescribed medications, no./246 (%)[c]	
Fluticasone propionate/salmeterol (AirDuo RespiClick)	14 (6)
Medroxyprogesterone acetate (Depo-Provera)	14 (6)
Albuterol sulfate (Proventil HFA)	12 (5)
Rosuvastatin (Crestor)	12 (5)
Sumatriptan (Imigran, Migraitan)	10 (4)
Estradiol (Estrace)	7 (3)
Atorvastatin (Lipitor)	5 (2)
Tamsulosin (Flomax)	5 (2)
Tretinoin (Altreno, Atralin, Avita, Retin-A)	4 (2)
Duloxetine (Cymbalta, Yentreve)	4 (2)

[a] Expensive medication was defined as >$20 per prescription.
[b] Data sources: patient electronic medical records and GoodRx (price per prescription).
[c] Includes multiple prescriptions of the same 113 unique expensive medications.

Table 3. The Top 10 Most Common Expensive[a] Medications Prescribed to Haven Free Clinic Patients, New Haven, Connecticut, March 2021–March 2023[b]

Generic name	Brand name	No. of patients	Medication count per patient	Price paid, range, $[c]	Mean price, $	Dose	Route	Pharmacy type	Quantity
Fluticasone propionate and salmeterol	AirDuo RespiClick	7	2.0	31.38–135.00	80.80	55–14, 113–14, and 232–14 μg per actuation	Inhaler	Retail	0.45 g
Medroxyprogesterone acetate	Depo-Provera	11	1.3	23.70–36.24	30.38	150 mg/mL	Intramuscular	Retail	1 mL
Albuterol sulfate	Proventil HFA	8	1.5	20.01–64.80	29.08	90 μg per actuation	Inhaler	Retail	6.7–8.5 g
Rosuvastatin	Crestor	6	2.0	21.00–33.14	27.97	5–40 mg	Oral	Retail and hospital	60–180 pills
Sumatriptan	Imigran, Migraitan	7	1.4	21.74–77.36	40.75	50–100 mg	Oral	Retail and mail order	30–90 pills
Estradiol	Estrace	6	1.2	22.00–48.42	30.58	0.01%	Topical	Retail	42.5 g
Atorvastatin	Lipitor	5	1.0	21.26–38.00	31.79	10–40 mg	Oral	Retail and mail order	90–180 pills
Tamsulosin	Flomax	3	1.7	22.84–40.31	31.56	0.4–0.8 mg	Oral	Retail and mail order	90–180 pills
Tretinoin	Altreno, Atralin, Avita, Retin-A	2	2.5	44.22–85.97	71.79	0.010%–0.025%	Topical	Retail	45 g
Duloxetine	Cymbalta, Yentreve	4	1.0	20.98–134.40	49.65	20–60 mg	Oral	Retail, mail order, and hospital	60–90 pills

[a] Expensive medication defined as >$20 per prescription.
[b] Data sources: patient electronic medical records and GoodRx (price per prescription).
[c] After applying GoodRx coupon discount at local pharmacies.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E19 MARCH 2024

ORIGINAL RESEARCH

Associations of Increased WIC Benefits for Fruits and Vegetables With Food Security and Satisfaction by Race and Ethnicity

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Accessible Version: www.cdc.gov/pcd/issues/2024/23_0288.htm

Suggested citation for this article: Tsai MM, Anderson CE, Whaley SE, Yepez CE, Ritchie LD, Au LE. Associations of Increased WIC Benefits for Fruits and Vegetables With Food Security and Satisfaction by Race and Ethnicity. Prev Chronic Dis 2024;21:230288. DOI: https://doi.org/10.5888/pcd21.230288.

PEER REVIEWED

Summary

What is already known on this topic?

Racial and ethnic disparities in food access and dietary intake persist. The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) serves a racially and ethnically diverse population with low income. Trends related to the augmented cash value benefit (CVB) have not been assessed among racial and ethnic groups.

What is added by this report?

Racial and ethnic groups experienced improvements in food security, satisfaction with CVB amounts, and likelihood to continue receiving WIC but differed in baseline levels and magnitude of increases. Results highlight the importance of studying WIC participants by racial and ethnic groups to optimize program quality.

What are the implications for public health practice?

Benefits reported among diverse WIC participants support policies to make the augmented CVB permanent.

Abstract

Introduction

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides nutrition support for racially and ethnically diverse populations. In 2021, the monthly cash value benefit (CVB) for the purchase of fruits and vegetables increased from $9 to $35 and was later adjusted to $24. This study investigated, by racial and ethnic groups, whether CVB increases were associated with increases in CVB redemption, household food security, child fruit and vegetable intake, satisfaction with CVB amount, and likelihood of continued participation in WIC if the CVB returned to $9 per month.

Methods

We conducted a longitudinal study of WIC participants (N = 1,770) in southern California at 3 time points, from April 2021 through May 2022; the CVB amount was $9 at baseline, $35 at Survey 2, and $24 at Survey 3. Racial and ethnic groups were Hispanic English-speakers, Hispanic Spanish-speakers, non-Hispanic Asian, non-Hispanic Black, non-Hispanic Other, and non-Hispanic White. We used mixed-effect and modified Poisson regressions to evaluate outcomes by group.

Results

At baseline, groups differed significantly in dollars of CVB redeemed, percentage of CVB redeemed, household food security, and satisfaction with CVB amount. After the increase in CVB, we found increases in all groups in CVB redemption, household food security, and satisfaction. Non-Hispanic Black and Hispanic English-speaking groups, who had low levels of satisfaction at baseline, had larger increases in satisfaction than other groups. Reported likelihood of continued WIC participation if the monthly CVB returned to $9 also differed significantly by group, ranging from 62.5% to 90.0%.

Conclusion

The increase in CVB for children receiving WIC benefited all racial and ethnic groups. Continued investment in an augmented CVB could improve health outcomes for a racially and ethnically diverse WIC population.

Introduction

The federally funded Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides nutritious food, nutrition education, breastfeeding support, and referrals to health and social services for infants, children, and pregnant and postpartum women from households with low income (1). The program serves a racially and ethnically diverse population: in 2018, 59% self-reported race as White, 22% as Black or African American, 9% as American Indian or Alaska Native, 6% as 2 or more races, 4% as Asian, and 1% as Native Hawaiian or Pacific Islander; 41% self-reported ethnicity as Hispanic (2).

The COVID-19 pandemic exacerbated racial and ethnic disparities in health and decreased household food security among households with children (3–5). In response, through the American Rescue Plan Act of 2021, the US Department of Agriculture temporarily increased the cash value benefit (CVB) for fruits and vegetables in the WIC food package for children aged 1 to 4 years from $9 per month per child to $35 per month per child from June through September 2021 (6,7). In October 2021, the CVB augmentation was extended and adjusted to $24 per month; in October 2022, it was further revised to $25 per month (8,9). Studies reported increases in fruit and vegetable intake, household food security, and satisfaction with the CVB amount after the CVB augmentation (10–14); however, no studies have assessed trends by race and ethnicity. Given the diverse racial and ethnic make-up of WIC participants and previously reported differences in the association between WIC program elements and outcomes among racial and ethnic groups, examining potential differences in outcomes across groups is an important consideration for program effectiveness (15–18).

The CVB for fruits and vegetables is a unique component of WIC food packages in that it maximizes flexibility in choices and allows for the food preferences of the many cultural, racial, and ethnic groups served (19). Fruit and vegetable consumption among US children falls below the recommendations of the *Dietary Guidelines for Americans, 2020–2025*, particularly among children from low-income households (20–22). Adherence to the dietary guidelines can reduce the risk of heart disease, diabetes, and obesity; these diet-related health conditions disproportionately affect racial and ethnic minority populations (21,23). An augmented CVB can reduce racial and ethnic disparities in health by increasing access to fruits and vegetables and program participation, through increased program appeal and cultural accessibility (19). Furthermore, differences in intake of fruits and vegetables, preferences for components of the WIC food package, and satisfaction with WIC services among racial and ethnic groups receiving WIC (15–18) support the need for evaluating the CVB augmentation by group. For example, a 2019 survey in California found that while the most common motivation across racial and ethnic groups for WIC participation was the fruit and vegetable component, Hispanic Spanish-speakers were more likely than other racial and ethnic groups to be satisfied with the CVB amount (16,17). The objective of this study was to investigate, by racial and ethnic group, whether the CVB augmentation was associated with increases in CVB redemption, household food security, fruit and vegetable intake, and satisfaction in CVB amounts in a racially and ethnically diverse sample of children in California receiving WIC.

Methods

The study team conducted a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1 [baseline], April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022). The survey population was selected to ensure that the sample included broad representation of the racially and ethnically diverse WIC population. Further detail on the 3 surveys is available elsewhere (10).

Participants and recruitment

We selected all caregivers with age-eligible children from WIC administrative records and notified them about the survey by SMS message. Up to 6 follow-up texts were sent. Survey 2 and Survey 3 were limited to participants of the baseline survey to facilitate assessment of changes in outcomes. We entered Survey 2 and Survey 3 participants into a raffle for $50 gift cards; 20 winners were chosen at random for each survey. At the end of each survey, participants were asked for their consent to use their responses for research. The California Department of Health and Human Services Institutional Review Board approved the study.

Instruments

Surveys were administered online in English or Spanish. To capture data on household composition and size, the survey assessed the number of children in the household receiving WIC and whether the household had children aged <18 years. The survey examined household food security, fruit and vegetable intake, satisfaction with the CVB amount, likelihood of continuing to participate in WIC, and change in amount and variety of fruits and vegetables consumed. Questions were written in English, translated into Spanish by native Spanish speakers, piloted, and revised accordingly. For each child receiving WIC, respondents reported the first 2 letters of the child's name and their sex, year of birth, and fruit and vegetable intake. We determined CVB redemption amounts and percentage by examining data from electronic benefit transfer card transactions.

We collected self-reported data on respondent race, ethnicity, and maternal language preference from WIC administrative data. Race categories were Asian (including Indian, Cambodian, Chinese, Filipino, Hmong, Japanese, Korean, Laotian, Vietnamese, Thai), Black (including Black or African American), White, and Other (including multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native). Ethnicity included Hispanic and non-Hispanic. We combined race, ethnicity, and language into the following categories: Hispanic English-speaking, Hispanic Spanish-speaking, non-Hispanic Asian, non-Hispanic Black, non-Hispanic Other, and non-Hispanic White. We conducted separate analyses of Hispanic groups by language because English-speaking and Spanish-speaking Hispanic participants have different levels of fruit and vegetable intake and satisfaction with WIC (18,24).

Outcome variables

Redemption of CVB. We assessed monthly CVB redemption by household in 2 ways: as a dollar amount of allotment redeemed and as percentage of total allotment redeemed. Data on redemption are captured at the household level, so households with multiple WIC participants receive higher CVB amounts than households with a single WIC participant. Redemption from May 2021, Sept 2021, and May 2022 align with Survey 1, Survey 2, and Survey 3, respectively.

Household food security. Household food security at each time point was assessed by using the US Department of Agriculture's 6-item Food Security Survey Module (25). The tool is designed to capture household food security status during the previous 30 days at the household level; we dichotomized responses as food secure or food insecure according to protocol.

Fruit and vegetable intake of child. Fruit and vegetable intake during the previous 30 days was assessed for each child receiving WIC, at each time point, by using the National Health and Nutrition Examination Survey Dietary Screener Questionnaire (26), a validated tool to measure dietary intake among US populations. Scoring algorithms converted responses to estimated quantities of fruit and vegetable intake (in cups per day), based on age- and sex-specific 24-hour dietary recall (27). We calculated total fruit and vegetable, including legumes, fried potatoes, and 100% juice.

Satisfaction with CVB amount. Respondents were asked, "What do you think about the [$9, $35, or $24] amount for fruits and vegetables for children ages 1 through 4 on WIC? Would you say it is [too much, not enough, just right, don't know]?" This question was adapted from a previous survey (24). We dichotomized these answers into satisfied (too much, just right) and not satisfied (not enough). We excluded from analyses responses of "don't know" (<5% of responses).

Changes in amount and variety of fruit and vegetable intake. Only Survey 3 assessed these outcomes. Respondents were asked, "Has the increase in the fruit and vegetable benefit changed the VARIETY or NUMBER of DIFFERENT TYPES of fruits your child eats?" and "Has the increase in fruit and vegetable benefit changed the AMOUNT of fruits your child eats?" Questions for vegetables followed the same format. Because some respondents had multiple children receiving WIC, questions were asked in reference to their eldest child receiving WIC. Respondents reported whether their child ate more, the same, or less variety and a greater, the same, or a lesser amount. Another response option was "don't know/not sure." We dichotomized responses into increased variety or amount and did not increase variety or amount. We excluded from analysis responses of "don't know/not sure" (<3% of responses). Questions were adapted from a previous WIC survey (28).

Likelihood of continuing WIC. Survey 3 respondents were asked, "If the amount you receive for fruits and vegetables went back to $9 instead of $24 per month, how likely are you to keep coming to WIC for your children between age 1-4?" Answer options were "very likely," "somewhat likely," "somewhat unlikely," and "not very likely." We dichotomized responses into likely (very likely, somewhat likely) and unlikely (somewhat unlikely, not very likely).

Data analysis

We identified and matched individual children across surveys at each time point by using the first 2 letters of their name, their sex, and birth year. We limited the analytic sample to children with at least 1 follow-up survey completed and analyzed these data at the child level. We calculated descriptive statistics for baseline demographic characteristics for the full sample and for each racial and ethnic group. We used analysis-of-variance F tests and χ^2 tests of independence to test for demographic differences between groups.

We assessed the dichotomous variables of household food security and satisfaction with CVB amount by using generalized estimating equation (GEE) modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families (29). We adjusted models for number of children receiving WIC in the household and the presence of 3 or more children (aged <18 y) in the household. We evaluated continuous outcomes (CVB redemption dollar amount, CVB redemption percentage, and child fruit and vegetable intake) in mixed-effects regression models accommodating repeated observations of individual children and clustering within families, and adjusted for number of children receiving WIC in the household and presence of 3 or more children (aged <18 y) in the household. The model with child fruit and vegetable intake as the outcome also adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

We assessed results by racial and ethnic group in 3 ways. First, we stratified data by group and calculated descriptive statistics on the outcomes of interest at each time point. We tested differences between average values of each outcome between time points separately by group to evaluate within-group trends. If the overall *P* value for differences over time was significant at a .05 level, we assessed pairwise comparisons. Second, we tested whether a racial or ethnic group modified the effect of time on average values of outcomes by including an interaction between group and time point in regression models. Baseline data served as the reference point. We expressed estimates for dichotomous outcomes as prevalence rate ratios (PRRs) and 95% CIs and estimates for continuous outcomes as mean differences and 95% CIs. Finally, we assessed between-group differences in outcomes at each time point, using Hispanic English-speakers as the reference; we expressed dichotomous outcomes as PRRs and 95% CIs and continuous outcomes as mean differences and 95% CIs. If the overall *P* value for differences by racial and ethnic group was significant at a .05 level, we assessed pairwise comparisons.

For the questions in Survey 3 about changes in amount and variety of fruit and vegetable intake and likelihood of continuing with WIC if the CVB amount returned to $9 per month, we assessed differences by racial and ethnic group by using GEE-modified Poisson regression models with robust SE estimation, accommodating clustering within families, adjusted for number of children receiving WIC in the household and presence of 3 or more children (aged <18 y) in the household. If the overall *P* value for differences by racial and ethnic group was significant at a .05 level, we assessed pairwise comparisons. We conducted all analyses in SAS version 9.4 (SAS Institute Inc). All statistical tests were 2-sided, and *P* < .05 was considered significant.

Results

Surveys were completed for a total of 3,000 children from 2,784 families at baseline (30% response rate). The analytic sample consisted of 1,770 children (1,578 households) with at least 1 follow-up survey completed (59% of baseline sample). Nearly half of the analytic sample were girls; mean age at Survey 1 was 2.8 years (Table 1). The largest group was Hispanic English-speakers, followed by Hispanic Spanish-speakers. The average number of children in the household aged 1 to 4 years receiving WIC was 1.3 and approximately one-third of households (35%) had 3 or more children (aged <18 y). The number of children in the household receiving WIC and number of households with 3 or more children differed across racial and ethnic groups.

CVB redemption dollar amount and percentage

The mean dollar amount of CVB redeemed at baseline ranged from $11.05 among non-Hispanic Asians to $14.61 among non-Hispanic Others (Table 2). The dollar amount of CVB redeemed changed among all racial and ethnic groups between time points, with the lowest redemption amount at Survey 1 and highest redemption amount at Survey 2. We found no effect modification by group on the change in the dollar amounts redeemed over time (Table 3). At Survey 1 and Survey 2, Hispanic English- and Spanish-speakers redeemed higher dollar amounts than other groups; we found no significant differences between groups at Survey 3 (Table 4).

Percentage of CVB redeemed at baseline ranged from 77.0% among non-Hispanic Black respondents to 92.0% among non-Hispanic Asian respondents. We found no significant change in redemption rates for any group throughout the study period (Table 2). However, percentage of CVB redeemed consistently differed between groups (Table 4). Hispanic Spanish-speakers had higher redemption rates than several other groups at all time points.

Household food security

The prevalence of household food security ranged from 33.3% among White respondents to 48.9% among Hispanic English-speakers (Table 2). Household food security improved from baseline for several groups at Survey 2 and Survey 3, including Hispanic English-speaking, Hispanic Spanish-speaking, and non-Hispanic Black groups. Race and ethnicity was not an effect modifier for change in household food security over time (Table 3). The prevalence of household food security differed significantly between groups at all 3 time points (Table 4). Non-Hispanic Black households had a lower prevalence than Hispanic English-speaking households at all 3 time points, and Hispanic Spanish-speakers and non-Hispanic Other households had a lower prevalence than Hispanic English-speaking households at Survey 2.

Child fruit and vegetable intake

Mean fruit and vegetable intake at baseline ranged from 2.6 cups per day among Hispanic English-speakers to 2.3 cups per day among non-Hispanic White respondents (Table 2). From baseline to Survey 3, Hispanic English-speaking and Hispanic Spanish-speaking groups reported a decrease in fruit and vegetable intake. For all other groups, we observed no significant associations across time points. Group was not an effect modifier (Table 3). For all time points, fruit and vegetable intake was not significantly different between racial and ethnic groups (Table 4).

Satisfaction with CVB amount

Baseline satisfaction with the $9 CVB ranged from 2.6% among non-Hispanic White respondents to 11.0% among Hispanic Spanish-speakers (Table 2). Satisfaction increased among all groups at both follow-up time points compared with baseline; satisfaction rates were highest in Survey 2. Changes in satisfaction differed significantly by racial and ethnic group (Table 3). At both follow-up time points, increases in satisfaction were larger among Hispanic English-speakers and non-Hispanic Black respondents than among Hispanic Spanish-speakers and the non-Hispanic Other group, who started with higher baseline values. At baseline, satisfaction was higher among Hispanic Spanish-speakers (PRR = 1.92, 95% CI, 1.32–2.79) and the non-Hispanic Other group (PRR = 1.87; 95% CI, 1.03–3.40) than among Hispanic English-speakers (Table 4). At Survey 2, satisfaction rates among Hispanic English-speaking and non-Hispanic Black groups (PRR = 1.01; 95% CI, 0.92–1.10) surpassed the rate among Hispanic Spanish-speakers (PRR = 0.91; 95% CI, 0.85–0.98). At Survey 3, satisfaction rates were similar across groups. Although the non-Hispanic Asian and non-Hispanic White groups were excluded from this analysis because of small sample sizes, from a descriptive standpoint, the 2 groups started with low rates of satisfaction and saw large increases, with 3.1% and 2.6% at baseline, then increasing to 66.7% and 69.2% at Survey 2, and 38.6% and 33.3% at Survey 3, respectively.

Survey 3 descriptive analyses

At Survey 3, a majority in each group reported that the variety and amount of fruits and vegetables consumed by their eldest child receiving WIC had increased from when the CVB was $9 per month (Table 5). The changes in variety of fruits and vegetables and amount of fruits consumed did not differ across groups. The change in the amount of vegetables consumed differed significantly among racial and ethnic groups; the percentage reporting an increase was significantly smaller among Hispanic English-speakers (60.1%) than among Hispanic Spanish-speakers (74.5%) and non-Hispanic Other respondents (78.7%). The likelihood of continuing with WIC if the CVB returned to $9 per month differed significantly across groups. Hispanic Spanish-speakers reported a higher likelihood of staying on the program (90.0%) than Hispanic English-speakers (75.2%), non-Hispanic Asian (62.5%), non-Hispanic Black (73.3%), and non-Hispanic Other (74.2%) respondents.

Discussion

Our study on the CVB augmentation in WIC in 2021 and 2022 identified its benefits among racial and ethnic groups. We observed the largest changes in the amount of CVB redeemed, food security, and satisfaction with the CVB amount for most groups at the $35-per-month level compared with the $9-per-month level; however, the $24-per-month benefit was associated with substantially better outcomes than the original $9 per month. Both CVB amount redeemed and household food security increased from baseline to follow-up, although disparities in household food security among non-Hispanic Black respondents persisted, indicating the need for interventions beyond CVB augmentation. Nonetheless, families faced hardships during the COVID-19 pandemic, and our study, along with other qualitative studies, demonstrated a need for increases in the CVB (14,30). Additionally, although the dollar amounts of CVB redeemed increased among all groups, we found that racial and ethnic groups varied in their percentage of CVB redeemed at each time point. Our findings were consistent with previous reports on racial and ethnic differences in WIC food package redemption, which found higher redemption percentages among Hispanic Spanish-speakers (31). While further research is needed on factors driving these differences, insufficient supply of WIC-eligible items in stores and access to WIC-approved vendors can be barriers to redemption (14). Future studies should explore how barriers and retail environments are experienced differently by racial and ethnic groups and examine their effects on CVB redemption. WIC clinics are also well positioned to provide culturally tailored nutrition counseling that features CVB-eligible items, which may influence use of CVB.

Our study also found substantial increases in satisfaction with the CVB, which differed across groups. Satisfaction is a critical indicator of retention in WIC — low satisfaction with the WIC food package is commonly cited as a reason for leaving the program (32). The substantial increases in satisfaction suggest that the augmented CVB was particularly well-received among non-Hispanic Asian, non-Hispanic Black, and non-Hispanic White respondents. These groups also reported that they would be less likely to continue with WIC if the CVB returned to $9. Taken together, our results suggest that CVB value may strongly influence the decision among people in these groups to participate in WIC. Nationally, these groups generally have lower WIC participation rates (33). Their lower participation rates may be due to perceived inadequacy of culturally appropriate foods in the WIC food package (16). Our results highlight the importance of examining the influence of the CVB on WIC participation among racial and ethnic groups and on reducing health disparities (33).

An unexpected result of our study was that fruit and vegetable intake did not increase across any racial and ethnic group. Notably, the lowest average intake among children in our sample (2.33 cups per day in the non-Hispanic White group) before CVB augmentation was higher than the average intake among all children (2.31 cups per day) in another, multistate study after CVB augmentation; participants in that study increased their intake by ⅓ cup (11). Because the recommended daily fruit and vegetable intake for WIC-aged children is approximately 2½ cups, it may be difficult to document increases in fruit and vegetable intake in a population that is already consuming relatively high levels (21). Results of a previous analysis found that children with the lowest baseline fruit and vegetable intake experienced significant increases in fruit and vegetable intake, indicating that benefits are likely reaching those with the greatest need (10). Results from Survey 3 indicated that, for most respondents, the CVB augmentation increased the variety and amount of fruits and vegetables consumed. The CVB augmentation may have allowed parents to offer a larger quantity or a wider variety of produce that included more expensive items (eg, berries in addition to apples), as supported by a study that used purchasing data from WIC participants (12,34).

Limitations

This study has several limitations. Participants were limited to English- and Spanish-speakers, and many non-Hispanic Asian and non-Hispanic White WIC participants in our study area prefer a language other than English or Spanish, limiting representativeness of the results. Among Los Angeles County WIC families in May 2021, 60% of Asian families and 20% of non-Hispanic White families preferred a language other than English or Spanish (35). The demographic characteristics of WIC participants in southern California may limit generalizability to other populations, reflected in the relatively small sample of non-Hispanic White participants. Furthermore, a small sample size in some racial and ethnic groups may have reduced our ability to detect statistical differences. Because the study sample consisted of participants who were willing to respond to texts and complete online surveys, there may be nonresponse bias, overrepresenting those with technology access. Finally, because we did not prespecify hypotheses on differences between racial and ethnic groups, our study was exploratory.

Conclusion

Augmentation of the CVB in the WIC program in 2021 and 2022 was associated with numerous benefits, including increases in redemption, food security, and satisfaction. It presents a promising strategy to increase the well-being of WIC participants in all racial and ethnic groups. In allowing participants the flexibility to select fruits and vegetables that meet their household and cultural preferences, continued investment in an augmented CVB will allow WIC to serve its diverse population and can improve health outcomes. Future research that examines differences among racial and ethnic groups in factors influencing CVB redemption, whether the augmented CVB increased the uptake and retention of WIC across groups, and how the CVB affects fruit and vegetable purchasing is needed.

Acknowledgments

The authors acknowledge Martha Meza, CLE, and Elizabeth Rodriguez, BA, CLE, from Public Health Foundation Enterprises WIC Program, Division of Research and Evaluation, City of Industry, California, for their important contributions to this work. This research was supported by Healthy Eating Research, a national program of The Robert Wood Johnson Foundation. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. No copyrighted materials were used in this article.

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Tables

Table 1. Baseline Characteristics of a Sample of Children Receiving WIC, Southern California, 2021–2022[a]

Characteristic	Total (N = 1,770)	Hispanic		Non-Hispanic			
		English-speaking (n = 798)	Spanish-speaking (n = 532)	Asian (n = 65)	Black (n = 222)	White (n = 39)	Other[b] (n = 114)
Age of child, mean (SD), y	2.8 (1.1)	2.7 (1.1)	2.9 (1.1)	2.8 (1.2)	2.8 (1.0)	2.6 (1.2)	2.7 (1.1)
Female child, no. (%)	832 (47.0)	363 (45.5)	253 (47.6)	33 (50.8)	108 (48.7)	18 (46.2)	57 (50.0)
No. of children aged 1–4 y in household currently receiving WIC, mean (SD)	1.3 (0.5)	1.3 (0.5)	1.2 (0.5)	1.2 (0.4)	1.3 (0.6)	1.5 (0.6)	1.4 (0.7)
≥3 Children in household (aged <18 y), no. (%)	618 (35.0)	268 (33.7)	226 (42.6)	14 (21.5)	56 (25.2)	9 (23.1)	45 (39.8)

Abbreviation: WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Values may not add to total because of survey nonresponse.

[b] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

Table 2. Outcomes at Each Time Point Among a Sample of Children Participating in WIC, by Race and Ethnicity, Southern California, 2021–2022[a]

Item	Survey 1 (n = 1,770)	Survey 2 (n = 1,458)	Survey 3 (n = 927)	*P* value
CVB redemption amount, mean (SD), US dollars[b]				
Hispanic English-speaking	12.52 (5.59)[c]	44.84 (19.69)[d]	33.98 (19.49)[d]	<.001
Hispanic Spanish-speaking	12.18 (5.57)[c]	43.74 (18.41)[d]	33.42 (17.73)[d]	<.001
Non-Hispanic Asian	11.05 (4.71)[c]	42.74 (18.51)[d]	29.24 (12.39)[d]	<.001
Non-Hispanic Black	11.36 (5.43)[c]	40.13 (20.02)[d]	29.77 (16.03)[d]	<.001
Non-Hispanic White	14.46 (5.58)	48.76 (20.62)[d]	33.37 (18.79)[d]	<.001
Non-Hispanic Other[e]	14.61 (7.62)[c]	48.36 (26.16)[d]	40.72 (24.10)[d]	<.001
Percentage of total CVB allotment that was redeemed, mean (SD)[b,f]				
Hispanic English-speaking	86.5 (31.6)	83.6 (28.6)	87.0 (29.2)	.09
Hispanic Spanish-speaking	90.7 (26.6)	90.7 (22.0)	94.1 (18.9)	.07
Non-Hispanic Asian	92.0 (21.4)	85.9 (28.3)	88.5 (28.2)	.17
Non-Hispanic Black	77.0 (39.2)	72.6 (37.2)	84.2 (30.3)	.09
Non-Hispanic White	87.6 (28.0)	85.0 (28.2)	82.2 (36.7)	.23
Non-Hispanic Other[e]	81.8 (35.1)	83.5 (25.5)	78.9 (33.8)	.91
Household reported being food secure, no. (%)[g,h]				
Hispanic English-speaking	390 (48.9)[c]	409 (62.8)[d]	235 (57.6)[d]	<.001
Hispanic Spanish-speaking	234 (44.0)[c]	229 (51.1)[d]	153 (50.8)[c]	.002
Non-Hispanic Asian	31 (47.7)	30 (54.6)	19 (59.4)	.24
Non-Hispanic Black	86 (38.7)[c]	93 (51.4)[d]	43 (41.0)[c]	.001
Non-Hispanic White	13 (33.3)	18 (56.3)	8 (42.1)	.07
Non-Hispanic Other[e]	48 (42.1)	46 (50.6)	28 (45.2)	.26
Fruit and vegetable intake, mean (SD), cups per day[b,i]				
Hispanic English-speaking	2.6 (1.0)[c]	2.5 (0.9)[d]	2.5 (0.8)[d]	<.001
Hispanic Spanish-speaking	2.4 (0.8)[c]	2.4 (0.8)[c]	2.2 (0.8)[d]	.01

Abbreviations: CVB, cash value benefit; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Values may not add to total because of survey nonresponse.

[b] Differences in continuous outcomes (CVB redemption amount, CVB redemption percentage, and fruit and vegetable intake) were evaluated in mixed effects regression models accommodating repeated observations of individual children and clustering within families and adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[c,d] Values sharing a common superscripted letter are not significantly different from each other in pairwise comparisons that use a .05 level of significance.

[e] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[f] Redemption data were assessed at the household level. Households with multiple WIC participants receive higher CVB amounts than households with a single WIC child, so means at each time point exceed $9 (Survey 1), $35 (Survey 2), $24 (Survey 3).

[g] Responses to question on food security were dichotomized as food secure or food insecure.

[h] Differences in dichotomous outcomes (household food security and satisfaction with CVB amount) were evaluated in generalized estimating equation modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[i] The model with fruit and vegetable intake was additionally adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

[j] Responses were dichotomized into satisfied (too much, just right) and not satisfied (not enough).

[k] Statistical testing for differences in satisfaction with CVB amount among Asian and White groups did not meet required regression assumptions and were not conducted.

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(continued)

Table 2. Outcomes at Each Time Point Among a Sample of Children Participating in WIC, by Race and Ethnicity, Southern California, 2021–2022[a]

Item	Survey 1 (n = 1,770)	Survey 2 (n = 1,458)	Survey 3 (n = 927)	*P* value
Non-Hispanic Asian	2.4 (0.6)	2.3 (0.7)	2.5 (0.7)	.34
Non-Hispanic Black	2.5 (1.0)	2.5 (1.0)	2.4 (1.0)	.39
Non-Hispanic White	2.3 (0.9)	2.4 (0.8)	2.5 (0.7)	.67
Non-Hispanic Other[e]	2.4 (0.9)	2.6 (0.9)	2.4 (0.9)	.23
Reported satisfaction with CVB amount, no. (%)[h,j]				
Hispanic English-speaking	45 (5.8)[c]	476 (79.9)[d]	153 (42.4)[d]	<.001
Hispanic Spanish-speaking	54 (11.0)[c]	288 (72.4)[d]	111 (41.9)[d]	<.001
Non-Hispanic Asian	2 (3.1)	34 (66.7)	10 (38.5)	—[k]
Non-Hispanic Black	17 (7.8)[c]	131 (80.9)[d]	53 (56.4)[d]	<.001
Non-Hispanic White	1 (2.6)	18 (69.2)	6 (33.3)	—[k]
Non-Hispanic Other[e]	12 (10.8)[c]	55 (74.3)[d]	24 (47.1)[d]	<.001

Abbreviations: CVB, cash value benefit; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Values may not add to total because of survey nonresponse.

[b] Differences in continuous outcomes (CVB redemption amount, CVB redemption percentage, and fruit and vegetable intake) were evaluated in mixed effects regression models accommodating repeated observations of individual children and clustering within families and adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[c,d] Values sharing a common superscripted letter are not significantly different from each other in pairwise comparisons that use a .05 level of significance.

[e] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[f] Redemption data were assessed at the household level. Households with multiple WIC participants receive higher CVB amounts than households with a single WIC child, so means at each time point exceed $9 (Survey 1), $35 (Survey 2), $24 (Survey 3).

[g] Responses to question on food security were dichotomized as food secure or food insecure.

[h] Differences in dichotomous outcomes (household food security and satisfaction with CVB amount) were evaluated in generalized estimating equation modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[i] The model with fruit and vegetable intake was additionally adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

[j] Responses were dichotomized into satisfied (too much, just right) and not satisfied (not enough).

[k] Statistical testing for differences in satisfaction with CVB amount among Asian and White groups did not meet required regression assumptions and were not conducted.

Table 3. Changes in Outcomes Among a Sample of Children Participating in WIC, by Race and Ethnicity, Southern California, 2021–2022[a]

Item	Survey 1 (n = 1,770)	Survey 2 (n = 1,458)	Survey 3 (n = 927)	*P* value[b]
CVB redemption amount, difference (95% CI), US dollars[c]				
Hispanic English-speaking	0 [Reference]	32.42 (31.14 to 33.71)	21.8 (20.27 to 23.33)	.17
Hispanic Spanish-speaking	0 [Reference]	31.88 (30.35 to 33.41)	22.35 (20.59 to 24.12)	
Non-Hispanic Asian	0 [Reference]	31.37 (27.03 to 35.71)	19.10 (13.73 to 24.46)	
Non-Hispanic Black	0 [Reference]	28.41 (25.82 to 30.99)	20.38 (17.26 to 23.50)	
Non-Hispanic White	0 [Reference]	34.29 (28.55 to 40.03)	20.53 (13.43 to 27.62)	
Non-Hispanic Other[d]	0 [Reference]	34.46 (31.06 to 37.87)	25.29 (21.31 to 29.27)	
Percentage of total CVB allotment that was redemption, difference (95% CI)[c]				
Hispanic English-speaking	0 [Reference]	−2.83 (−5.38 to −0.29)	−0.46 (−3.52 to 2.60)	.33
Hispanic Spanish-speaking	0 [Reference]	−0.31 (−3.39 to 2.78)	3.05 (−0.56 to 6.65)	
Non-Hispanic Asian	0 [Reference]	−5.96 (−14.71 to 2.78)	−4.78 (−15.69 to 6.13)	
Non-Hispanic Black	0 [Reference]	−4.23 (−9.10 to 0.65)	5.19 (−0.94 to 11.32)	
Non-Hispanic White	0 [Reference]	−1.68 (−13.21 to 9.85)	−7.90 (−21.69 to 5.90)	
Non-Hispanic Other[d]	0 [Reference]	1.57 (−5.20 to 8.33)	−0.06 (−7.85 to 7.73)	
Household reported being food secure, PRR (95% CI)[e,f]				
Hispanic English-speaking	1 [Reference]	1.28 (1.20 to 1.36)	1.17 (1.08 to 1.27)	.15
Hispanic Spanish-speaking	1 [Reference]	1.16 (1.07 to 1.26)	1.12 (1.00 to 1.25)	
Non-Hispanic Asian	1 [Reference]	1.13 (0.92 to 1.39)	1.36 (0.97 to 1.90)	
Non-Hispanic Black	1 [Reference]	1.32 (1.14 to 1.53)	1.07 (0.88 to 1.30)	
Non-Hispanic White	1 [Reference]	1.69 (1.09 to 2.63)	1.42 (0.82 to 2.46)	
Non-Hispanic Other[d]	1 [Reference]	1.20 (0.96 to 1.50)	1.06 (0.83 to 1.35)	
Child fruit and vegetable intake, difference (95% CI), cups per day[c,g]				
Hispanic English-speaking	0 [Reference]	−0.08 (−0.15 to −0.02)	−0.17 (−0.25 to −0.09)	.30
Hispanic Spanish-speaking	0 [Reference]	−0.02 (−0.11 to 0.06)	−0.14 (−0.23 to −0.04)	
Non-Hispanic Asian	0 [Reference]	−0.06 (−0.29 to 0.18)	0.14 (−0.14 to 0.43)	

Abbreviations: CVB, cash value benefit; PRR, prevalence rate ratio; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Associations represent the estimated difference from the reference time point (Survey 1) for all outcomes.

[b] *P* values are for the interaction between race and ethnicity and time point.

[c] Associations for continuous outcomes (CVB redemption amount, CVB redemption percentage, and fruit and vegetable intake) were evaluated with interaction terms between race and ethnicity and time point in mixed effects regression models accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[d] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[e] Associations for dichotomous outcomes (household food security and satisfaction with CVB amount) were evaluated with interaction terms between race and ethnicity and time point in generalized estimating equation modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[f] Responses to question on food security were dichotomized as food secure or food insecure.

[g] The model with fruit and vegetable intake was additionally adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

[h] Responses were dichotomized into satisfied (too much, just right) and not satisfied (not enough). Non-Hispanic Asian and non-Hispanic White groups were excluded from this analysis due to small cell sizes.

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Table 3. Changes in Outcomes Among a Sample of Children Participating in WIC, by Race and Ethnicity, Southern California, 2021–2022[a]

Item	Survey 1 (n = 1,770)	Survey 2 (n = 1,458)	Survey 3 (n = 927)	*P* value[b]
Non-Hispanic Black	0 [Reference]	−0.05 (−0.18 to 0.08)	−0.12 (−0.28 to 0.04)	
Non-Hispanic White	0 [Reference]	0.10 (−0.21 to 0.41)	0.16 (−0.22 to 0.54)	
Non-Hispanic Other[d]	0 [Reference]	0.12 (−0.06 to 0.30)	−0.04 (−0.26 to 0.17)	
Reported satisfaction with CVB amount, PRR (95% CI)[e,h]				
Hispanic English-speaking	1 [Reference]	13.66 (10.31 to 18.11)	7.33 (5.50 to 9.78)	.002
Hispanic Spanish-speaking	1 [Reference]	6.48 (5.06 to 8.30)	3.76 (2.89 to 4.88)	
Non-Hispanic Black	1 [Reference]	10.28 (6.50 to 16.27)	7.45 (4.70 to 11.80)	
Non-Hispanic Other[d]	1 [Reference]	6.96 (4.16 to 11.66)	4.12 (2.29 to 7.44)	

Abbreviations: CVB, cash value benefit; PRR, prevalence rate ratio; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Associations represent the estimated difference from the reference time point (Survey 1) for all outcomes.

[b] *P* values are for the interaction between race and ethnicity and time point.

[c] Associations for continuous outcomes (CVB redemption amount, CVB redemption percentage, and fruit and vegetable intake) were evaluated with interaction terms between race and ethnicity and time point in mixed effects regression models accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[d] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[e] Associations for dichotomous outcomes (household food security and satisfaction with CVB amount) were evaluated with interaction terms between race and ethnicity and time point in generalized estimating equation modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[f] Responses to question on food security were dichotomized as food secure or food insecure.

[g] The model with fruit and vegetable intake was additionally adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

[h] Responses were dichotomized into satisfied (too much, just right) and not satisfied (not enough). Non-Hispanic Asian and non-Hispanic White groups were excluded from this analysis due to small cell sizes.

Table 4. Racial and Ethnic Differences in Outcomes, Stratified by Time Point, Among a Sample of Children Participating in WIC, Southern California, 2021–2022[a]

Item	Hispanic		Non-Hispanic				*P* value
	English-speaking (n = 798)	Spanish-speaking (n = 532)	Asian (n = 65)	Black (n = 222)	White (n = 39)	Other[b] (n = 114)	
CVB redemption amount, difference (95% CI), in US dollars[c]							
Survey 1	0 [Reference][d]	0.30 (−1.19 to 1.78)[d]	−0.25 (−3.58 to 3.08)[e,f]	−0.50 (−2.62 to 1.62)[g]	−1.53 (−5.85 to 2.80)[f]	0.11 (−2.61 to 2.84)[e]	.002
Survey 2	0 [Reference][f]	−0.25 (−1.85 to 1.35)[f]	−1.30 (−4.94 to 2.34)[e,g]	−4.51 (−6.80 to −2.23)[e]	0.34 (−4.38 to 5.06)[d,e]	2.15 (−0.72 to 5.03)[d,g]	.02
Survey 3	0 [Reference]	0.85 (−1.15 to 2.85)	−2.95 (−7.85 to 1.95)	−1.92 (−4.90 to 1.07)	−2.80 (−9.17 to 3.58)	3.61 (−0.02 to 7.23)	.44
Percentage of total CVB allotment that was redeemed, difference (95% CI)[c]							
Survey 1	0 [Reference][f]	4.47 (1.25 to 7.70)[e]	5.24 (−2.15 to 12.62)[d]	−9.81 (−14.20 to −5.42)[g]	0.66 (−8.73 to 10.06)[d]	−4.89 (−10.67 to 0.89)[d,g]	<.001
Survey 2	0 [Reference][e,d]	7.00 (3.50 to 10.50)[d]	2.11 (−5.84 to 10.05)[e,f]	−11.21 (−16.00 to −6.42)[g,h]	1.82 (−8.57 to 12.20)[f,g]	−0.49 (−6.81 to 5.83)[f]	<.001
Survey 3	0 [Reference][d,f]	7.98 (3.67 to 12.30)[d]	0.92 (−9.50 to 11.34)[e,f]	−4.16 (−10.48 to 2.16)[e,f]	−6.77 (−19.71 to 6.18)[e,g]	−4.49 (−12.11 to 3.13)[e,g]	.001
Household reported being food secure, PRR (95% CI)[i,j]							
Survey 1	1 [Reference][d]	0.91 (0.81 to 1.03)[d,e]	0.96 (0.74 to 1.25)[d,e]	0.78 (0.65 to 0.94)[e]	0.66 (0.42 to 1.03)[d,e]	0.86 (0.69 to 1.08)[d,e]	.03
Survey 2	1 [Reference][d]	0.83 (0.75 to 0.92)[e]	0.85 (0.67 to 1.08)[d,e]	0.81 (0.70 to 0.94)[e]	0.87 (0.64 to 1.19)[d,e]	0.81 (0.66 to 1.00)[e]	.002
Survey 3	1 [Reference][d]	0.87 (0.77 to 0.99)[d,e]	1.11 (0.84 to 1.47)[d,e]	0.71 (0.58 to 0.88)[e]	0.80 (0.49,1.29)[d,e]	0.78 (0.60 to 1.01)[d,e]	.02
Child fruit and vegetable intake, difference (95% CI), cups per day[c,k]							
Survey 1	0 [Reference]	−0.11 (−0.19 to −0.03)	−0.12 (−0.30 to 0.06)	0.01 (−0.10 to 0.11)	−0.13 (−0.36 to 0.10)	−0.08 (−0.22 to 0.06)	.14
Survey 2	0 [Reference]	−0.05 (−0.14 to 0.04)	−0.09 (−0.29 to 0.11)	0.04 (−0.08 to 0.16)	0.05 (−0.21 to 0.31)	0.12 (−0.03 to 0.28)	.22
Survey 3	0 [Reference]	−0.07 (−0.18 to 0.03)	0.19 (−0.07 to 0.45)	0.05 (−0.10 to 0.21)	0.20 (−0.14 to 0.53)	0.04 (−0.16 to 0.24)	.05
Reported satisfaction with CVB amount, PRR (95% CI)[i,l]							
Survey 1	1 [Reference][d]	1.92 (1.32 to 2.79)[e]	—[m]	1.34 (0.78 to 2.29)[d,e]	—[m]	1.87 (1.03 to 3.40)[e]	.01
Survey 2	1 [Reference][e]	0.91 (0.85 to 0.98)[d]	—[m]	1.01 (0.92 to 1.10)[e]	—[m]	0.95 (0.83 to 1.09)[d,e]	.03
Survey 3	1 [Reference]	0.98 (0.82 to 1.18)	—[m]	1.36 (1.11 to 1.67)	—[m]	1.05 (0.76 to 1.45)	.11

Abbreviations: CVB, cash value benefit; PRR, prevalence rate ratio; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). Associations represent the estimated difference from the reference group, Hispanic English-speakers, for all outcomes.

[b] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[c] Associations for continuous outcomes (CVB redemption amount, CVB redemption percentage, and fruit and vegetable intake) were evaluated in mixed effects regression models accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[d,e,f,g,h] Values sharing a common superscripted letter are not significantly different from each other in pairwise comparisons that used a .05 level of significance.

[i] Associations for dichotomous outcomes (household food security and satisfaction with CVB amount) were evaluated in generalized estimating equation modified Poisson regression models with robust standard error estimation, accommodating repeated observations of individual children and clustering within families, adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[j] Responses to question on food security were dichotomized as food secure or food insecure.

[k] The model with fruit and vegetable intake was additionally adjusted for baseline fruit and vegetable intake and child sex and included random intercepts and random slope for child age.

[l] Responses were dichotomized into satisfied (too much, just right) and not satisfied (not enough).

[m] Non-Hispanic Asian and non-Hispanic White groups were excluded from this analysis due to small cell sizes.

Table 5. Perception of Changes in Variety and Amount of Fruits and Vegetables Consumed by Child After Cash Value Benefit Was Augmented to $24 per Month, and Likelihood of Continued WIC Participation Among a Sample of Children Participating in WIC, Southern California, 2022[a]

Item	Hispanic		Non-Hispanic				P value[c]
	English-speaking (n = 408)	Spanish-speaking (n = 301)	Asian (n = 32)	Black (n = 105)	White (n = 19)	Other[b] (n = 62)	
Increased variety of fruits	337 (83.4)	256 (87.4)	29 (90.6)	86 (84.3)	18 (94.7)	53 (88.3)	.28
Increased amount of fruits	311 (77.9)	240 (83.0)	25 (80.7)	84 (82.4)	14 (73.7)	49 (81.7)	.62
Increased variety of vegetables	270 (68.5)	223 (76.4)	23 (74.2)	74 (72.6)	16 (84.2)	44 (73.3)	.21
Increased amount of vegetables	241 (60.1)[d]	216 (74.5)[e]	22 (71.0)[d,e]	71 (69.6)[d,e]	12 (63.2)[d,e]	48 (78.7)[d]	.001
Likely to come back to WIC if cash value benefit went back to $9	306 (75.2)[e]	271 (90.0)[e]	20 (62.5)[e]	77 (73.3)[e]	13 (68.4)[e]	46 (74.2)[e]	<.001

Abbreviation: WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Data source: a prospective cohort study comprising 3 survey waves of caregivers with children aged 1 to 4½ years at baseline who were receiving WIC in 7 WIC clinics in southern California at the following 3 time points: pre-augmentation at $9 per month (Survey 1, baseline, April–May 2021), during the 4-month increase to $35 per month (Survey 2, August–September 2021), and after the CVB was adjusted to $24 per month (Survey 3, April–May 2022) (10). All responses are from Survey 3. All values are number (percentage) unless indicated otherwise; total sample size may vary because of nonresponse.

[b] Includes multiple races, Fijian, Samoan, Tongan, Guamanian or Chamorro, Native Hawaiian, American Indian or Alaska Native.

[c] Differences in frequency by race and ethnicity were tested by using generalized estimating equation modified Poisson regression models with robust SE estimation, accommodating repeated observations of individual children and clustering within families adjusted for number of children receiving WIC in the household and the presence of ≥3 children (aged <18 y) in the household.

[d,e] Values sharing a common superscripted letter are not significantly different from each other in pairwise comparisons that used a .05 level of significance.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E68 SEPTEMBER 2024

ORIGINAL RESEARCH

Effect of an Inflatable Colon on Colorectal Cancer Knowledge and Screening Intent Among Male Attendees at State Fairs in Two Midwestern States, 2023

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0020.htm

Suggested citation for this article: Sedani AE, Rifelj KK, Bevel MS, McCall C, Rogalla M, Laliberte L, et al. Effect of an Inflatable Colon on Colorectal Cancer Knowledge and Screening Intent Among Male Attendees at State Fairs in Two Midwestern States, 2023. Prev Chronic Dis 2024;21:240020. DOI: https://doi.org/10.5888/pcd21.240020.

PEER REVIEWED

Summary

What is already known on this topic?

Knowledge and beliefs are factors that enable health behaviors such as participation in early-detection screening. Community education and outreach events are common approaches to fostering health-related knowledge and awareness.

What is added by this report?

Self-guided tours of an interactive, inflatable colon can be an effective and low-resource intervention to increase colorectal cancer knowledge and screening intent among men at state fairs.

What are the implications for public health practice?

State fairs and similar large recreational gatherings can reach populations who may not typically have easy access to or knowledge about cancer prevention and control services.

Abstract

Introduction

Colorectal cancer (CRC) is the third most-diagnosed cancer among men and women in the US. This study aimed to evaluate the influence of an interactive inflatable colon exhibit on CRC knowledge and screening intent among men attending state fairs in 2 midwestern states.

Methods

At the 2023 state fairs in 2 midwestern states, eligible participants (men aged 18–75 y who could speak and read English and resided in 1 of the 2 states) completed a presurvey, an unguided tour of the inflatable Super Colon, and a postsurvey. Primary outcomes were changes in knowledge (actual and perceived) and CRC screening intent from presurvey to postsurvey. We used χ^2 tests to examine differences in survey results between the 2 sites and the association between demographic characteristics and behaviors (knowledge and intentions) before entering the Super Colon exhibit. We used the McNemar test to examine differences in presurvey to postsurvey distributions.

Results

The study sample (N = 940) comprised 572 men at site A (60.8%) and 368 men at site B (39.2%). Except for 1 question, baseline CRC knowledge was relatively high. Greater perceived knowledge was inversely associated with greater actual knowledge. After touring the Super Colon, participants improved their actual knowledge of CRC prevention and self-perceived CRC knowledge. Most participants (95.4%) agreed that the Super Colon was effective for teaching people about CRC.

Conclusion

These findings emphasize the role of community-based educational initiatives in encouraging CRC screening uptake and increasing research participation among men and affirm that the inflatable colon is as an effective educational tool for increasing CRC knowledge and encouraging early-detection screening behavior among men.

Introduction

Colorectal cancer (CRC) is the third most-diagnosed cancer among men and women in the US and the second most common cause of cancer-related death in men and women combined (1), with both incidence and death rates higher among men (2). CRC rates among people younger than 50 years (ie, early-onset CRC) have increased by approximately 50% since the mid-1990s; thus, the US Preventive Services Task Force now recommends that average-risk adults start CRC screening at age 45 years (3,4). Moreover, the rate of early-onset CRC is 16% to 30% higher among men than women (5). Given the high incidence of and deaths from CRC among men, prioritizing CRC prevention efforts is a public health imperative.

The association of CRC knowledge and awareness with CRC screening uptake is well established (6–10). Community education and outreach events are common approaches to fostering health-related knowledge and awareness. Despite some data suggesting that special events — especially those that provide onsite screening services — may lead to increases in cancer screening, evidence to date is insufficient to demonstrate that such events are effective at boosting cancer screening (11).

An innovative resource, the inflatable colon — a super-sized model of the human colon through which visitors can walk— is a tool for teaching about the digestive system and for engaging and educating people about CRC and other colon diseases. Multiple studies have demonstrated that the use of the inflatable colon can improve CRC-related knowledge among young adults, Hispanic people, African American men, and others (12–18). A giant inflatable colon was shown to offer (14) a promising community-level intervention focused on enhancing CRC screening and prevention through a novel population-based strategy; while not independently sufficient, the colon exhibit could complement other evidence-based approaches to CRC prevention and education. To date, however, most participants in inflatable-colon studies have been female (12–15). Additional research is needed to better understand the usefulness of this resource for CRC prevention and control among men. The objective of our study was to evaluate the influence of an inflatable colon as an educational tool to increase CRC knowledge and screening intent among men aged 18 to 75 years attending state fairs in 2 midwestern states.

Methods

Study participants

This observational study, which followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines for cohort studies (www.strobe-statement.org), was conducted in summer 2023, during the final weekends of state fairs in 2 midwestern states. The Medical College of Wisconsin's institutional review board approved all study procedures, marketing materials, and survey instruments before data collection (approval no. PRO47143). To encourage study participation, advertisements were posted at public community locations, on social media, via email, and on the study website, leading up to the events. To assist with recruitment and study implementation, research staff were recruited from community settings, including local universities, Craigslist, gastroenterology centers, the American Cancer Society, and social media platforms.

Individuals were eligible to participate if they self-identified as male, were aged 18 to 75 years, resided in state A (for site A) or state B (for site B), attended the state fair in their state of residence, and could read and speak English. Before participation, informed consent was obtained from all participants via an Apple iPad or cellphone by using the internet-based IRB-compliant PsychData survey system (Divergent Web Solutions, LLC). Participants could request access to preliminary study results and provide recommendations for future research and advocacy efforts via a community dialogue session held at a later time.

Intervention

The Super Colon, an inflatable educational exhibit through which participants can walk, allows participants to closely observe models of normal and inflamed colon tissue, benign and malignant polyps, and invasive and metastatic CRC. Participants at each study site completed a presurvey, an unguided tour, and a postsurvey. After completing the postsurvey, participants were given a drawstring bag (with study logo on it and an ACS colorectal cancer brochure inside it) and an opportunity to enter a drawing for additional incentives such as gift cards, an iPad, or a television.

Data collection

Data were collected through PsychData surveys completed on iPads or cellphones. We adapted our questions based on previously used survey items (14,17,19,20). The forced-choice surveys had 64 items (56 on the presurvey, 8 on the postsurvey). On average, study completion (presurvey, tour, and postsurvey) took 10 to 15 minutes. The surveys were administered in English. Staff were available to help read questionnaires to participants who needed assistance.

Measures

The primary outcomes of interest were changes in CRC knowledge (actual and perceived) and behavioral intent to obtain CRC screening from baseline (presurvey) to intervention completion (postsurvey). Actual knowledge was defined as the comprehensive understanding and awareness of factual information, whereas self-perceived knowledge related to a participant's own assessment of their understanding or familiarity with CRC. Actual knowledge was assessed by correct responses to 3 true-or-false statements in both surveys. The presurvey (but not the postsurvey) had this statement: “Men at average risk should have their first screening for colorectal cancer at age 35.” The correct answer is “false.” (The inflatable colon did not have information on age at first screening, and we observed that participants were wondering if they had missed the information and needed to walk through the inflatable colon again. Because of the confusion created by the item, we did not assess it at postsurvey.) The first statement assessed at both time points was, “If I have a family member with colorectal cancer, I am at a higher risk of having it too.” The correct answer is “true.” The second statement was, “Removing a polyp from my colon can prevent colorectal cancer.” The correct answer is “true.” The third question was, “Colorectal cancer always has symptoms that you can feel.” The correct answer is “false.”

Perceived knowledge was assessed with 3 items. One was the following true-or-false statement: “I know what a colon polyp is.” The second and third items were questions: 1) “How much do you feel you know about colorectal cancer now?” and 2) “How much do you feel you know about how colorectal cancer progresses now?” Response options were “a lot,” “some things,” and “nothing.”

Lastly, we assessed CRC screening intent with the question, “Do you plan to obtain colorectal cancer screening in the future?” Response options were 1) yes, in the next 6 months, 2) yes, in the next 7 months to 1 year, 3) yes, in 13 months to 2 years, 4) yes, sometime but not within 2 years, 5) no, but have considered getting screened, or 6) no, will not get screened. Participants were categorized as having screening intent if they chose options 1, 2, 3, or 4.

We collected data on the following demographic characteristics in the presurvey: age, self-identified race and ethnicity, sexual orientation, relationship status, educational attainment, type of health insurance coverage, having a regular health care provider, personal and family history of CRC, and history of participation in CRC screening. The race and ethnicity variable was used to reflect membership in a societally imposed marginalized racial and ethnic group and as a proxy for systematic and structural racism. We combined responses for the 2 concepts of race and ethnicity, as recommended due to high nonresponse rates among Hispanic and Latino individuals when separate questions are used (21,22). Categories were combined for cell sizes of 10 or fewer participants.

Statistical analysis

We used SAS version 9.4 (SAS Institute, Inc) to manage data and conduct our analysis in October 2023. We checked data through exploratory analysis statistics, including inspection for missing values and data-entry errors. Because less than 5% of participants were lost to follow-up (ie, did not complete the postsurvey), we excluded from analysis any participant with missing data for the outcomes of interest (ie, we used complete case analyses).

We generated descriptive statistics to examine the distribution of characteristics in the full study sample. We used US Census 2022 data (23) to compare the demographic characteristics of our study participants with the demographic characteristics of the population of men aged 18 to 75 years residing in the 2 states in which the state fairs were held (the population of interest). We used χ^2 tests to examine differences in characteristics by study site and the association between selected demographics and behaviors (ie, knowledge and intentions) before entry into the Super Colon exhibit. We calculated the percentage of participants who responded correctly to the actual knowledge questions, the percentage of participants who indicated they knew what a colon polyp is, the percentage of participants who responded “a lot” or “some things” to the 2 items on perceived knowledge, and the percentage of participants who indicated they intended to be screened for CRC within the next 2 years in the presurvey and postsurvey and by study site. We used the McNemar test to examine differences in distributions from presurvey to postsurvey; a 2-sided P value <.05 was considered significant.

Results

A total of 953 eligible participants completed the presurvey. The final sample comprised 940 men who finished both the presurvey and postsurvey (572 [60.8%] at site A; 368 [39.2%] at site B) (Figure). The largest proportion of participants self-reported their race and ethnicity as non-Hispanic White, sexual orientation as heterosexual, and relationship status as either married (site A) or never married (site B) (Table 1). Many participants had completed at least some college, had private health insurance, and reported having a health care provider whom they saw regularly. Slightly more than half of the participants reported having completed a stool-based test or an examination-based test. Most men aged 45 or older had been previously screened for CRC with either a stool-based test or an examination-based test. Approximately 1 in 8 participants had walked through an inflatable colon previously.

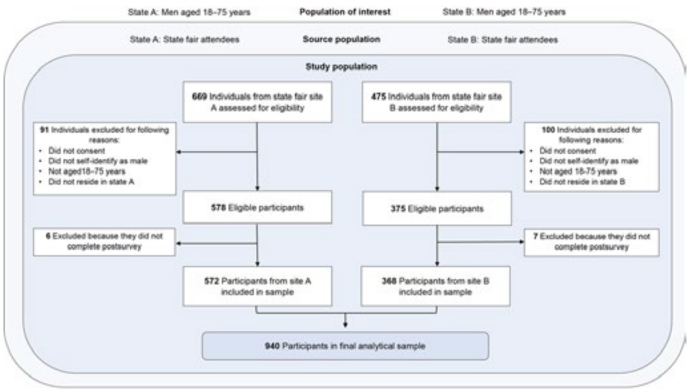

Figure. Flowchart showing how men aged 18 to 75 years were selected to participate in a study of colorectal screening knowledge and intent at state fairs in 2 midwestern states, 2023.

A comparison of demographic characteristics at the 2 study sites showed significant differences by age group, race and ethnicity, relationship status, educational attainment, type of health insurance coverage, having a regular health care provider, and completion of a stool-based test (Table 1). Compared with participants at site A, participants at site B were less likely to be non-Hispanic White (75.4% vs 66.6%), married (52.8% vs 45.4%), to have completed college (bachelor's degree, 40.1% vs 26.3%; master's degree, 27.5% vs 17.2%), to have private health insurance (79.0% vs 72.0%), and not to have a regular health care provider (33.6% vs 26.1%). Participants at site B were more likely than participants at site A to report ever completing a stool-based test (35.9% vs 21.5%).

In a comparison of the demographic characteristics of our study sample with 2022 US Census data for men aged 18 to 75 years residing in the 2 midwestern states, we found that at both study sites, participants aged 60 to 75 years (site A: 17.8% vs 24.5%; site B: 10.6% vs 25.7%) and participants with high school or less were less frequent in our study samples than in the US Census populations (site A: 11.2% vs 31.3%; site B: 24.2% vs 38.8%). Similarly, participants aged 18 to 30 years (site A: 33.6% vs 24.0%; site B: 32.6% vs 24.0%), participants who never married (site A: 43.4% vs 34.7%; site B: 48.1% vs 35.4%), and participants with a bachelor's degree or more (site A: 67.6% vs 34.8%; site B: 43.5% vs 28.4%) were more frequent in our study samples than in the US Census populations (Table 2). In addition, at study site B, participants who self-identified as non-Hispanic Black (12.0% vs 5.4%) or Hispanic/Latino (12.0% vs 6.8%) and participants who had no health insurance (12.2% vs 7.6%) were more frequent in our study sample than in the US Census populations.

Knowledge and intentions

Before entering the Super Colon, approximately one-third of participants correctly answered the question about when men at average risk should initiate CRC screening (Table 3). However, most (90.1%) knew that a family history of CRC increases their own CRC risk. Participants of screening age (ie, aged 45–75 y), compared with participants aged 45 years or younger, had significantly greater actual CRC knowledge but less self-perceived knowledge and were more likely to intend to be screened within 2 years.

We observed significant differences in responses to the knowledge and intent items by educational attainment on the presurvey. Participants with some college or less, compared with participants with a bachelor's degree or more, had greater self-perceived knowledge of CRC on the presurvey (for 2 of the 3 items) but were less likely to answer the knowledge items correctly. Participants with a regular health care provider were more likely than participants without one to know the recommended age to start CRC screening, that removing polyps can prevent CRC, to have lower self-perceived CRC knowledge (for 2 of the 3 items), and to intend to be screened within the next 2 years. Participants who had never completed a blood-based test or an examination-based test were more likely than those who had completed one to have greater self-perceived knowledge (for 2 of the 3 items).

We found significant improvements at both sites from presurvey to postsurvey in knowing that removing a polyp can prevent CRC; in self-perceived knowledge about what a colon polyp is, what CRC is, and how CRC progresses; and in intention to be screened within next 2 years (Table 4). At Site B, from presurvey to postsurvey, participants significantly decreased in knowledge that CRC does not always have symptoms that can be felt (from 84.8% to 79.9%). In the postsurvey, 94.5% of participants agreed that an inflatable colon is an effective tool for teaching people about CRC.

Discussion

To our knowledge, this study is the first to evaluate the effectiveness of an inflatable colon as an educational tool to increase CRC knowledge and screening intent among men in a state fair setting. In our sample of 940 men aged 18 to 75 years, touring the inflatable colon led to significant improvements in knowledge and screening intent. Apart from the question on when men should have their first CRC screening, our study sample at baseline demonstrated relatively high actual CRC knowledge. Compared with a similar study conducted in Alaska and Canada that used similar knowledge questions, our study demonstrated less knowledge among participants about the appropriate age to start CRC screening (35.6% vs 65.0%) and that CRC does not always have symptoms that can be felt (88.0% vs 92.0%) (14). Conversely, participants in our study demonstrated more knowledge about family CRC risk (90.1% vs 88.0%), with no meaningful difference in understanding the role of polyp removal in preventing CRC (81.8% vs 81.0%) (14).

Among participants with educational attainment of some college or less, 90.9% felt they knew "some things" or "a lot" about how CRC progresses, compared with 87.5% of those with higher educational attainment. However, participants with some college or less had a lower prevalence of correct answers on actual knowledge statements compared with those with higher educational attainment. We observed similar patterns among other subgroups (ie, an inverse relationship between perceived knowledge and actual knowledge) including among participants of screening-eligible age, CRC screening-participation history, and marital status. Subgroups with higher CRC knowledge also had a higher prevalence of screening intent, supporting previous findings that associated higher education levels with higher CRC screening participation (24–26). Participants aged 45 years or younger and racial and ethnic minority men had less knowledge and screening intent than their older and non-Hispanic White counterparts. Given the prominent health disparities affecting racial and ethnic minority populations and the projected increase in CRC-related deaths among adults aged less than 50 years by 2030, heightened research efforts and national funding directed to improving CRC knowledge and screening intent in both the under-45 and racial and ethnic minority populations are imperative (11).

Knowledge and beliefs are important factors that enable health behaviors such as participation in early detection screening. In line with other literature (12–15,17,18,27,28), we observed significant improvements in participants' actual and self-perceived knowledge about colon polyps and screening intent after they completed the inflatable-colon tour. Our findings support the effectiveness of community education and outreach events in promoting CRC knowledge and awareness. Specifically, our study highlights the value of self-guided tours of an inflatable colon as a low-resource–intensive intervention at such events.

Large recreational gatherings such as state fairs can attract populations that might not otherwise have ready access to or familiarity with cancer prevention and control services (11). These events may also reach groups that differ according to demographic characteristics (eg, education). These differences may be related to the higher rate of screening participation in our sample compared with that observed elsewhere (29–32). Men aged 60 to 75 years and men with a high school education or less were less frequently represented at the 2 study sites than they were in our population of interest. In contrast, men aged 18 to 30 years, never-married men, and men with higher educational attainment were more frequently represented in our study samples than in the population of interest. Specifically, at site B, participants who self-identified as non-Hispanic Black and Hispanic/Latino and participants who were uninsured were more frequently represented in our study sample than in the population of interest. Because the current body of evidence is inconclusive about whether special events effectively enhance CRC screening rates among men, future research is warranted.

Limitations

Although this study contributes to the literature on the effectiveness of using an inflatable colon to improve CRC knowledge, the use of a descriptive epidemiologic approach has limitations related to measurement accuracy, potential selection bias, and the lack of a control group (33,34). Our use of self-reported data may have increased susceptibility to misclassification (ie, information bias). Although we believe our use of self-reported data did not significantly affect the collection of demographic data, because the use of self-reported race and ethnicity is currently considered the gold standard and less likely to result in misclassification (35), social desirability bias may have influenced our outcomes of interest (knowledge and intent). To address this concern, we incorporated proactive measures into the study design, including collecting no personal identifying information and having at least 1 research staff member nearby while participants completed the presurveys and postsurveys. Although the reliability and validity for actual knowledge scales and CRC screening intent scales have been reported elsewhere (16,36), further assessment of the psychometric properties of our questions that assessed perceived CRC knowledge postintervention is necessary (17). Of note, social desirability bias would likely have affected responses to both surveys, ensuring consistency in our conclusions. However, the alignment of our findings with existing literature reinforces our confidence in them.

Self-selection can bias descriptive studies when study participation is associated with the outcome. Using convenience samples, especially when participation involves opting in, often leads to study samples that differ from the population of interest in terms of sociodemographic factors and health behaviors. While our study sample differed slightly from the population of interest, it may have been more inclined to make behavioral changes; for example, more willing to participate in CRC screening because of high educational attainment. Additionally, our approach of mandating responses to all questions, while eliminating the problem of missing data, may have had the unintended consequence of causing individuals to exit the survey when they were unable to skip questions they preferred not to answer (ie, none of their data were saved).

Strengths

Despite these limitations, our study demonstrates several strengths. Descriptive studies that precisely estimate a parameter of interest and are easily interpretable to clinicians and policymakers contribute substantially to the advancement of public health. Our study adds to the literature on inflatable colons as a CRC education tool (14,15). Whereas previous studies relied on data from 1 geographical region, ours used data from participants with diverse sociodemographic backgrounds in 2 midwestern states. Our study's inability to determine whether reported CRC screening intent translated into screening completion presents an avenue for exploration in future research. Community engagement, partnerships, and relationship building were additional anecdotal study benefits.

Conclusions

Our research highlights the importance of community-based educational programs in promoting CRC screening and increasing men's participation in research. It confirms that the inflatable colon serves as an effective educational tool for raising CRC knowledge and encouraging men to undergo early-detection screening. These findings can inform the development of future health promotion initiatives tailored to men and contribute to our understanding of the effect of community education and outreach events focusing on men.

Acknowledgments

The authors extend gratitude to the participants who made the study possible and to Eleanor Mayfield, ELS, for editorial support. We thank Dr Darrell M. Gray II for his valuable assistance in survey development support. The fruitful execution of this study would not have been possible without assistance from DAPD, D-Brand Designs, MNGI Digestive Health, the International Leadership Institute, and investigation team volunteer staff.

This research was supported in part by the Medical College of Wisconsin; the V Foundation for Cancer Research; the Colorectal Cancer Equity Foundation; the University of Minnesota Masonic Cancer Center; and the National Cancer Institute, an entity of the National Institutes of Health (award number K01CA234319). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Medical College of Wisconsin, the V Foundation for Cancer Research, the Colorectal Cancer Equity Foundation, the Centers for Disease Control and Prevention, or the University of Minnesota.

The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article. Dr Rogers offers scientific input to research studies through an investigator service agreement with Exact Sciences; this scientific input is not related to our study. No copyrighted material, surveys, instruments, or tools were used in the research described in this article.

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Tables

Table 1. Characteristics of Study Sample, Men Aged 18–75 Years at 2 State Fairs in Midwestern States A and B (N = 940), by Site, 2023[a]

Characteristics	Total	Study site A	Study site B	*P* value[b]
No. (%)	940 (100.0)	572 (60.8)	368 (39.2)	—
Demographic characteristics				
Age, mean (SD), y	40.9 (15.1)	41.5 (15.6)	39.9 (14.4)	.10
Age group, y				
18–30	312 (33.2)	192 (33.6)	120 (32.6)	.009
31–45	269 (28.6)	149 (26.0)	120 (32.6)	
46–59	218 (23.2)	129 (22.6)	89 (24.2)	
60–75	141 (15.0)	102 (17.8)	39 (10.6)	
Self-identified race and ethnicity				
Hispanic or Latino	72 (7.7)	28 (4.9)	44 (12.0)	<.001
Non-Hispanic Asian	50 (5.2)	39 (6.8)	11 (3.0)	
Non-Hispanic Black	81 (8.6)	37 (6.5)	44 (12.0)	
Non-Hispanic White	676 (71.9)	431 (75.4)	245 (66.6)	
Non-Hispanic multiracial	25 (2.6)	14 (2.4)	11 (3.0)	
Non-Hispanic Other[c]	36 (3.8)	23 (4.0)	13 (3.5)	
Sexual orientation				
Straight or heterosexual	853 (90.7)	513 (89.7)	340 (92.4)	.16
Nonheterosexual	87 (9.3)	59 (10.3)	28 (7.6)	
Relationship status				
Married	469 (49.9)	302 (52.8)	167 (45.4)	.03
Divorced, widowed, or separated	46 (4.9)	22 (3.8)	24 (6.5)	
Never married	425 (45.2)	248 (43.4)	177 (48.1)	
Educational attainment				
High school or less	153 (16.3)	64 (11.2)	89 (24.2)	<.001
Some college	244 (26.2)	122 (21.4)	122 (33.8)	
Bachelor's degree	324 (34.8)	229 (40.1)	95 (26.3)	
Master's degree or more	219 (23.5)	157 (27.5)	62 (17.2)	
Health insurance coverage				
Private	717 (76.3)	452 (79.0)	265 (72.0)	.01
Public (Medicare, Medicaid, Tricare)	141 (15.0)	83 (14.5)	58 (15.8)	
Uninsured	82 (8.7)	37 (6.5)	45 (12.2)	
Has a regular health care provider				
Yes	652 (69.4)	380 (66.4)	272 (73.9)	.02
No	288 (30.6)	192 (33.6)	96 (26.1)	

Abbreviation: CRC, colorectal cancer.

[a] All values are number (percentage) unless otherwise indicated. Data were collected at baseline (before entry into the Super Colon exhibit) only.

[b] Determined by χ^2 test; $P < .05$ considered significant.

[c] Includes Native Hawaiian or Pacific Islander, American Indian or Alaska Native, and "Other race."

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Table 1. Characteristics of Study Sample, Men Aged 18–75 Years at 2 State Fairs in Midwestern States A and B (N = 940), by Site, 2023[a]

Characteristics	Total	Study site A	Study site B	*P* value[b]
Personal and family history of cancer				
Family history of cancer				
Yes	424 (45.1)	273 (47.7)	151 (41.0)	.12
No	423 (45.0)	247 (43.2)	176 (47.8)	
Not sure	93 (9.9)	52 (9.1)	41 (11.1)	
Family history of colorectal cancer				
Yes	128 (13.6)	86 (15.0)	42 (11.4)	.09
No	691 (73.5)	421 (73.6)	270 (73.4)	
Not sure	121 (12.9)	65 (11.4)	56 (15.2)	
Diagnosed colorectal cancer				
Yes	13 (1.4)	7 (1.2)	6 (1.6)	.60
No	927 (98.6)	565 (98.8)	362 (98.4)	
History of participation in CRC screening				
Completed stool-based test				
Yes	255 (27.1)	123 (21.5)	132 (35.9)	<.001
No	685 (72.9)	449 (78.5)	236 (64.1)	
Completed examination-based test				
Yes	394 (41.9)	249 (43.5)	145 (39.4)	.21
No	546 (58.1)	323 (56.5)	223 (60.6)	
Completed stool-based test or examination-based test among those aged 45–75 years				
Either test	333 (86.7)	215 (88.8)	118 (83.1)	.11
Neither test	51 (13.3)	27 (11.2)	24 (16.9)	
Have you walked through an inflatable-colon exhibit before today?				
Yes	120 (12.8)	70 (12.2)	50 (13.6)	.55
No	820 (87.2)	502 (87.8)	318 (86.4)	

Abbreviation: CRC, colorectal cancer.

[a] All values are number (percentage) unless otherwise indicated. Data were collected at baseline (before entry into the Super Colon exhibit) only.

[b] Determined by χ^2 test; $P < .05$ considered significant.

[c] Includes Native Hawaiian or Pacific Islander, American Indian or Alaska Native, and "Other race."

Table 2. Demographic Characteristics of Study Sample, Men Aged 18–75 Years at 2 State Fairs in Midwestern States A and B (N = 940), by Site, Compared With Population of Interest, 2023

Characteristic	Site A		Site B	
	Study sample	State A[a]	Study sample	State B[a]
Total	572	2,063,254	368	2,155,860
Age group, y				
18–30	192 (33.6)	495,687 (24.0)	120 (32.6)	516,560 (24.0)
31–45	149 (26.0)	590,521 (28.6)	120 (32.6)	565,491 (26.2)
46–59	129 (22.6)	472,077 (22.9)	89 (24.2)	519,778 (24.1)
60–75	102 (17.8)	504,969 (24.5)	39 (10.6)	554,031 (25.7)
Self-identified race and ethnicity				
Hispanic/Latino/Spanish[b]	28 (4.9)	111,640 (5.4)	44 (12.0)	145,567 (6.8)
Non-Hispanic Black	37 (6.5)	136,322 (6.6)	44 (12.0)	115,712 (5.4)
Non-Hispanic White	431 (75.4)	1,610,606 (78.1)	245 (66.6)	1,745,683 (81.0)
Non-Hispanic Other	76 (13.3)	204,686 (9.9)	35 (9.5)	148,898 (6.9)
Relationship status				
Married	302 (52.8)	1,115,152 (54.0)	167 (45.4)	1,121,536 (52.0)
Divorced, widowed or separated	22 (3.8)	232,210 (11.2)	24 (6.5)	270,048 (12.5)
Never married	248 (43.4)	715,892 (34.7)	177 (48.1)	764,276 (35.4)
Educational attainment				
High school or less	64 (11.2)	646,286 (31.3)	89 (24.2)	837,625 (38.8)
Some college	122 (21.4)	664,737 (32.2)	122 (33.8)	681,997 (31.6)
Bachelor's degree	229 (40.1)	490,685 (23.8)	95 (26.3)	415,900 (19.3)
Master's degree or more	157 (27.5)	227,583 (11.0)	62 (17.2)	196,973 (9.1)
Health insurance coverage				
Insured	535 (93.5)	1,928,916 (93.5)	323 (87.8)	1,991,826 (92.4)
Uninsured	37 (6.5)	134,338 (6.5)	45 (12.2)	164,034 (7.6)

[a] Data source: US Census Bureau (23). All values are number (percentage) unless otherwise indicated. Data for study participants were collected at baseline (before entry into the Super Colon exhibit) only.
[b] US Census Bureau data included the term "Spanish."

Table 3. Actual Knowledge and Self-Perceived Knowledge About CRC and Screening Intention for CRC Before Viewing an Inflatable Colon, Men Aged 18–75 Years at 2 State Fairs in the Midwest (N = 940), 2023[a]

	Actual knowledge (answered correctly)				Self-perceived knowledge			
Characteristic	**Item 1 (age at first screen)[b]**	**Item 2 (family risk)[c]**	**Item 3 (polyp removal)[d]**	**Item 4 (feeling symptoms)[e]**	**Item 1 (know what a polyp is)[f]**	**Item 2 (know about CRC)[g]**	**Item 3 (know about CRC progression)[h]**	**Intend to be screened[i]**
No. (%) of participants	335 (35.6)	847 (90.1)	769 (81.8)	827 (88.0)	705 (75.0)	707 (75.2)	609 (64.8)	740 (78.7)
Age group, y								
≤45	160 (27.5)	527 (90.7)	452 (77.8)	495 (85.2)	376 (64.7)	519 (89.3)	535 (92.1)	409 (70.4)
>45	175 (48.8)	320 (89.1)	317 (88.3)	332 (92.5)	329 (91.6)	284 (79.1)	301 (83.8)	331 (92.2)
P value[j]	<.001	.44	<.001	<.001	<.001	<.001	<.001	<.001
Educational attainment								
Some college or less	105 (26.4)	342 (86.2)	302 (76.1)	335 (84.4)	263 (66.2)	354 (89.2)	361 (90.9)	292 (73.6)
Bachelor's degree or more	230 (42.4)	505 (93.0)	467 (86.0)	492 (90.6)	442 (81.4)	449 (82.7)	475 (87.5)	448 (82.5)
P value[j]	<.001	<.001	<.001	.004	<.001	.005	.10	<.001
Has a regular health care provider								
Yes	247 (37.9)	583 (89.4)	547 (83.9)	582 (89.3)	511 (78.4)	534 (81.9)	561 (86.0)	534 (81.9)
No	88 (30.6)	264 (91.7)	222 (77.1)	245 (85.1)	194 (67.4)	269 (93.4)	275 (95.5)	206 (71.5)
P value[j]	.03	.29	.01	.07	<.001	<.001	<.001	<.001
Self-identified race and ethnicity								
Non-Hispanic White	268 (39.6)	622 (92.0)	572 (84.6)	621 (91.9)	534 (79.0)	582 (86.1)	607 (89.8)	556 (82.2)
All other races	67 (25.4)	225 (85.2)	197 (74.6)	206 (78.0)	171 (64.8)	221 (83.7)	229 (86.7)	184 (69.7)
P value[j]	<.001	.002	<.001	<.001	<.001	.35	.18	<.001
Study site								
A	235 (41.1)	526 (92.0)	472 (82.5)	515 (90.0)	437 (76.4)	484 (84.6)	510 (89.2)	469 (82.0)
B	100 (27.2)	321 (87.2)	297 (80.7)	312 (84.8)	268 (72.8)	319 (86.7)	326 (88.6)	271 (73.6)
P value[j]	<.001	.02	.48	.02	.22	.38	.78	.002
Ever completed a stool-based test or an examination-based test or both								
Yes	189 (36.9)	454 (88. 7)	440 (85.9)	445 (86.9)	441 (86.1)	416 (81.2)	436 (85.2)	435 (85.0)
No	146 (34.1)	393 (91.8)	329 (76.9)	382 (89.2)	264 (61.7)	387 (90.4)	400 (93.5)	305 (71.3)
P value[j]	.37	.11	<.001	.27	<.001	<.001	<.001	<.001

Abbreviation: CRC, colorectal cancer.

[a] All values are number (percentage) of participants who answered correctly to items on actual knowledge or who answered as indicated to items on self-perceived knowledge or intent to be screened.

[b] The true–false item was "Men at average risk should have their first screening for CRC at age 35?" The correct answer is "false."

[c] The true–false item was "If I have a family member with CRC, I am at a higher risk of having it too." The correct answer is "true."

[d] The true–false item was "Removing a polyp from my colon can prevent CRC." The correct answer is "true."

[e] The true–false item was "CRC always has symptoms that you can feel." The correct answer is "false."

[f] Response of "true" to the true–false item, "I know what a colon polyp is."

[g] Response of "a lot" or "some things" to question, "How much do you feel you know about CRC now?" Response options were "a lot," "some things," or "nothing."

[h] Response of "a lot" or "some things" to question, "How much do you feel you know about how CRC progresses now?" Response options were "a lot," "some things," or "nothing."

[i] Response of yes, regardless of time, to question, "Do you plan to obtain colorectal cancer screening in the future?". Response options were yes, in the next 1) 6 months, 2) 7 months to 1 year, 3) 13 months to 2 years, 4) sometime but not within 2 years; or no, 5) but have considered getting screened, or 6) will not get screened.

[j] Determined by χ^2 test.

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(continued)

Table 3. Actual Knowledge and Self-Perceived Knowledge About CRC and Screening Intention for CRC Before Viewing an Inflatable Colon, Men Aged 18–75 Years at 2 State Fairs in the Midwest (N = 940), 2023[a]

Characteristic	Actual knowledge (answered correctly)				Self-perceived knowledge			Intend to be screened[i]
	Item 1 (age at first screen)[b]	Item 2 (family risk)[c]	Item 3 (polyp removal)[d]	Item 4 (feeling symptoms)[e]	Item 1 (know what a polyp is)[f]	Item 2 (know about CRC)[g]	Item 3 (know about CRC progression)[h]	
Relationship status								
Married	196 (41.8)	430 (91.7)	409 (87.2)	432 (92.1)	396 (84.4)	387 (82.5)	402 (85.7)	400 (85.3)
Not married	139 (29.5)	417 (88.5)	360 (76.4)	395 (83.9)	309 (65.6)	416 (88.3)	434 (92.1)	340 (72.2)
P value[j]	<.001	.11	<.001	<.001	<.001	.01	.002	<.001

Abbreviation: CRC, colorectal cancer.

[a] All values are number (percentage) of participants who answered correctly to items on actual knowledge or who answered as indicated to items on self-perceived knowledge or intent to be screened.

[b] The true–false item was “Men at average risk should have their first screening for CRC at age 35?” The correct answer is “false.”

[c] The true–false item was “If I have a family member with CRC, I am at a higher risk of having it too.” The correct answer is “true.”

[d] The true–false item was “Removing a polyp from my colon can prevent CRC.” The correct answer is “true.”

[e] The true–false item was “CRC always has symptoms that you can feel.” The correct answer is “false.”

[f] Response of “true” to the true–false item, “I know what a colon polyp is.”

[g] Response of “a lot” or “some things” to question, “How much do you feel you know about CRC now?” Response options were “a lot,” “some things,” or “nothing.”

[h] Response of “a lot” or “some things” to question, “How much do you feel you know about how CRC progresses now?” Response options were “a lot,” “some things,” or “nothing.”

[i] Response of yes, regardless of time, to question, “Do you plan to obtain colorectal cancer screening in the future?”. Response options were yes, in the next 1) 6 months, 2) 7 months to 1 year, 3) 13 months to 2 years, 4) sometime but not within 2 years; or no, 5) but have considered getting screened, or 6) will not get screened.

[j] Determined by χ^2 test.

Table 4. Actual Knowledge and Self-Perceived Knowledge About CRC and Screening Intention for CRC Screening Before and After Viewing an Inflatable Colon, Men Aged 18–75 Years at 2 State Fairs in Midwestern States A and B (N = 940), 2023[a]

Item	Total sample			Site A			Site B		
	Pre	Post	*P* value[b]	Pre	Post	*P* value[b]	Pre	Post	*P* value[b]
Actual knowledge									
Item 1 (age at first screening)[d]	35.6	—[c]	—	41.0	—[c]	—	27.2	—[c]	—
Item 2 (family risk)[e]	90.1	89.9	.85	92.0	90.6	.28	87.2	88.9	.43
Item 3 (polyp removal)[f]	81.8	91.3	<.001	82.5	92.7	<.001	80.7	89.1	<.001
Item 4 (feeling symptoms)[g]	88.0	85.6	.05	90.0	89.3	.62	84.8	79.9	.02
Self-perceived knowledge									
Answered “true” to “I know what a colon polyp is.”	75.0	96.2	<.001	76.4	96.0	<.001	72.8	96.5	<.001
“How much do you feel you know about CRC now?”[h]									
A lot	14.6	33.6	<.001	15.4	33.2	<.001	13.3	34.2	<.001
Some things	60.6	62.8		60.0	64.2		61.7	60.6	
“How much do you feel you know about how CRC progresses now?”[h]									
A lot	11.1	36.7	<.001	10.8	37.2	<.001	11.4	35.9	<.001
Some things	53.7	60.2		53.7	60.0		53.8	60.6	
Intend to be screened, %[i]	78.7	86.1	<.001	82.0	87.4	<.001	73.6	84.0	<.001

Abbreviation: —, does not apply; CRC, colorectal cancer.

[a] All values are number (percentage) of participants who answered correctly to items on actual knowledge or who answered as indicated to items on self-perceived knowledge or intent to be screened.

[b] Determined by McNemar test.

[c] Not assessed at postsurvey because the inflatable colon did not have information on age at first screening, and we observed that participants were wondering if they had missed the information and needed to walk through the inflatable colon again.

[d] The true–false item was “Men at average risk should have their first screening for CRC at age 35?” The correct answer is “false.” The item was not included on the postsurvey.

[e] The true–false item was “If I have a family member with CRC, I am at a higher risk of having it too.” The correct answer is “true.”

[f] The true–false item was “Removing a polyp from my colon can prevent CRC.” The correct answer is “true.”

[g] The true–false item was “CRC always has symptoms that you can feel.” The correct answer is “false.”

[h] Response options were “a lot,” “some things,” or “nothing.”

[i] Percentage of participants who answered yes, regardless of time, to question, “Do you plan to obtain colorectal cancer screening in the future?” Response options were yes, in the next 1) 6 months, 2) 7 months to 1 year, 3) 13 months to 2 years, 4) sometime but not within 2 years; or no, 5) but have considered getting screened, or 6) will not get screened.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E05 JANUARY 2024

ORIGINAL RESEARCH

The Effect of Disability and Social Determinants of Health on Breast and Cervical Cancer Screenings During the COVID-19 Pandemic

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Accessible Version: www.cdc.gov/pcd/issues/2024/23_0234.htm

Suggested citation for this article: Rolle LD, Chery MJ, Larson M, Lopez-Pentecost M, Calfa CJ, Schlumbrecht MP, et al. The Effect of Disability and Social Determinants of Health on Breast and Cervical Cancer Screenings During the COVID-19 Pandemic. Prev Chronic Dis 2024;21:230234. DOI: https://doi.org/10.5888/pcd21.230234.

PEER REVIEWED

Summary

What is already known on this topic?

Prior research investigated the effect of disability status and social determinants of health on cancer screenings. Few studies have considered the implications of these factors on breast and cervical cancer screening during health crises such as the COVID-19 pandemic.

What is added by this report?

We compared cancer screening rates among women before (2018) and amid (2020) the COVID-19 pandemic. Women with disabilities and lower income, and women lacking health insurance coverage had reduced odds of being up to date on mammograms and Pap tests, before as well as amid the COVID-19 pandemic.

What are the implications for public health practice?

The findings highlight the critical need for health policies and interventions tailored for people who have disabilities and are socially marginalized, especially during times of health crises, when disparities, including disparities in access to essential preventive screenings, are exacerbated.

Abstract

Introduction

The objective of this study was to examine the effect of disability status and social determinants of health (SDOH) on adherence to breast and cervical cancer screening recommendations during the COVID-19 pandemic.

Methods

We conducted a secondary analysis of the 2018 and 2020 Behavioral Risk Factor Surveillance System (BRFSS) data sets. We defined adherence to screenings according to the US Preventive Services Task Force guidelines for breast and cervical cancer screening. The analysis included respondents assigned female at birth, aged 50 to 74 years (breast cancer screening) or aged 21 to 65 years (cervical cancer screening). We performed logistic regression to evaluate breast and cervical cancer screening adherence, by disability status and SDOH (health insurance coverage, marital status, and urban residency), independently and simultaneously.

Results

Our analysis included 27,526 BRFSS respondents in 2018 and 2020. In 2018, women with disabilities had lower adjusted odds than women without disabilities of being up to date with mammograms (adjusted odds ratio [AOR] = 0.76, 95% CI, 0.63–0.93) and Pap (Papanicolaou) tests (AOR = 0.73; 95% CI, 0.59–0.89). In 2020, among women with disabilities, the adjusted odds of mammogram and Pap test adherence decreased (AOR = 0.69; 95% CI, 0.54–0.89; AOR = 0.59; 95% CI, 0.47–0.75, respectively). In 2018, the adjusted odds of mammogram adherence among rural residents with and without disabilities were 0.83 (95% CI, 0.70–0.98), which decreased to 0.76 (95% CI, 0.62–0.93) in 2020.

Conclusion

The findings of this study highlight the effect of disability status and SDOH on breast and cervical cancer screening rates during the COVID-19 pandemic. Public health strategies that acknowledge and address these disparities are crucial in preparing for future public health crises.

Introduction

Breast cancer is the most prevalent type of cancer among women in the US; an estimated 287,850 cases and 43,250 deaths attributed to breast cancer occur annually (1). Additionally, nearly 13,000 new cases of cervical cancer and 4,000 cervical cancer deaths occur annually (2). Adherence to cervical cancer screening recommendations can substantially mitigate the incidence and death associated with the disease. Similarly, biennial breast cancer screenings can decrease breast cancer mortality by up to 40% (3–5). However, disparities in breast and cervical cancer screening rates and access to health care services persist according to race, ethnicity, and social determinant of health (SDOH), and these disparities were exacerbated during the COVID-19 pandemic (6–9). In 2020, the pandemic led to a reduction or halt in breast and cervical cancer screening services in many parts of the US (7,8,10), and the precise implications arising from these reductions in cancer screening as a result of this global event are inconclusive.

Approximately 61 million adults in the US live with a disability (11). A disability is a condition that impairs normal body function or cognition, restricts activity, and limits participation in societal roles (11). The nature and effect of disabilities, which can be congenital, developmental, injury-related, or associated with other health conditions, are diverse and can affect areas such as vision, movement, thinking, communication, and social relationships (11). Cancer screening uptake among people with disabilities is lower than among people without disabilities (12). Disability status and SDOH can substantially affect breast and cervical cancer screening rates. People with disabilities, particularly those with low socioeconomic status, have lower rates of breast and cervical cancer screening (13). Addressing disparities in cancer screening uptake among people with disabilities and varying socioeconomic circumstances calls for a multilevel, comprehensive approach that goes beyond individual interventions to address the broader SDOH. Interventions, such as tailored education programs, can enhance awareness and understanding of the importance of regular screenings (14). The objective of this study was to fill gaps in knowledge by investigating disparities in adherence to breast and cervical cancer screening among women with disabilities; exploring the effect of SDOH, including health insurance coverage, income, marital status, employment, education, and urban residency, during the COVID-19 pandemic; and assessing the degree of need for tailored interventions to improve access and use of screening services and address health equity.

Methods

We conducted a secondary analysis of data from the 2018 and 2020 Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is an annual, nationwide cross-sectional survey that collects data on risk behaviors, chronic health conditions, and use of preventive services by US residents. In 2018, BRFSS had an overall landline response rate of 53.3% and a cell phone response rate of 43.4% (15), resulting in 437,436 records collected for 2018. In 2020, BRFSS had an overall response rate of 47.9% (16), collecting 401,958 records for the year. The inclusion criteria for our study were based on US Preventive Services Task Force (USPSTF) recommendations for breast cancer screening updated in 2016 (17) and recommendations for cervical cancer screening updated in 2018 (18). For breast cancer screening, our analysis included respondents aged 50 to 74 years assigned female at birth (hereinafter, women); we considered respondents who received a mammogram in the previous 2 years to be up to date with screening. For cervical cancer screening, our analysis included respondents aged 21 to 65 years assigned female at birth (hereinafter, women); we considered respondents who received a Papanicolaou (Pap) test in the previous 3 years to be up to date with screening. We used the weighted calculated variables procedures outlined by BRFSS and applied weight, cluster, and strata variables to obtain population-based estimates and odds ratios (ORs) representative of the general population of US women (19).

Dependent variables

The BRFSS-calculated variables MAM5023 (women aged 50–74 years who had a mammogram in the previous 2 years) and _RFPAP35 (women aged 21–65 years who had a Pap test in the previous 3 years) were the main dependent variables.

Independent variables

Per the guidelines from the Centers for Disease Control and Prevention's "A Data Users' Guide to the Disability Questions," we combined the variables deaf; blind; difficulty concentrating, remembering, or making decisions; difficulty walking or climbing stairs; difficulty dressing or bathing; and difficulty doing errands alone due to a physical, mental, or emotional condition to create the binary (yes/no) variable disability (20). We included race and ethnicity to investigate the intersection of race and ethnicity and screening in the sample. We included the variables health insurance coverage, annual household income, marital status, employment, educational attainment, and urban or rural residence in the multivariate regression models. These variables represent key SDOH, in alignment with the Healthy People 2030 SDOH domains: economic stability (income), education access and quality (educational attainment), health care access and quality (health insurance coverage), neighborhood and built environment (urban or rural residence), and social and community context (marital status).

Statistical analyses

We first conducted descriptive analyses to characterize the sample of women, categorizing them as either up to date or not on mammograms and Pap tests, by disability status and SDOH. We generated bivariate and multivariable logistic regression models to examine the association between disability status and SDOH (independently and simultaneously) and the odds of being up to date on mammograms and Pap tests. We evaluated SDOH through measures of health insurance coverage, annual household income, marital status, employment, educational attainment, and urban or rural residence. We assessed the odds of women with disabilities being up to date on mammograms and Pap tests, taking into account the influence of SDOH by using a domain statement. All tests were 2-sided, with an α of < .05. We used SAS version 9.4 (SAS Institute, Inc) for all statistical analyses.

Results

Of the 27,526 respondents in both years, a substantial majority were current with mammograms and Pap tests in both 2018 and 2020. In 2018, 78.4% (n = 13,138) were up to date on mammograms, and 78.4% (n = 13,067) were up to date on Pap tests. In 2020, 77.8% (n = 8,388) were up to date on mammograms and 77.4% (n = 8,235) on Pap tests. In 2018, 24.6% (4,099 of 16,669) of respondents reported having a disability; in 2020, 22.6% (n = 2,456 of 10,857) of respondents reported having a disability. Among women with disabilities, 72.1% (n = 2,991) were up to date on mammograms in 2018, and 69.6% (n = 1,744) were up to date in 2020. Pap test uptake among women with disabilities was 69.4% (n = 2,915) in 2018 and 66.1% (n = 1,639) in 2020 (Table 1).

In 2018 and 2020, more than 95% of women with health insurance coverage were current with both mammograms and Pap tests. In contrast, among women without health insurance coverage, 3.9% (2018) and 3.4% (2020) were up to date on mammograms and 4.3% (2018) and 4.1% (2020) were up to date on Pap tests. In 2018, by annual household income, women with incomes of $75,000 or more had the highest rates of being up to date on both mammograms (47.7%) and Pap tests (48.0%). Similarly, in 2020, this income bracket had the highest rates (48.6% for mammograms and 49.3% for Pap tests). Married women had consistently higher rates of being up to date on both tests in both years (2018: 69.6% for mammograms, 70.0% for Pap tests; 2020: 70.0% for mammograms, 70.2% for Pap tests). College graduates had the highest rates of being up to date on both mammograms (2018: 35.6%, 2020: 37.6%) and Pap tests (2018: 36.6%, 2020: 38.3%). Additionally, urban residents had higher rates than their rural counterparts in both years for mammograms (2018: 82.8%, 2020: 83.3%) and Pap tests (2018: 83.5%, 2020: 83.3%).

Adjusted model: independent comparison of mammogram and Pap test screening rates based on SDOH and disability status before (2018) vs during COVID-19 (2020)

In 2018, women with disabilities had lower odds than women without disabilities of being up to date on mammograms (AOR = 0.76; 95% CI, 0.63–0.93) and Pap tests (AOR = 0.73; 95% CI, 0.59–0.89). In 2020, these odds decreased to 0.69 (95% CI, 0.54–0.89) for mammograms and 0.59 (95% CI, 0.47–0.75) for Pap tests (Figure 1 and Figure 2). Women without health insurance coverage in 2018 had odds of 0.27 (95% CI, 0.20–0.37) for mammograms and 0.37 (95% CI, 0.27–0.52) for Pap tests, compared with women with health insurance coverage. In 2020, these odds changed to 0.26 (95% CI, 0.18–0.35) for mammogram and 0.42 (95% CI, 0.30–0.58) for Pap tests. In 2018, women with an annual household income of less than $25,000, compared with women with an annual household income of $75,000 or more, had an adjusted odds of 0.54 (95% CI, 0.40–0.73) for mammograms and 0.59 (95% CI, 0.43–0.82) for Pap tests. In 2020, these odds were 0.59 (95% CI, 0.43–0.82) for mammograms and 0.50 (95% CI, 0.36–0.69) for Pap tests. In 2018, married women, compared with women who were not married, had an adjusted odds of 1.12 (95% CI, 0.93–1.36) for mammograms and 1.21 (95% CI, 0.99–1.49) for Pap tests. In 2020, these odds changed to 1.25 (95% CI, 1.01–1.56) for mammograms and 1.18 (95% CI, 0.96–1.45) for Pap tests. Among rural residents, compared with urban residents, the adjusted odds in 2018 were 0.83 (95% CI, 0.70–0.98) for mammograms and 0.76 (95% CI, 0.62–0.93) for Pap tests. In 2020, these odds were 0.76 (95% CI, 0.62–0.93) for mammograms and 0.78 (95% CI, 0.64–0.95) for Pap tests. In 2018, women with some high school education, compared with women who were college graduates, had an adjusted odds of 1.47 (95% CI, 1.00–2.17) for mammograms and 1.61 (95% CI, 1.03–2.53) for Pap tests. These odds changed in 2020 to 1.61 (95% CI, 1.03–2.53) for mammograms and 1.11 (95% CI, 0.68–1.82) for Pap tests. Additionally, in 2018, unemployed women had significantly lower odds than employed women (AOR = 0.78; 95% CI, 0.65–0.95) of being up to date on Pap tests; in 2020, the AOR for Pap tests became nonsignificant (AOR = 1.08; 95% CI, 0.87–1.34).

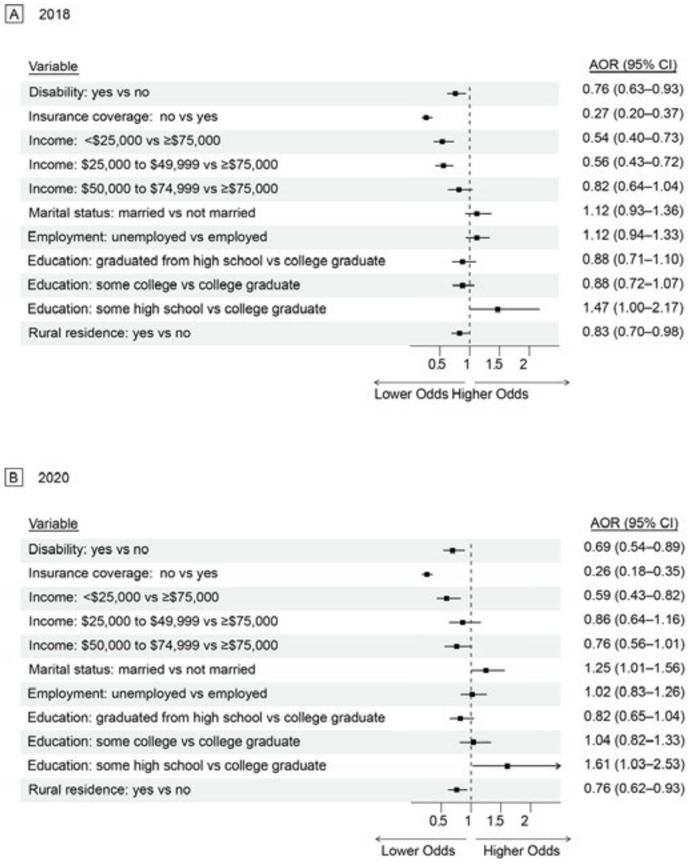

Figure 1. Adjusted odds of being up to date on mammogram screening in A) 2018 and B) 2020 by social determinants of health among all women eligible for screening, Behavioral Risk Factor Surveillance System, 2018 and 2020.

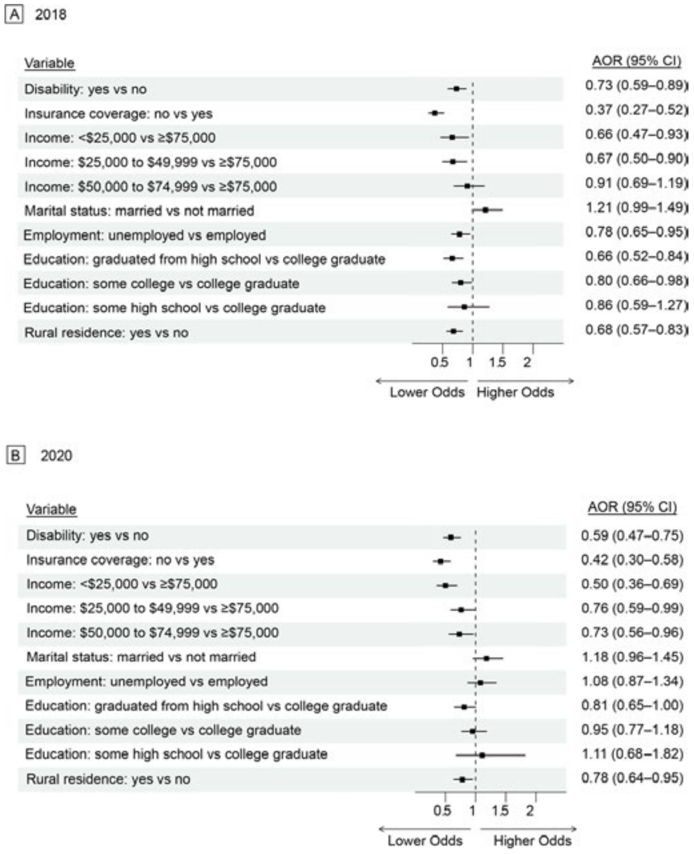

Figure 2. Adjusted odds of being up to date on Pap test screening in A) 2018 and B) 2020 by social determinants of health among all women eligible for screening, Behavioral Risk Factor Surveillance System, 2018 and 2020.

Adjusted model: analysis of SDOH and race and ethnicity among women with disabilities

In 2018, among women with disabilities, the likelihood of being up to date with mammograms was higher among Hispanic (AOR = 2.42; 95% CI, 1.37–4.26) and non-Hispanic Black women (AOR = 2.20; 95% CI, 1.27–3.83) than non-Hispanic White women (Table 2). Income disparities were evident: women with an annual household income of $25,000 to $49,999 had lower odds than women with an annual household income of $75,000 or more of being up to date with mammograms (AOR = 0.47; 95% CI, 0.29–0.74). Compared with non-Hispanic White women with disabilities, Hispanic (AOR = 2.08; 95% CI, 1.16–3.74) and non-Hispanic Black (AOR = 2.04; 95% CI, 1.08–3.87) women with disabilities were more likely to have Pap tests. Women with an annual household income of less than $25,000 had lower odds than women with an annual household income of $75,000 or more of being up to date with Pap tests (AOR = 0.54; 95% CI, 0.31–0.93). In 2020, non-Hispanic Black women had higher odds for mammograms (AOR = 2.70; 95% CI, 1.40–5.21) and Pap tests (AOR = 2.15; 95% CI, 1.19–3.87) than they did in 2018.

Discussion

Building on existing evidence of how disability status and SDOH influence preventive screening behaviors, our study offers a novel perspective by examining these factors during the COVID-19 pandemic. By analyzing SDOH and disability separately, we aimed to shed light on the unique influence of each on access to preventive care and health outcomes. The pandemic likely heightened or introduced new barriers to use of health care services. Our adjusted models underscored the intricate relationships and complexities of disability status and SDOH in influencing preventive screening behaviors for breast and cervical cancer during the pandemic.

In 2018, SDOH shaped the screening behaviors of women with disabilities. Those earning below $50,000 had lower odds, compared with those earning $75,000 or more, of receiving a Pap test or mammogram, and married women had higher odds than unmarried women of receiving a mammogram. Regardless of the screening type, health insurance access was critical, and its absence hampered rates of receipt.

During the COVID-19 pandemic in 2020, we found shifts in screening dynamics among racial and ethnic minority groups. Racial differences in rates of receipt for mammograms were more pronounced in 2020 than in 2018: the odds of being up to date with screening among non-Hispanic Black women, compared with non-Hispanic White women, were higher in 2020 than in 2018. Although screening rates might be increasing among racial and ethnic minority groups, addressing the broader disparities in breast and cervical cancer outcomes requires a comprehensive approach that encompasses early detection, equitable access to high-quality care, culturally sensitive health care delivery, and ongoing support throughout the cancer care journey. Meanwhile, disparities in being up to date with screening persisted from 2018 to 2020, but with attenuated intensity. The central role of health insurance coverage also persisted, with lack of insurance consistently associated with reduced odds of screening uptake.

We found that mammogram and Pap test screening rates among women with disabilities declined by 2.5 percentage points (from 72.1% to 69.6% for mammograms) and 3.3 percentage points (from 69.4% to 66.1% for Pap tests), respectively, from 2018 to 2020, indicating an exacerbation of disparities based on disability during COVID-19. The finding that women with disabilities had lower odds than the general population of being up to date on breast and cervical cancer screenings before and during the pandemic corroborates previous findings that highlighted challenges in accessing health care services among people with disabilities (13). Similar patterns of health care underutilization have been reported among people with disabilities across a range of preventive services and medical examinations (21,22). This underutilization may be attributed to various factors, such as physical accessibility, communication barriers, and lack of health care provider expertise in managing patients with disabilities; these factors warrant further research (23). Research on disability and health behaviors underscores the effect of these factors on the engagement of people with disabilities in preventive behaviors (24,25). During the COVID-19 pandemic, these factors were most likely intensified.

Interventions need to be tailored to the unique needs and challenges of people with disabilities, encompassing strategies such as individualized communication, physical adjustments, and specialized health care provider training (23). The design of interventions aimed at promoting mammograms and Pap tests among this group must prioritize the accessibility and adaptability of health care facilities and services, especially during a public health crisis.

We examined the relationship between economic factors and mammograms and Pap tests. Women with higher income and health insurance coverage had higher odds of being up to date with screening. Our findings resonate with recent studies indicating financial constraints and lack of health insurance as barriers to mammogram screening (26). Expanding access to affordable health insurance and reducing out-of-pocket costs for preventive services should be prioritized.

Studies by Wong et al and Friedman demonstrated that people with disabilities were more financially affected by the pandemic than their counterparts without disabilities. These financial challenges, including job loss and reductions in income, amplified the existing barriers to preventive health care services. More than half of people with disabilities surveyed reported difficulties in paying for usual household expenses during the pandemic (27). Many people relied on credit cards, loans, or borrowing from friends and family to meet their needs (27). Increased financial hardship among people with disabilities, particularly women, could extend to preventive health services such as mammograms and Pap tests (27,28). Women with disabilities, low income, or lost income may forgo these services, potentially leading to late-stage diagnosis and poorer health outcomes. Our findings, in alignment with previous literature, emphasize the necessity to address the economic barriers influencing health-seeking behaviors and the need for inclusive health care strategies during public health emergencies.

Our research provides a nuanced understanding of how marital status and educational attainment influenced screenings during the pandemic. The observed association between marital status and adherence to mammograms and Pap tests highlights the crucial role of SDOH in health behaviors. Although we did not find a significant association between educational attainment and odds of being up to date on mammograms or Pap tests in our adjusted model, higher educational attainment has been shown to positively affect health-seeking behaviors in other studies (29). The discrepancy between our findings and previous findings may suggest that the influence of education may interact with other factors in complex ways, requiring further research. Nevertheless, considering the broader evidence linking educational attainment to health-seeking behaviors, public health initiatives should focus on strategies that can appeal to people with lower education levels or people who lack social support. These interventions could be implemented through community-based interventions or partnerships with educational institutions.

Our research uniquely evaluated health care accessibility and use in the context of rural and urban disparities. We found a significant association between urban residency and adherence to mammogram and Pap test screening: the odds of being up to date with mammograms and Pap tests were lower among rural residents than urban residents. Differences in health care access between urban and rural areas may contribute to disparities in adherence to mammograms and Pap test screening (30). Innovative solutions, such as mobile mammography units and telemedicine consultations, can improve access to screening services in rural and underserved areas (31). Novel approaches, such as mail-in self-sampling for cervical cancer screening, can help address accessibility and acceptability issues in this population (32). An evaluation of health care accessibility and use among disabled people during the COVID-19 pandemic is of paramount importance.

Limitations

Our study has several limitations. First is the cross-sectional design of the data set. Although our approach allowed us to generate a snapshot of data at 2 points in time, it inherently precluded the ability to infer causality. Second, our reliance on the BRFSS data set, which uses self-reported data, might have introduced recall bias, response bias, or social desirability bias. Although the BRFSS data set is a robust and widely used resource in public health research, the potential discrepancies in self-reported data versus actual behaviors or status cannot be ignored. Third, we did not test whether changes in being up to date on screening from 2018 to 2020 were significant. Future studies using a longitudinal design and validated self-reported data with objective measures may provide more precise findings and elucidate the causal relationships between disability status, SDOH, and cancer screenings during health crises such as the COVID-19 pandemic.

Conclusion

Our study reaffirms the significance of SDOH in mammogram and Pap test screening behaviors. The effect of disability status, income, health insurance coverage, marital status, educational attainment, and urban or rural residence on screening adherence for breast and cervical cancer during the COVID-19 pandemic has magnified pre-existing health care challenges and disparities. Considering the unique circumstances brought about by the pandemic, it is crucial to design interventions that address the barriers imposed by sociodemographic factors. By enhancing accessibility, affordability, and awareness of screenings, especially among populations who lack access to health care, we could mitigate the detrimental effects of a health care crisis like the pandemic on breast and cervical cancer screening rates. A tailored approach could contribute to reducing disparities and improving breast cancer outcomes.

Acknowledgments

We express our gratitude to Crane Research Lab for their continued support and mentorship throughout this project. The authors received no external financial support for the research, authorship, and/or publication of this article. The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. No copyrighted materials were used in this article.

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Tables

Table 1. Sample Characteristics by Mammogram and Pap Test Uptake in 2018 (n = 16,669) and 2020 (n = 10,857), BRFSS

	Up to date on mammogram, no. (%[a])				Up to date on Pap test, no. (%[a])			
	2018		2020		2018		2020	
Variable	Yes	No	Yes	No	Yes	No	Yes	No
Overall	13,138 (78.4)	3,531 (21.6)	8,388 (77.8)	2,469 (22.2)	13,067 (78.4)	3,602 (21.6)	8,235 (77.4)	2,622 (22.6)
Disability								
Yes	2,991 (72.1)	1,108 (27.9)	1,744 (69.6)	712 (30.4)	2,915 (69.4)	1,184 (30.6)	1,639 (66.1)	817 (33.9)
No	10,147 (80.7)	2,423 (19.3)	6,644 (80.4)	1,757 (19.6)	10,152 (81.5)	2,418 (18.5)	6,596 (81.0)	1,805 (19.0)
Health insurance coverage								
Yes	12,715 (96.1)	3,101 (85.6)	8,131 (96.6)	2,150 (85.9)	12,595 (95.7)	3,221 (87.1)	7,939 (95.9)	2,342 (88.3)
No	423 (3.9)	430 (14.4)	257 (3.4)	319 (14.1)	472 (4.3)	381 (12.9)	296 (4.1)	280 (11.7)
Annual household income, $								
<25000	2,271 (17.9)	1,008 (29.1)	1,316 (15.8)	656 (28.6)	2,224 (17.2)	1,055 (31.4)	1,254 (15.1)	718 (30.6)
25,000–49,999	2,575 (16.9)	891 (24.3)	1,656 (19.7)	604 (20.8)	2,537 (17.1)	929 (23.5)	1,595 (19.5)	665 (21.5)
50,000–74,999	2,422 (17.5)	576 (15.3)	1,489 (15.9)	433 (16.4)	2,400 (17.6)	598 (14.8)	1,468 (16.0)	454 (15.9)
>75,000	5,870 (47.7)	1,056 (31.3)	3,927 (48.6)	776 (34.2)	5,906 (48.0)	1,020 (30.2)	3,918 (49.3)	785 (32.0)
Marital status								
Married	8,185 (69.6)	1,888 (60.9)	5,396 (70.0)	1,381 (60.5)	8,213 (70.0)	1,860 (59.8)	5,373 (70.2)	1,404 (59.8)
Not married	4,953 (30.4)	1,643 (39.1)	2,992 (30.0)	1,088 (39.5)	4,854 (30.0)	1,742 (40.2)	2,862 (29.8)	1,218 (40.2)
Employment								
Employed	8,002 (58.6)	1,997 (54.3)	5,051 (57.5)	1,352 (51.2)	8,099 (60.5)	1,900 (47.4)	5,022 (57.8)	1,381 (50.2)
Unemployed	5,136 (41.4)	1,534 (45.7)	3,337 (42.5)	1,117 (48.8)	4,968 (39.5)	1,702 (52.6)	3,213 (42.2)	1,241 (49.8)
Education								
Some high school	403 (6.4)	163 (7.0)	209 (7.0)	91 (6.4)	375 (5.8)	191 (9.0)	196 (6.5)	104 (8.3)
Graduated from high school	2,900 (26.3)	964 (32.0)	1,763 (23.9)	706 (32.8)	2,852 (25.3)	1,012 (35.2)	1,708 (24.0)	761 (32.2)
Some college	3,493 (31.7)	1,052 (34.3)	2,296 (31.4)	693 (30.6)	3,478 (32.2)	1,067 (32.3)	2,219 (31.2)	770 (31.5)
College graduate	6,342 (35.6)	1,352 (26.7)	4,120 (37.6)	979 (30.2)	6,362 (36.6)	1,332 (23.4)	4,112 (38.3)	987 (28.0)
Rural residence								
No	8,718 (82.8)	2,150 (77.5)	5,523 (83.3)	1,438 (76.1)	8,735 (83.5)	2,133 (74.8)	5,406 (83.3)	1,555 (76.3)
Yes	4,420 (17.2)	1,381 (22.5)	2,865 (16.7)	1,031 (23.9)	4,332 (16.5)	1,469 (25.2)	2,829 (16.7)	1,067 (23.7)

Abbreviations: BRFSS, Behavioral Risk Factor Surveillance System; Pap, Papanicolaou.

[a] Percentages were calculated as column percentages, except for the category for disability, which were calculated as row percentages. All percentages were weighted by using the BRFSS dataset methodology, accounting for the complex survey design of BRFSS, which includes stratification (_ststr), clustering (_psu), and weight (_llcpwt) variables.

Table 2. Adjusted Odds[a] of Being Up to Date on Mammogram and Pap Test by SDOH and Race and Ethnicity Among Women With Disabilities, Behavioral Risk Factor Surveillance System, 2018 and 2020

Variable	Mammogram, AOR (95% CI)		Pap test, AOR (95% CI)	
	2018	2020	2018	2020
Race and ethnicity				
Hispanic	2.42 (1.37–4.26)	1.43 (0.51–4.01)	2.08 (1.16–3.74)	2.25 (0.74–6.83)
Non-Hispanic Black	2.20 (1.27–3.83)	2.70 (1.40–5.21)	2.04 (1.08–3.87)	2.15 (1.19–3.87)
Non-Hispanic White	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Health insurance coverage				
No	0.24 (0.15–0.37)	0.27 (0.14–0.52)	0.34 (0.21–0.55)	0.49 (0.26–0.94)
Yes	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Annual household income, $				
<25,000	0.64 (0.38–1.05)	0.67 (0.36–1.24)	0.54 (0.31–0.93)	0.63 (0.34–1.17)
25,000–49,999	0.47 (0.29–0.74)	0.93 (0.49–1.77)	0.53 (0.33–0.83)	0.83 (0.46–1.52)
50,000–74,999	0.88 (0.50–1.54)	1.23 (0.62–2.40)	0.74 (0.41–1.35)	0.90 (0.43–1.88)
>75,000	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Marital status				
Married	1.39 (1.01–1.91)	1.48 (0.96–2.29)	1.32 (0.91–1.92)	1.30 (0.86–1.98)
Not married	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Employment				
Unemployed	1.04 (0.74–1.45)	1.33 (0.90–1.98)	0.82 (0.59–1.14)	1.14 (0.78–1.68)
Employed	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Educational attainment				
Graduated from high school	0.83 (0.59–1.17)	0.78 (0.45–1.36)	0.74 (0.50–1.09)	0.75 (0.44–1.26)
Some college	0.85 (0.61–1.20)	1.26 (0.75–2.10)	0.86 (0.61–1.20)	0.88 (0.53–1.45)
Some high school	0.93 (0.56–1.55)	2.09 (0.99–4.42)	0.72 (0.45–1.16)	1.10 (0.54–2.24)
College graduate	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Residence				
Rural	0.86 (0.64–1.14)	1.10 (0.72–1.68)	0.82 (0.62–1.10)	0.89 (0.60–1.31)
Urban	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]

Abbreviation: AOR, adjusted odds ratio; Pap, Papanicolaou; SDOH, social determinants of health.

[a] Adjusted for race, annual household income, marital status, employment status, health insurance coverage, education level, and rural/urban residence, taking into account the complex survey design factors such as weighting, stratification, and clustering.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E98 DECEMBER 2024

ORIGINAL RESEARCH

Trends in Gestational Weight Gain and Prepregnancy Obesity in South Carolina, 2015–2021

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0137.htm

Suggested citation for this article: Simpson SE, Malek AM, Wen C, Neelon B, Wilson DA, Mateus J, et al. Trends in Gestational Weight Gain and Prepregnancy Obesity in South Carolina, 2015–2021. Prev Chronic Dis 2024;21:240137. DOI: https://doi.org/10.5888/pcd21.240137.

PEER REVIEWED

Summary

What is already known on this topic?

The prevalence of prepregnancy obesity, inadequate weight gain, and excessive weight gain is high among pregnant women and varies by race and ethnicity. However, whether the COVID-19 pandemic (eg, food shortages, isolation due to lockdown measures) had a significant long-term effect on weight gain in this population is unclear.

What is added by this report?

The COVID-19 pandemic did not alter trends of gestational weight gain. It did, however, have a small effect on trends in prepregnancy obesity, with differential effects across racial and ethnic groups.

What are the implications for public health practice?

Prepregnancy obesity and gestational weight gain are public health issues that can lead to the development of adverse maternal and infant pregnancy outcomes, warranting effective public health interventions.

Abstract

Introduction

We examined trends in prepregnancy obesity and gestational weight gain, with a focus on racial and ethnic differences, before and during the COVID-19 pandemic in South Carolina.

Methods

Hospital and emergency department discharge codes were linked to birth certificates. Prepregnancy obesity was defined as a body mass index (kg/m^2) of 30 or higher. Gestational weight gain was defined as inadequate, adequate, or excessive based on the 2009 Institute of Medicine guidelines. A generalized linear model with a multinomial distribution and glogit link estimated the risk of inadequate weight gain and excessive weight gain with adequate weight gain as the reference group. The generalized linear model with a modified Poisson distribution and log link estimated prepregnancy obesity risk with nonobese as the reference group.

Results

Our study included 306,344 full-term, singleton live births among 239,597 mothers from 2015 through 2021. The prevalence of inadequate weight gain increased across all racial and ethnic groups prepandemic (relative risk [RR] = 1.02; 95% CI, 1.01–1.02) and attenuated during the pandemic (RR = 0.99; 95% CI, 0.96–1.01). The prevalence of excessive weight gain was high and remained stable across all races and ethnicities before and during the pandemic. The prevalence of prepregnancy obesity increased across all racial and ethnic groups prepandemic; the prevalence after the start of the pandemic increased only among women of “other” races and ethnicities (RR = 1.12; 95% CI, 1.05–1.19) while attenuating among Hispanic, non-Hispanic Black, and non-Hispanic White women.

Conclusion

The COVID-19 pandemic did not alter trends of gestational weight gain; however, it did have a small effect on trends in prepregnancy obesity, with differential effects across racial and ethnic groups. The prevalence of prepregnancy obesity, inadequate weight gain, and excessive weight gain remains high among pregnant women in South Carolina. Obesity and weight gain are risk factors for many adverse maternal and infant preg-

nancy outcomes. Their high prevalence indicates the importance of developing effective weight management programs for women of childbearing age and pregnant women.

Introduction

Over the past 40 years, obesity and weight gain have increased rapidly in the US, particularly among children, adolescents, and young adults. However, the literature is lacking assessment of how obesity and weight gain have changed over time among women of childbearing age. The Centers for Disease Control and Prevention's (CDC's) Pregnancy Risk Assessment Monitoring System and the National Vital Statistics System reported the prevalence of adequate weight gain during pregnancy as 32.1% during 2012 and 2013 (1). During the same period, the prevalence of inadequate weight gain during pregnancy was 20.4%, and the prevalence of excessive weight gain was 47.5%. Stratified by prepregnancy body mass index (BMI) (kg/m^2) category, underweight women (32.2%) were more likely to gain inadequate weight during pregnancy, whereas 61.6% of overweight and 55.8% of obese women were more likely to gain excessive weight than women of normal weight (1).

CDC's National Vital Statistics System reported that 27.2% of women were overweight before pregnancy and 30% had obesity in 2020. Among women who had obesity, 16.1% were classified as class I obese (BMI 30.0 to 34.9), 8.1% as class II obese (BMI 35.0 to 39.9), and 5.9% as class III obese (BMI ≥40.0) (2). Additionally, the prevalence of obesity was significantly higher among non-Hispanic Black women (40.3%) compared with non-Hispanic White (27.4%) and Hispanic women (33.6%) (2).

Prepregnancy obesity and gestational weight gain are associated with many adverse infant outcomes (low birthweight, preterm birth, large size for gestational age, admission to neonatal intensive care unit, macrosomia, childhood obesity, infant mortality) and poor maternal outcomes (cesarean delivery, gestational hypertension, preeclampsia) (3–7).

Although the association between prepregnancy obesity, gestational weight gain, and adverse maternal and infant outcomes has been established, few studies have focused on how the prevalence of these conditions has changed over time, especially during the COVID-19 pandemic. The pandemic has affected not only the health care system and subsequent health outcomes but also people's physical activity and eating behaviors because of social distancing measures (both self-imposed and mandated) and disruptions in the US food supply chain. Initial studies on the pandemic's effect on obesity and weight gain differ by whether the increase was significant (8–15). Our objective was to examine trends in prepregnancy obesity and gestational weight gain with a focus on racial and ethnic differences and associated sociodemographic and clinical factors before and during the COVID-19 pandemic in South Carolina, from January 2015 through December 2021.

Methods

Study design and population

Our sample population was South Carolina resident mothers who delivered live singleton births from January 2015 through December 2021. Because gestational weight gain is affected by preterm birth, we limited the population to full-term (37 weeks) deliveries. The South Carolina Department of Health and Environmental Control provided information from birth certificates. Data from birth certificates were linked to maternal inpatient hospital discharge records and emergency department (ED) visit records by the South Carolina Revenue and Fiscal Affairs office. Beginning in 2012, that office also provided data at least 3 years before each delivery on maternal inpatient discharges and ED visits to identify pre-existing health conditions. Database linkages were based on an algorithm created by the South Carolina Revenue and Fiscal Affairs office that used personal identifying information. The institutional review board of the Medical University of South Carolina approved our study as exempt research.

Variable definition

Maternal race and ethnicity were categorized as Hispanic, non-Hispanic Black, non-Hispanic White, or "other" race or ethnicity based on what was commonly reported on birth certificate and inpatient and ED visit records. However, a mother was classified as Hispanic if she identified as Hispanic 3 or more times in the dataset. The "other" race or ethnicity group included women who self-identified as Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander or for whom race/ethnicity was missing. Birth certificates reported education (categorized as less than high school graduate, high school diploma or General Educational Development [GED], some college, or undergraduate or associate degree or more); residence (rural vs urban); receipt of Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) benefits during pregnancy; smoking during pregnancy or prepregnancy (smoker vs nonsmoker); and maternal prepregnancy weight and height. Women were classified as underweight (BMI 14.0–18.4), normal (BMI 18.5–24.9), overweight (BMI 25.0–29.9), or obese (BMI ≥30.0). For our analysis, the outcome of prepregnancy obesity was defined as obese versus nonobese. Firstborn was defined as the first live or stillborn birth from 2015 through 2021 of a mother without a history of a previous live birth or stillbirth on the birth certificate. Medicaid status was defined as being Medicaid eligible within 2 months of giving birth based on the statewide Medicaid eligibility file. Gestational weight gain was categorized as adequate, inadequate, or excessive based on the mother's prepregnancy BMI, according to the 2009 Institute of Medicine guidelines (16). These guidelines state how much weight women with singleton pregnancies should gain during pregnancy based on the mother's prepregnancy weight status: underweight, 28 to 40 lb; normal weight, 25 to 35 lb; overweight, 15 to 25 lb; and obese, 11 to 20 lb.

Statistical analysis

We used the χ^2 test in preliminary statistical analyses to examine bivariate associations between sociodemographic, lifestyle, and clinical factors and outcomes of interest by maternal racial and ethnic group. A generalized linear model with a modified Poisson distribution and log link was used to estimate the risk of prepregnancy obesity, with nonobese as the reference group. A second generalized linear model with a multinomial distribution and glogit link was used to estimate the risk of inadequate or excessive weight gain with adequate weight gain as the reference group. Modified Poisson models were used to express estimates as risk ratios (RRs) because log–binomial models can have convergence issues as the model's complexity increases (17,18). Additionally, the point estimates of the modified Poisson model are proven to be unbiased when the link function is misspecified or the response rate is low (18). Generalized estimating equations with an exchangeable working correlation were used to account for mothers who had multiple pregnancies. To assess trends over time, a predetermined change point at the first quarter of 2020 (ie, March 2020), defining the start of the COVID-19 pandemic, was included in the models. No sensitivity analyses were conducted to assess robustness of results. Interaction terms were included to assess the association between racial and ethnic groups and trends over time. Covariates included in the models were identified a priori. For prepregnancy obesity, we ran an unadjusted model with the main effects of time before the change point, time after the change point, and race and ethnicity as well as interaction terms between time (before and after the change point) and race and ethnicity. For gestational weight gain, we ran an unadjusted model with the main effects of time before the change point, time after the change point and race and ethnicity. For both outcomes, models were adjusted for sociodemographic factors (age, education, rural residence, Medicaid, WIC receipt during pregnancy) and lifestyle and clinical factors (smoking during or prepregnancy, firstborn, prepregnancy BMI).

We then plotted the prevalence of each outcome from 2015 to 2021 by using the unadjusted models of each outcome for the specified period with 95% CIs. *P* values of.05, and corresponding 95% CIs were used to determine significance. Analyses were conducted in SAS (SAS Institute), and figures were created in R (R Foundation) software.

Results

Study population

Of 266,146 South Carolina mothers with at least 1 pregnancy from 2015 through 2021 (331,979 births), 671 (0.25%) were excluded because information on maternal age was inconsistent across multiple sources (defined as varying by more than ±2 years). We excluded 159 mothers (0.06%) who did not have a live birth during the study time frame, 881 (0.33%) who resided outside South Carolina, 64 (0.02%) who had a live birth of triplets or quadruplets during the study period, 6,417 (2.4%) who had a twin birth, and lastly, 18,357 (7.1%) who did not have a full-term (≥37 weeks) singleton birth. The final dataset consisted of 239,597 mothers with 1 or more live, full-term, singleton births (306,344 pregnancies) (Figure 1). Some sociodemographic, lifestyle, and clinical information was available for all mothers from linked inpatient hospital and ED visit data procedure and diagnostic code files.

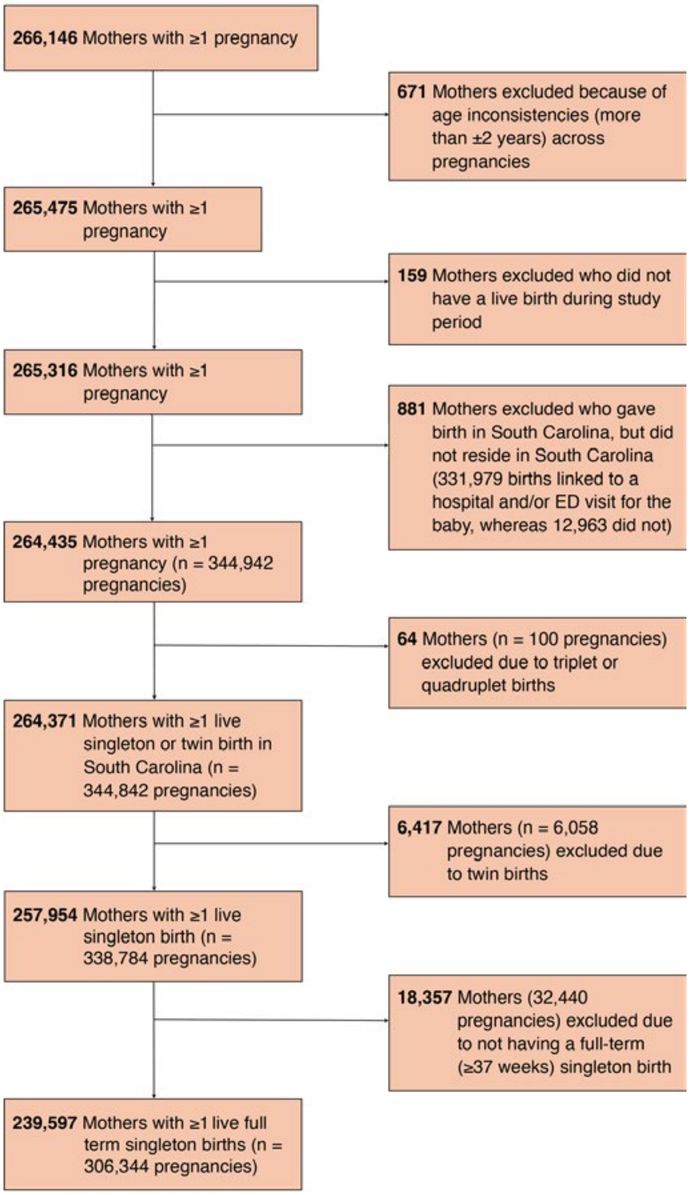

Figure 1. Flowchart of exclusion criteria for study sample, study of trends in gestational weight gain and prepregnancy obesity in South Carolina, 2015 through 2021.

Characteristics of the 306,344 pregnancies resulting in a live singleton birth varied by race and ethnicity (Table 1). From 2015 through 2021, 57.4% of pregnancies were among non-Hispanic White women, 30.2% were among non-Hispanic Black women, 7.6% were among Hispanic women, and 4.8% were among women of other racial or ethnic groups. Average (SD) age at delivery ranged from 29.1 (5.9) years among women of other races or ethnicities to 26.7 (5.7) years among non-Hispanic Black women. Among Hispanic women, approximately 42.9% had less than a high school education, compared with only 9.4% of non-Hispanic White women. Medicaid eligibility at delivery was 72.2% among non-Hispanic Black women, 70.4% among Hispanic women, 49.4% among women of other racial or ethnic groups, and 39.1% among non-Hispanic White women. WIC receipt during pregnancy was 61.8% among non-Hispanic Black women, 43.9% among Hispanic women, 31.5% among women of other racial or ethnic groups, and 27.5% among non-Hispanic White women. Maternal prepregnancy obesity ranged from 44.8% of pregnancies among non-Hispanic Black women to 22.2% of pregnancies among women of other racial or ethnic groups. Excessive weight gain during pregnancy ranged from 51.8% of pregnancies among non-Hispanic White women to 39.2% of pregnancies among Hispanic women.

Gestational weight gain by race and ethnicity

In the assessment of unadjusted trends in gestational weight gain before and after the start of the COVID-19 pandemic, the interactions between time and race and ethnicity were not significant (P = .30 and .47, respectively), indicating that trends over time were similar across all racial and ethnic groups.

Inadequate weight gain. For non-Hispanic White women, the prevalence of inadequate weight gain in 2015, quarter 1 was 18.0%; in 2020, quarter 1, 19.1%; and in 2021, quarter 4, 19.1% (Figure 2, Panel A). Among non-Hispanic Black women, the prevalence in 2015, quarter 1 was 27.3%; in 2020, quarter 1, 29.0%; and in 2021, quarter 4, 29.0%. Among Hispanic women, the prevalence in 2015, quarter 1 was 27.5%; in 2020, quarter 1, 29.3%; and in 2021, quarter 4, 29.2%. The prevalence among women of other races or ethnicities in 2015, quarter 1 was 27.4%; in 2020, quarter 1, 29.1%; and in 2021, quarter 4, 29.1%.

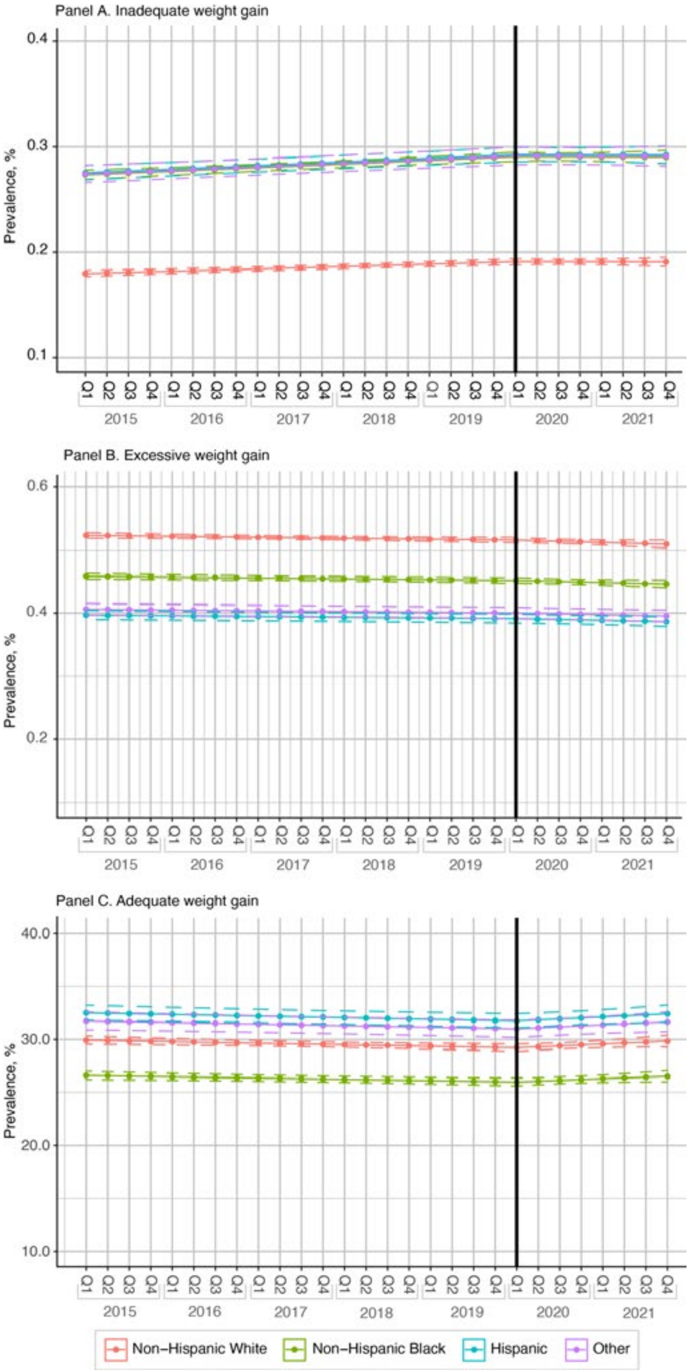

Figure 2. Prevalence of 3 categories of gestational weight gain among women with 1 or more full-term (≥37 weeks) singleton births in South Carolina, by race or ethnicity, from 2015 through 2021: inadequate weight gain (Panel A), excessive weight gain (Panel B), and adequate weight gain (Panel C). Thick black vertical line indicates the start of the COVID-19 pandemic. Dotted lines indicate 95% CIs. Other race or ethnicity includes women who self-identified as Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander or those whose race/ethnicity was missing. Abbreviation: Q, quarter of year.

In the unadjusted model assessing the main effect for race and ethnicity (Table 2, Model 1), the RR for inadequate weight gain relative to adequate weight gain for a 1-year increase in calendar time was 1.02 (95% CI, 1.01–1.02) before the pandemic (ie, change point) and 0.99 (95% CI, 0.96–1.01) after the pandemic (ie, after the change point). Across all racial and ethnic groups, non-Hispanic Black (RR = 1.71, 95% CI, 1.67–1.75), Hispanic (RR = 1.41; 95% CI, 1.36–1.46), and women of other racial and ethnic groups (RR = 1.44; 95% CI, 1.37–1.51) were more likely to gain inadequate relative to adequate weight during each pregnancy compared with non-Hispanic White women.

In the fully adjusted model (Table 2, Model 2), the RR of inadequate weight gain relative to adequate weight gain for a 1-year increase in calendar time before the pandemic (ie, change point) was 1.02 (95% CI, 1.01–1.03) and 0.99 (95% CI, 0.97–1.02) after the start of the pandemic (ie, after the change point). Age, higher maternal education, Medicaid eligibility, rural residence, smoking during or prepregnancy, having a firstborn, and having obesity or being overweight prepregnancy were associated with inadequate weight gain during pregnancy.

Excessive weight gain. Among non-Hispanic White women, the prevalence of excessive weight gain for pregnancies in 2015, quarter 1, was 52.3%; in 2020, quarter 1, 51.6%; and in 2021, quarter 4, 50.9% (Figure 2, Panel B). Among non-Hispanic Black women, the prevalence in 2015, quarter 1 was 45.8%; in 2020, quarter 1, 45.2%; and in 2021, quarter 4, 44.6%. Among Hispanic women, the prevalence in 2015, quarter 1 was 39.7%; in 2020, quarter 1, 39.1%; and in 2021, quarter 4, 38.6%. Among women of other races or ethnicities, the prevalence in 2015, quarter 1 was 40.6%; in 2020, quarter 1, 40.0%; and in 2021, quarter 4, 39.5%.

In the unadjusted model assessing the main effect of race and ethnicity (Table 2, Model 1), the RR for excessive weight gain relative to adequate weight gain for a 1-year increase in calendar time was 1.00 (95% CI, 1.00–1.01) before the pandemic (ie, before the change point) and 0.98 (95% CI, 0.96–1.00) after the start of pandemic (ie, after the change point). Across racial and ethnic groups, non-Hispanic Black women (RR = 0.99, 95% CI, 0.97–1.01) had similar risk during each pregnancy of excessive weight gain, whereas Hispanic women (RR = 0.70; 95% CI, 0.67–0.72) and women of other racial and ethnic groups (RR = 0.73; 95% CI, 0.70–0.76) were less likely to gain excessive weight compared with non-Hispanic White women.

In the fully adjusted model (Table 2, Model 2), the risk of excessive weight gain relative to adequate weight gain for a 1-year increase in calendar time before the pandemic (ie, before the change point) was 1.00 (95% CI, 0.99–1.00) and 0.98 (95% CI, 0.96–1.00) after the start of the pandemic (ie, after the change point). Age, higher maternal education, WIC receipt during pregnancy, smoking during or prepregnancy, having a firstborn, and having obesity or being overweight before pregnancy were associated with increased likelihood of excessive weight gain during pregnancy.

Adequate weight gain. Across all groups, the prevalence of adequate weight gain decreased before the pandemic and rose after the pandemic (Figure 2, Panel C). The prevalence of adequate weight gain among non-Hispanic White women in 2015, quarter 1, was 30.0%; in 2020, quarter 1, 29.2%; and in 2021, quarter 4, 29.8%. Among non-Hispanic Black women, the prevalence in 2015, quarter 1 was 26.6%; in 2020, quarter 1, 26.0%; and in 2021, quarter 4, 26.5%. Among Hispanic women, the prevalence in 2015, quarter 1 was 32.5%; in 2020, quarter 1, 31.8%; and 2021, quarter 4, 32.4%. Among women of other races or ethnicities, the prevalence in 2015, quarter 1 was 31.8%; in 2020, quarter 1, 31.0%; and in 2021, quarter 4, 31.7%.

Obesity

The prevalence of prepregnancy obesity was 23.7% in 2015 quarter 1, 29.2% in 2020 quarter 1, and 29.4% in 2021 quarter 4 for non-Hispanic White women (Figure 3). For non-Hispanic Black women, the prevalence of prepregnancy obesity was 41.2% in 2015, quarter 1 and increased to 47.0% in 2020, quarter 1, then further increased to 48.0% in 2021, quarter 4. For Hispanic women, prepregnancy obesity increased from 25.2% to 31.4% between 2015, quarter 1 and 2020, quarter 1, and then decreased slightly to 31.0 % in 2021, quarter 1. Among women of other racial and ethnic groups, the prevalence of prepregnancy obesity in 2015, quarter 1 was 18.7% then increased to 23% in 2020, quarter 1 and further increased to 28.1% in 2021, quarter 4.

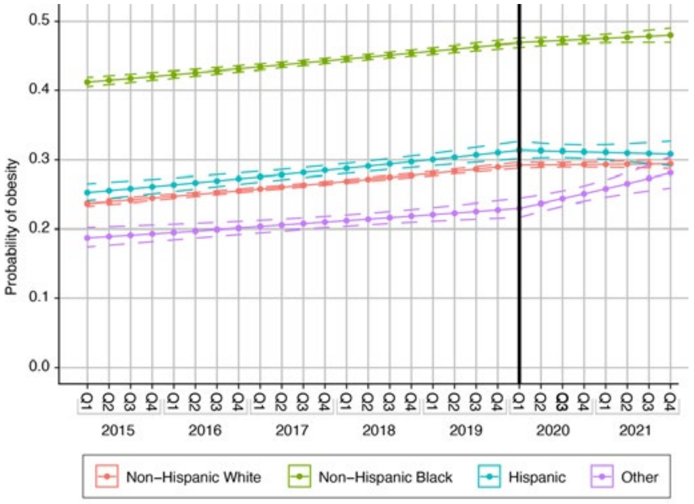

Figure 3. Prevalence of prepregnancy obesity among women with 1 or more full term (≥37 weeks) singleton births in South Carolina, by race and ethnicity, from 2015 through 2021. The change point was the start of the COVID-19 pandemic, quarter (Q) 1, the first quarter of 2020. Dotted lines indicate 95% CIs.

RRs of prepregnancy obesity, unadjusted and adjusted for sociodemographic and lifestyle and clinical factors, varied by racial and ethnic groups before and after the change point (start of the pandemic, 2020, quarter 1) (Table 3). Temporal trends differed by racial or ethnic group before (*P* =. 002) and after (*P* =. 03) the pandemic. In the model assessing the main effect of race and ethnicity (Table 3, Model 1), the RR of prepregnancy obesity among non-Hispanic White women for a 1-year increase in calendar time before the pandemic was 1.04 (95% CI, 1.04–1.05); among non-Hispanic Black women, 1.03 (95% CI, 1.02–1.03); among Hispanic women, 1.04 (95% CI, 1.03–1.06); and among women of other races or ethnicities, 1.04 (95% CI, 1.02–1.07). After the pandemic, the risk of prepregnancy obesity for a 1-year increase in calendar time attenuated among non-Hispanic White (RR = 1.01, 95% CI, 0.99–1.02), non-Hispanic Black (RR = 1.01, 95% CI: 1.00–1.03) and Hispanic women (RR = 0.99, 95% CI, 0.95–1.04). However, among women of other racial and ethnic groups, the risk of prepregnancy obesity for a 1-year increase in calendar time increased significantly after the pandemic (RR = 1.12, 95% CI, 1.05–1.19).

In the fully adjusted model (Table 3, Model 2), RRs of prepregnancy obesity for a 1-year increase in calendar time before and after the pandemic for racial and ethnic groups were similar to their unadjusted values after adjusting for sociodemographic, lifestyle and clinical factors. Age, higher maternal education, rural residence, Medicaid eligibility at delivery, and WIC eligibility during pregnancy were significantly associated with an elevated risk of prepregnancy obesity.

Discussion

The objective of our study was to assess trends in gestational weight gain and prepregnancy obesity before and after March 2020 in South Carolina because we believed trends would be significantly affected by the COVID-19 pandemic in its early stage. Our principal findings showed the relative prevalence of prepregnancy obesity increased 3% to 4% per year across all racial and ethnic groups before the pandemic; however, the level stabilized after the pandemic for non-Hispanic White and Hispanic women, while increasing rapidly among non-Hispanic Black women and women of other racial and ethnic groups. The prevalence of inadequate weight gain increased 1% to 2% across all racial and ethnic groups before the pandemic and then stabilized afterwards. The prevalence of inadequate weight gain was significantly higher among non-Hispanic Black women, Hispanic women, and women of other racial and ethnic groups across the whole study period compared with non-Hispanic White women. In contrast, the prevalence of excessive weight gain was high across all racial and ethnic groups and remained stable before the pandemic, while decreasing slightly after the pandemic.

Literature on the COVID-19 pandemic's effect on body weight, prepregnancy BMI, and gestational weight gain among women of reproductive age (both teens and adults) remains sparse, although preliminary studies have begun to emerge. Two US studies reported a significant increase (0.06 kg and 0.46 kg) in gestational weight gain during the COVID-19 pandemic (19,20). Additionally, among women who were obese before pregnancy, gestational weight gain increased 0.17 kg during the pandemic (19). However, a Washington State study found a nonsignificant decrease in gestational weight gain (11.2 ±4.3 kg vs 10.6 ±5.4 kg) between women who delivered before and during the pandemic (21).

Though studies assessing the effect of the COVID-19 pandemic on prepregnancy weight and gestational weight gain among pregnant women are limited, several studies have been published on the effect of the pandemic on body weight, weight gain, and dietary and lifestyle behaviors among the overall adult population in the US and worldwide. In general, the pandemic appears to have had mixed effects on eating and lifestyle behaviors, because the prevalence of weight gain and mean increase in body weight and BMI varied between studies, with some people gaining weight and others losing weight. Most studies found that weight gain was due to physical inactivity, sedentary behaviors (eg, increased screen time), unhealthy eating habits (eg, increased consumption of highly processed food, increased number of meals, snacking, alcohol consumption), reduced sleep, emotional eating, stress, depression, and anxiety (8–15). People who were overweight and obese before the pandemic were more likely to gain weight during the pandemic (12–14).

Although the aforementioned studies showed that the pandemic affected body weight, weight gain, and eating and lifestyle behaviors, whether the effect is clinically significant and long-term remains in question. Furthermore, because most of these studies were cross-sectional (eg, self-reported online survey), they cannot be used to infer causality and they are vulnerable to bias, which can affect reliability and generalizability of their findings. Such bias includes selection bias (eg, some studies had mostly female or male participants), recall bias (eg, self-reported body weight, BMI, height), and reporting bias (eg, participants may not answer truthfully to questions asked on social and lifestyle behaviors).

Strengths and limitations

The main strengths of our study were that first, we were able to follow women over time by linked vital statistics and inpatient hospital discharge and ED visit encounter data. Second, though administrative data and birth certificates may have some reliability and validity issues, they provide information on all births at the population level and provide important population-based estimates.

Our study had limitations, including the use and reliability of administrative data and miscoding of BMI classification, gestational weight gain, and race and ethnicity. BMI was based on self-reported prepregnancy weight and height taken from medical records, which can lead to misclassification. Similarly, with gestational weight gain, misclassification could result from BMI misclassification and incorrect report of weight before pregnancy. Self-reported weight tends to be underestimated and individuals who are overweight or obese tend to be more likely to underestimate their weight (22). Pregnant women tend to underreport prepregnancy and delivery weight and overreport gestational weight gain; however, misclassification has been found not to bias the association between BMI, pregnancy weight, and pregnancy outcomes (23). Misclassification of race and ethnicity could have occurred because it was based on information found in administrative data and might not reflect self-reported race and ethnicity. Information was lacking on such factors as diet, physical activity, stress, and neighborhood characteristics, which may be related to obesity and gestational weight gain. Lastly, we excluded pregnant women who had preterm birth from the analysis because early delivery reduces overall gestational weight gain.

Conclusion

In South Carolina, the COVID-19 pandemic did not alter trends of gestational weight gain. The pandemic did, however, have a small effect on trends in prepregnancy obesity, with differential effects across racial and ethnic groups. Prepregnancy obesity and gestational weight gain are important public health issues that affect maternal and infant pregnancy outcomes and therefore warrant effective public health interventions. More studies are needed to fully understand the pandemic's effect on BMI, prepregnancy obesity, and gestational weight gain among women of childbearing age and pregnant women, with an emphasis on racial and ethnic differences. A better understanding of patterns and determinants of pregnancy outcomes after the pandemic can inform effective public health strategies in this population.

Acknowledgments

This work was supported by the National Institutes of Health National Heart, Lung, and Blood Institute grant R01HL163963 (multiple principal investigators, A.M.M. and K.J.H.). The funding agency did not participate in the design and conduct of the study; collection, management, analysis, and interpretation of the data; or preparation, review, and approval of the manuscript. The article represents the views of the authors and not those of the Veterans Health Administration or the Health Services Research and Development Service. S.E.S. was responsible for analyzing the data, interpreting the data and preparing/revising the manuscript. A.M.M. and K.J.H. conceived/designed the study, conducted/supervised the research, helped with analysis/interpretation of the data and reviewed/edited the manuscript. C-C.W., B.N., D.A.W., J.E.K., K.C., M.A., and M.F. assisted with analysis/interpretation of the data and reviewed/edited the manuscript. J.M., J.P. and H.F. interpreted the data and reviewed/edited the manuscript. All authors were involved in writing the manuscript and gave final approval of the submitted version. The data used for this study cannot be shared due to policies of the South Carolina Revenue and Fiscal Affairs Office, Health and Demographics Section and the South Carolina Department of Health and Environmental Control. The policies of these data sources also require that small numbers of less than 5 be reported as <5. The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article. The authors received no other external financial support for the research, authorship, or publication of this article. No copyrighted material, surveys, instruments, or tools were used in this article.

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Tables

Table 1. Characteristics of 306,344 Pregnancies Resulting in a Live Full-Term (≥37 Weeks) Singleton Birth, South Carolina, 2015–2021[a]

Characteristic	Racial and or ethnic group			
	Non-Hispanic White (n = 175,991)	Non-Hispanic Black (n = 92,402)	Hispanic (n = 23,423)	Other (n = 14,708)
Sociodemographic				
Age at delivery, mean (SD), y	28.4 (5.5)	26.7 (5.7)	28.2 (6.1)	29.1 (5.9)
Education, %[b]				
Less than high school education	9.4	13.3	42.9	17.0
High school diploma or GED	20.0	34.4	27.0	20.6
Some college	23.1	30.4	13.6	17.8
College or associates degree or more	47.5	22.0	16.5	44.6
Rural residence, %	29.9	36.0	28.1	23.3
Medicaid eligibility at delivery, %	39.1	72.2	70.4	49.4
WIC receipt during pregnancy, %[a]	27.5	61.8	43.9	31.5
Lifestyle and clinical factors				
Smoking during or prepregnancy, %[a]	14.8	8.5	2.0	4.7
Firstborn, %[b]	33.1	29.3	25.9	34.2
Prepregnancy BMI (kg/m^2), %[b]				
Underweight (<18.5)	3.6	2.8	2.0	4.6
Normal (18.5–24.9)	44.2	27.6	36.5	46.7
Overweight (25.0–29.9)	25.1	24.8	32.4	26.6
Obese (≥30.0)[b]	27.1	44.8	29.1	22.2
Gestational weight gain, %[b,c]				
Adequate	29.6	26.3	32.1	31.4
Inadequate	18.7	28.4	28.6	28.5
Excessive	51.8	45.3	39.2	40.2

Abbreviations: BMI, body mass index; GED, General Educational Development; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Stratified by racial and ethnic group.

[b] Number of women with missing data values on outcomes and covariates: education, 844; smoking during or prepregnancy, 195; firstborn, 66; prepregnancy BMI, 3,696; WIC, 14; prepregnancy obesity, 3,696; gestational weight gain classification, 3,696.

[c] Adequate weight gain during pregnancy for women who were underweight was 50 to 62 lb; normal weight gain, 25 to 35 lb; overweight, 15 to 25 lb; and obese, 11 to 20 lbs. Inadequate weight gain was defined as gaining less than the recommended weight during pregnancy. Excessive weight gain was defined as gaining more than the recommended weight during pregnancy. In our study, 87,350 women gained adequate weight during pregnancy, 68,998 women gained inadequate weight, and 146,300 gained excessive weight.

Table 2. Trends in Inadequate and Excessive Weight Gain Among Live Full Term (≥37 Weeks) Singleton Births, Unadjusted and Adjusted for Sociodemographic and Lifestyle and Clinical Factors, South Carolina, 2015–2021

Characteristic	Inadequate, relative risk (95% CI)[a]		Excessive, relative risk (95% CI)[a]	
	Model 1[b]	Model 2[c]	Model 1[b]	Model 2[c]
Time before change point (per year)[d]	1.02 (1.01–1.02)[e]	1.02 (1.01–1.03)[e]	1.00 (1.00–1.01)	1.00 (0.99–1.00)
Time after change point (per year)[d]	0.99 (0.96–1.01)	0.99 (0.97–1.02)	0.98 (0.96–1.00)	0.98 (0.96–1.00)
Trend by sociodemographic characteristic				
Race or ethnicity				
Non-Hispanic White	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Non-Hispanic Black	1.71 (1.67–1.75)[e]	1.45 (1.42–1.49)[e]	0.99 (0.97–1.01)	0.85 (0.83–0.87)[e]
Hispanic	1.41 (1.36–1.46)[e]	1.17 (1.13–1.22)[e]	0.70 (0.67–0.72)[e]	0.67 (0.65–0.69)[e]
Other[f]	1.44 (1.37–1.51)[e]	1.42 (1.36–1.49)[e]	0.73 (0.70–0.76)[e]	0.76 (0.73–0.79)[e]
Age at delivery (per year)	—[g]	1.00 (0.995–0.996)[e]	—[g]	1.00 (0.994–0.998)[e]
Education				
Less than high school education	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
High school diploma or GED	—[g]	0.85 (0.82–0.88)[e]	—[g]	1.08 (1.05–1.12)[e]
Some college	—[g]	0.73 (0.70–0.76)[e]	—[g]	1.13 (1.10–1.17)[e]
College or associate degree or more	—[g]	0.62 (0.60–0.64)[e]	—[g]	1.08 (1.04–1.12)[e]
Rural residence (vs urban)	—[g]	1.07 (1.05–1.10)[e]	—[g]	1.01 (0.99–1.03)
Medicaid eligibility at delivery (yes vs no)	—[g]	1.11 (1.08–1.14)[e]	—[g]	1.01 (0.99–1.03)
WIC receipt during pregnancy (yes vs no)	—[g]	1.01 (0.99–1.04)	—[g]	1.05 (1.02–1.07)[e]
Trends by lifestyle and clinical factors				
Smoking during or prepregnancy (yes vs no)	—[g]	1.07 (1.03–1.10)[e]	—[g]	1.26 (1.22–1.30)[e]
Firstborn (yes vs no)	—[g]	0.91 (0.88–0.93)[e]	—[g]	1.31 (1.28–1.33)[e]
Prepregnancy BMI (kg/m^2)				
Underweight (<18.5)	—[g]	1.02 (0.97–1.07)	—[g]	0.55 (0.52–0.58)[e]
Normal (18.5–24.9)	—[g]	1 [Reference]	—[g]	1 [Reference]
Overweight (25.0–29.9)	—[g]	0.79 (0.77–0.81)[e]	—[g]	2.26 (2.21–2.32)[e]
Obese (≥30.0)	—[g]	1.28 (1.25–1.32)[e]	—[g]	2.11 (2.06–2.15)[e]

Abbreviations: BMI, body mass index; GED, General Education Development; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

[a] Relative risks represent the risk of inadequate and excessive weight gain for a 1-year increase in calendar time.

[b] Model 1: relative risks for time before and after change point (first quarter of 2020) for the main effect for race and ethnicity. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[c] Model 2: relative risks for time before and after change point (first quarter of 2020) adjusted for sociodemographic characteristics and lifestyle and clinical factors. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[d] Interaction *P* value for time before change point and race or ethnicity was.30. Interaction *P* value for time after change point and race or ethnicity was .47 in Model 1. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[e] Significant at *P* <. 05.

[f] Includes women who self-identified as Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, or those whose race/ethnicity was missing or unknown.

[g] Indicates no relative risks were estimated for sociodemographic characteristics and lifestyle and clinical factors.

Table 3. Trends in Prepregnancy Obesity Among Live, Full Term (≥37 Weeks) Singleton Births, Unadjusted and Adjusted for Sociodemographic and Lifestyle and Clinical Factors, South Carolina, 2015–2021

Characteristic	Prepregnancy obesity, relative risk (95% CI)[a]	
	Model 1[b]	Model 2[c]
Time before change point (per year)[d]		
Race or ethnicity		
Non-Hispanic White	1.04 (1.04–1.05)[e]	1.04 (1.04–1.05)[e]
Non-Hispanic Black	1.03 (1.02–1.03)[e]	1.03 (1.02–1.03)[e]
Hispanic	1.04 (1.03–1.06)[e]	1.06 (1.04–1.07)[e]
Other[f]	1.04 (1.02–1.07)[e]	1.05 (1.03–1.07)[e]
Time after change point (per year)[a]		
Race or ethnicity		
Non-Hispanic White	1.01 (0.99–1.02)	1.01 (0.99–1.02)
Non-Hispanic Black	1.01 (1.00–1.03)	1.01 (1.00–1.03)
Hispanic	0.99 (0.95–1.04)	1.00 (0.96–1.04)
Other[f]	1.12 (1.05–1.19)[e]	1.13 (1.06–1.20)[e]
Trend by sociodemographic characteristic		
Age at delivery (per year)	—[g]	1.02 (1.02–1.03)[e]
Education		
Less than high school education	—[g]	1 [Reference]
High school diploma or GED	—[g]	1.05 (1.03–1.07)[e]
Some college	—[g]	1.09 (1.07–1.11)[e]
College or associates degree or more	—[g]	0.84 (0.82–0.85)[e]
Rural residence (vs urban)	—[g]	1.11 (1.10–1.13)[e]
Medicaid eligibility at delivery (yes vs no)	—[g]	1.11 (1.09–1.12)[e]
WIC receipt during pregnancy (yes vs no)	—[g]	1.21 (1.19–1.22)[e]
Trends by lifestyle and clinical characteristic		
Smoking during or prepregnancy (yes vs no)	—[g]	0.94 (0.92–0.96)[e]
Firstborn (yes vs no)	—[g]	0.89 (0.88–0.90)[e]

Abbreviations: BMI, body mass index; GED, General Educational Development; WIC, Supplemental Nutrition Program for Women, Infants, and Children.

[a] Relative risks represent the risk of prepregnancy obesity for a 1-year increase in calendar time.

[b] Model 1: relative risks for the interaction of time before and after the change point (first quarter of 2020) and the main effect for race and ethnicity. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[c] Model 2: relative risks for the interaction of time before and after the change point (first quarter of 2020) adjusted for sociodemographic characteristics and lifestyle and clinical factors. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[d] Interaction *P* value for time before the change point and race or ethnicity was <.001. Interaction *P* value for time after change point and race and ethnicity was. 03 in Model 1. The change point is a predetermined point at the first quarter of 2020 (ie, March 2020) defining the start of the COVID-19 pandemic.

[e] Significant at *P* <.05.

[f] Includes women who self-identified as Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, or those whose race/ethnicity was missing.

[g] Indicates no relative risks were estimated for sociodemographic characteristics and lifestyle and clinical factors.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E92 NOVEMBER 2024

ORIGINAL RESEARCH

Continuity of Care and Lifestyle Intervention Programs for Spanish-Speaking Immigrants Without Health Insurance at a Free Clinic in Rhode Island

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0136.htm

Suggested citation for this article: Wang C, Yang J, Testa J, Gill M, Leonard M, De Groot AS. Continuity of Care and Lifestyle Intervention Programs for Spanish-Speaking Immigrants Without Health Insurance at a Free Clinic in Rhode Island. Prev Chronic Dis 2024;21:240136. DOI: https://doi.org/10.5888/pcd21.240136.

PEER REVIEWED

Summary

What is already known on this topic?

Lifestyle education programs can improve patient health and decrease use of emergency services, leading to savings for patients and health care systems. However, the effects of destabilizing factors (such as the COVID-19 pandemic) on access to care and health education programs have not been widely studied.

What is added by this report?

This report examines the resilience of a chronic disease management program in an uninsured, low-income Hispanic patient population from 2019 through 2022, during the COVID pandemic.

What are the implications for public health practice?

The results of this report support the implementation of lifestyle change programs to improve health outcomes during times of reduced access to care.

Abstract

Introduction

We conducted a retrospective cohort study to evaluate changes in metabolic biomarkers among participants in Bridging the [Health Equity] Gap (BTG), a free program run by Clínica Esperanza/Hope Clinic (CEHC) for Spanish-speaking immigrants without health insurance in Rhode Island.

Methods

From July 2019 through June 2021, 471 people volunteered to participate in the BTG program. Participants enrolled in lifestyle change classes and visited quarterly with health care providers. We reviewed medical records to collect data on blood glucose, total cholesterol, hemoglobin A_{1c} (HbA_{1c}), and systolic and diastolic blood pressure at baseline and at 6, 12, 18, and 21 months after enrollment. We used paired *t* tests to identify changes in measurements and conducted a regression analysis to analyze trends in longitudinal patient outcomes.

Results

From baseline to 6-month follow-up, we observed significant decreases in all participants' mean HbA_{1c} (−0.71%), systolic (−5 mm Hg), and diastolic blood pressure (−2 mm Hg). At 12 months, significant decreases in mean HbA_{1c} persisted among participants with diabetes and prediabetes (−1.07%). At 12 months, participants with mean systolic blood pressure >120 mm Hg also had significant decreases in mean systolic blood pressure (−9 mm Hg), and patients with diastolic blood pressure >80 mm Hg had significant decreases in mean diastolic blood pressure (−9 mm Hg). Local population-level surges in COVID-19 due to Delta and Omicron variants were associated with increases in HbA_{1c} and blood glucose measurements above trendlines.

Conclusion

The BTG program demonstrated resilience in supporting improvement in the metabolic biomarkers of participants, despite disruptions caused by the COVID-19 pandemic, the continued engagement of participants in self-care despite limited health care access, and underscores the positive role of free clinics among low-income, Spanish-speaking immigrants.

Introduction

Inadequate health insurance coverage is a public health challenge in the US (1). Without the negotiation of health insurance providers, health care visits have substantially higher costs (2) and increased population reliance on preventable emergency care (3). Free clinics provide safety-net health care for populations that lack health insurance, some developing innovative health improvement programs or developing workforces that are linguistically and culturally tailored to their patient population (4). However, research is scant on the assessment of health outcomes during stressful periods, such as pandemics, in the population that uses free clinics.

Clínica Esperanza/Hope Clinic (CEHC) is a nonprofit free clinic for adults without health insurance in Providence, Rhode Island. More than 80% of CEHC patients speak primarily Spanish, and a large proportion are first-generation immigrants. CEHC patients face challenges as a result of poor health literacy and chronic health problems. The Bridging the [Health Equity] Gap (BTG) program was initiated at CEHC in 2015 with a mission to reduce health inequities among patients with chronic diseases through continuity of care, goal-setting appointments, and healthy lifestyle interventions. Program participants visit quarterly with CEHC health care providers and enroll in a healthy lifestyle intervention program, either *Vida Sana* or the National Diabetes Prevention Program (DPP). An evaluation of the financial and clinical effects of the BTG program before the pandemic is available elsewhere (4).

The objective of this study was to describe changes in 5 metabolic biomarkers among participants of the BTG program from July 2019 through July 2022. In this study, the COVID-19 pandemic enabled a natural stress-test of the resilience of the BTG program and improvements in the metabolic biomarkers of program participants. Our hypothesis was that BTG could support continual improvement in the metabolic biomarkers of program participants, despite disruptions caused by the COVID-19 pandemic. We expected to see a significant difference from the alternative (the null hypothesis) that metabolic biomarkers would not improve or change during participants' enrollment in the BTG program.

Methods

This retrospective cohort study was conducted in March 2024. We reviewed the medical records of 471 patients enrolled in BTG during regular clinical operations at CEHC. The evaluation period began on July 1, 2019, and ended on July 1, 2022.

Participants

From October 1, 2019, through October 31, 2021, community health workers, who explained the nature and purpose of the BTG program, recruited participants from the main clinic of CEHC. Outreach efforts, such as those conducted at the Neighborhood Health Station (an outreach clinic opened during COVID-19), helped eligible participants find the main clinic to seek care and participation in BTG. Eligibility for BTG enrollment at CEHC was extended to all residents in Rhode Island who lacked health insurance and were living with diabetes or prediabetes, hypertension, cardiovascular disease, or overweight or obesity. Previous enrollees in the BTG program could also opt in to the new cohort.

Of the 805 participants enrolled in BTG from January 2016 through June 2019, 22 elected to join the new cohort. All participants signed (or signed again, if they were from the previous cohort) a partnership form giving CEHC permission to record individual data in a de-identified spreadsheet, documenting quarterly and yearly chronic disease assessments. Of 516 people recruited, 471 met enrollment criteria in the BTG program and had sufficient follow-up data (1 baseline measurement and at least 1 follow-up measurement) to be included in this evaluation (Figure 1).

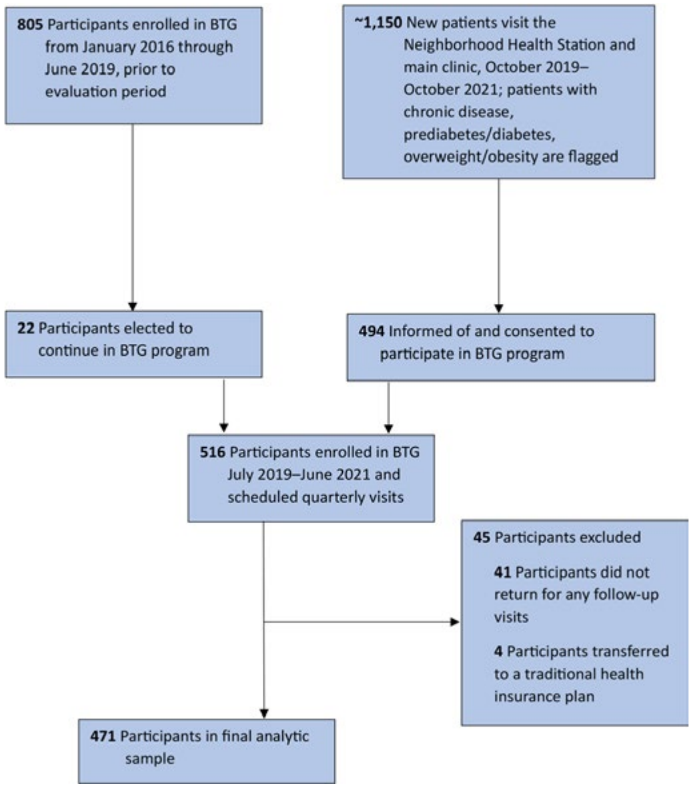

Figure 1. Flow of participants in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap program, Providence, Rhode Island, 2019–2022.

Timeline

At enrollment in the BTG program (baseline), we measured the following metabolic biomarkers for each participant: blood glucose, HbA_{1c}, total cholesterol, and systolic and diastolic blood pressure. At the conclusion of each visit, participants scheduled a follow-up appointment for 3 months later. We tracked each participant for a maximum of 8 calendar quarters after their enrollment date. Because the CEHC clinic population is transient as a result of fluctuating employment and documentation status, participants did not always schedule or attend a return visit. We called no-show participants once every calendar quarter until they either scheduled a follow-up or were discontinued from the study. If participants did not have a second set of measurements taken within 2 years after their baseline values, we excluded them from the dataset. We included metrics for all continuing participants in the longitudinal analysis until the date of their last follow-up visit. We determined instructional groups for our lifestyle programs based on start date or entry into the BTG program. We calculated the retention rate as a ratio of the number of participants who attended 1 or more follow-up visits to the total number of participants initially enrolled in the program.

Lifestyle program

A locally developed lifestyle program (*Vida Sana*) involves classes taught to participants by using culturally attuned, linguistically appropriate materials, with teaching styles meeting the unique needs of participants' low levels of health literacy (5). The course is taught by CEHC-trained multilingual, multicultural community health workers known as *Navegantes* (6). A pre-pandemic review of the *Vida Sana* program found significant improvements in blood pressure during the program (7,8).

CEHC also provides a formal DPP class to BTG participants with prediabetes. The objective of DPP is to reduce the risk of type 2 diabetes through a review of diet and physical activity (9). Participants receive structured, program-specific education on how to achieve and maintain lifestyle changes for 1 year. At CEHC, the course is taught in Spanish by *Navegantes*, who receive training from the Rhode Island Department of Health (6).

Individualized health coaching sessions in the *Vida Sana* and DPP formats were provided by *Navegantes* for patients whose schedules did not allow them to attend group classes or who needed to schedule a makeup class after missing a session of the group class. These sessions were charted as "One-on-Ones," which were available to patients throughout the analysis period along with recurring cycles of *Vida Sana* and DPP classes (Figure 2). Participants were also invited to participate in repeated program sessions to maintain lifestyle changes and healthy habits.

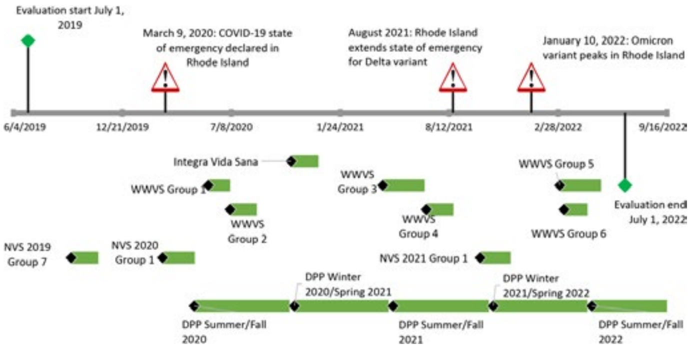

Figure 2. Timeline for the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap program in Providence, Rhode Island, for the evaluation period, July 1, 2019, to July 1, 2022. Names of programs reflect funding sources. Abbreviations: NVS, *Navegante Vida Sana*; WWVS, Wisewoman *Vida Sana*.

Data collection

This evaluation focused on patients enrolled from July 2019 through July 2021; outcomes were evaluated through July 2022.

Data were collected during normal clinic operations and later accessed for analysis by review of patient medical records. In addition to collecting data on metabolic biomarkers for each participant at baseline and at each subsequent clinic visit, we collected baseline data on participant sex (male or female), age, race and ethnicity, and height and weight. We calculated body mass index (BMI) as weight in kilograms divided by height in meters squared. We used adult BMI categories as specified by the Centers for Disease Control and Prevention: underweight (BMI <18.5), normal weight (BMI 18.5 to <25.0), overweight (BMI 25.0 to <30.0), and obese (BMI ≥30.0) (10).

We defined prediabetes as an HbA_{1c} of 5.7-6.4%, diabetes as HbA_{1c} ≥6.5%, hypertension as systolic blood pressure ≥130 mm Hg or diastolic blood pressure ≥80 mm Hg, and hyperlipidemia as total cholesterol ≥240 mg/dL.

We did not routinely collect data on income or educational level as part of this study; however, CEHC is situated in the Olneyville area of Providence and mostly serves patients from this neighborhood. The annual median family income of the Olneyville neighborhood is estimated at $23,200, based on weighted averages of census tracts and block groups from the 2010 census data and the 2010–2016 American Community Survey (11). In 2024, the federal poverty level for a family of 3 was $25,820, and for a family of 4 was $31,200 (12). CEHC has also been an awardee of the federal Community Development Block Grants program every year since 2015, and reports household income of its patients to the program in furtherance of its mission to help low-income people. Additionally, we surmise that the average educational level of most CEHC clinic patients is below high school level, and some are only able to read with difficulty (unpublished observation of A.D.G.).

The COVID-19 pandemic and clinic operations

COVID-19 presented unique challenges to scheduling follow-up visits and providing the intervention. In the beginning of the pandemic (March 2020), all in-person visits were discontinued to reduce the chances of virus transmission at the clinic. After implementation of transmission prevention measures at the clinic, including previsit COVID-19 antigen testing and the installation of air filters in each examination room, we resumed in-person visits. We set up COVID-19 antigen testing and blood pressure tests at the Neighborhood Health Station to facilitate BTG visits; participants could also participate in *Vida Sana* or DPP group classes, or have One-on-One sessions with a *Navegante* at this location.

Class participation was flexible during the pandemic. With masking and testing, participants could attend in person. If participants were unable to attend group classes or when in-person classes were suspended during surges in COVID-19 rates, they could meet with *Navegantes* by video chat and in person for One-on-One visits to discuss goal setting, nutrition, and chronic disease management. Almost all lifestyle intervention programs, including *Vida Sana* and One-on-Ones, were conducted online in spring 2020 due to COVID restrictions, with DPP suspended, but by fall 2020, visits were in-person to maintain their effectiveness and attendance. Descriptions of the effect of COVID-19 on the uninsured Spanish-speaking population in Providence and the means by which CEHC provided access to free COVID-19 testing and vaccines for this population are described elsewhere (13,14).

Statistical analysis

We organized participant counts in a symmetrical 4-term elliptical figure (a Venn diagram [15]). The 4 terms were the 4 risk factors: obesity/overweight, hypertension, hyperlipidemia, and diabetes/prediabetes.

We used paired *t* tests to identify significant changes in blood glucose, HbA_{1c}, cholesterol, and systolic and diastolic blood pressure among participants overall. We also compared measurements that were matched by chronic condition: we examined measurements of HbA_{1c} and blood glucose among participants with prediabetes or diabetes, measurements of total cholesterol among participants with hyperlipidemia, and measurements of blood pressure among participants with hypertension. In addition, we compared baseline measurements between participants with at least 1 follow-up visit and participants who had only baseline measurements. We used the Analysis ToolPak feature in Excel version 16.62 (Microsoft Corp) for initial analysis and later verified with R version 4.4.0 (R Foundation for Statistical Computing), with the help of the packages ggplot2 (16) and OI-biostat (Dave Harrington, OI-biostat Labs; https://github.com/dave-harrington/oi_biostat_labs).

We calculated the mean HbA_{1c} and blood glucose levels of all participants in BTG for each calendar quarter from July 2019 through July 2022, for a total of 12 calendar quarters. Using these calculated means, we performed linear regression in R with the open-source ggplot package and subsequently added 95% CIs. We excluded outliers that resulted from surges caused by COVID-19 variants and used baseline and follow-up measurements in our calculation of means.

In a priori power analysis with G*Power version 3.1.9.7 (Heinrich-Heine-Universität Düsseldorf), the required sample size for significant results from a paired *t* test was 327 given a 2-sided significance level of .05 and an estimated effect size of 0.2, considered small for behavioral science (17). Two months after recruitment began, a meta-analysis of diabetes self-management education among Latino adults found a pooled effect size of −0.24 (±0.105 at 95% CI) for HbA_{1c} outcomes across 23 studies, validating our conservative estimate of effect size (18). G*Power estimated that the required sample size for an effect size of 0.24 with all other settings unchanged in the paired *t* test was 227. We conducted a sensitivity analysis with imputation based on a last-observation-carried-forward approach, followed by 2-sample *t* tests, which found no significant difference in participant outcomes at 6 and 12 months.

Results

During the study period, 45 participants transferred to a traditional health insurance plan or were otherwise lost to follow-up.

Of 471 participants, 211 (44.7%) were women and 260 (55.2%) were men. Most participants self-identified as Hispanic or Latino (91%). The mean (IQR) age was 50 (40–59). Moreover, 52.7% of participants lived with hypertension, 51.8% lived with diabetes or prediabetes, 39.2% lived with hyperlipidemia, and 62.5% lived with overweight or obesity; 69.6% of participants lived with 2 or more of these conditions, and 30.4% of participants lived with 3 or more. For example, 29 (6.1%) had hyperlipidemia, diabetes or prediabetes, obesity or overweight, and hypertension (Figure 3). Overall, the program retention rate was 91%.

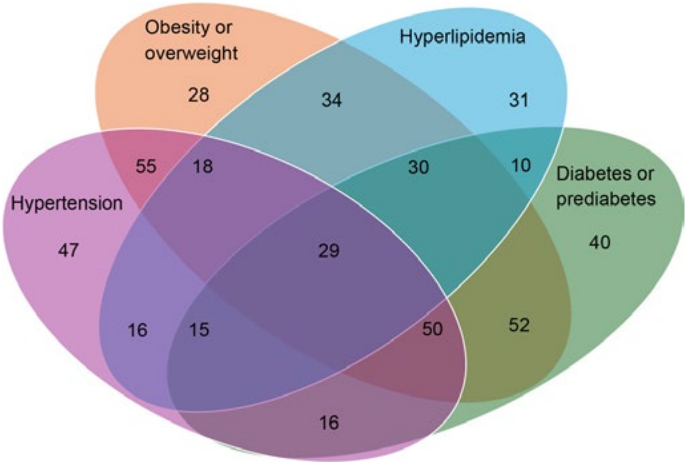

Figure 3. Venn diagram for the distribution of chronic conditions among participants in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap program in Providence, Rhode Island, for the evaluation period, July 1, 2019, to July 1, 2022. All values are number of participants.

Evaluation at 6, 12, 18, and 21 months showed that mean blood glucose levels among participants with diabetes or prediabetes declined between −45.8 and −136.0 points, mean HbA_{1c} among participants with diabetes or prediabetes declined between −0.43 and −1.17 points, and the blood pressure of participants with hypertension declined by −2 to −11 mm Hg (systolic) and −1 to −9 mm Hg (diastolic) (Table).

The evaluation of participant outcomes as a function of their time spent in the BTG program demonstrates improvement at the 1-year mark, with results diminishing after that point. We found significant improvements in metabolic biomarkers at 6 and 12 months, but none at 18-month follow-up and only one at 21-month follow-up (Table). The average HbA_{1c} declined significantly among all BTG participants from baseline to 6 months (from 7.17% to 6.46%; $P = .005$) and among BTG participants with diabetes or prediabetes at 6 months (8.18% to 7.01%; $P < .001$) and 12 months (8.10% to 7.03%; $P = .002$) (Table). In addition, we found a significant decline in blood glucose among participants with diabetes or prediabetes at 6 months, in systolic blood pressure among all participants and participants with hypertension at 6 and 12 months, in diastolic blood pressure among all participants at 6, 12, and 21 months, and among participants with hypertension at 12 months. We also found a significant decline in blood glucose from baseline among all patients who remained in the program at 21 months (n = 14). We found no other significant changes.

In the comparison of participants with at least 1 follow-up visit and participants who had only baseline measurements, participants lost to follow-up did not have significantly different measurements of blood pressure, HbA_{1c}, or blood glucose levels at baseline, but they did tend to have significantly higher total cholesterol levels (Appendix).

In a comparison of mean blood glucose in each calendar quarter in the overall BTG cohort, the trendline had a significantly negative slope ($R^2 = 0.89$) that was, however, interrupted during periods of high rates of COVID-19 transmission (Figure 4). This finding was corroborated by mean HbA_{1c}, which also had a significantly negative slope but had a worse fit, with an adjusted R^2 of 0.53 and outliers in the same calendar quarters (Figure 5).

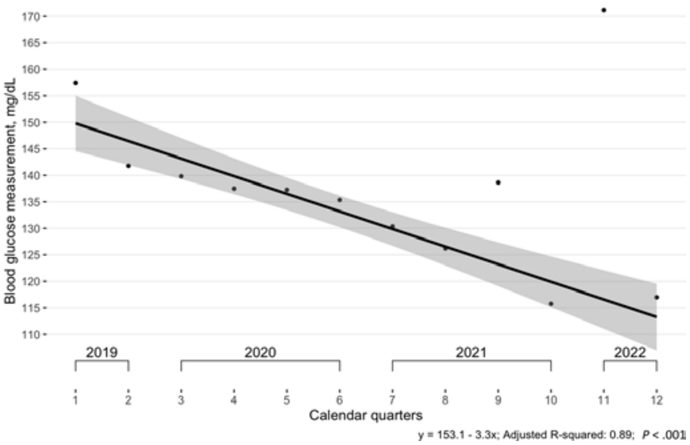

Figure 4. Mean blood glucose measurements among participants (N = 471) in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap Program, Providence, Rhode Island, July 2019–July 2022. All visits (baseline and follow-up) were used in calculation of means. The regression excluded outliers found during the Delta (August 2021) and Omicron (January 2022) waves of COVID-19. Shading indicates 95% CIs.

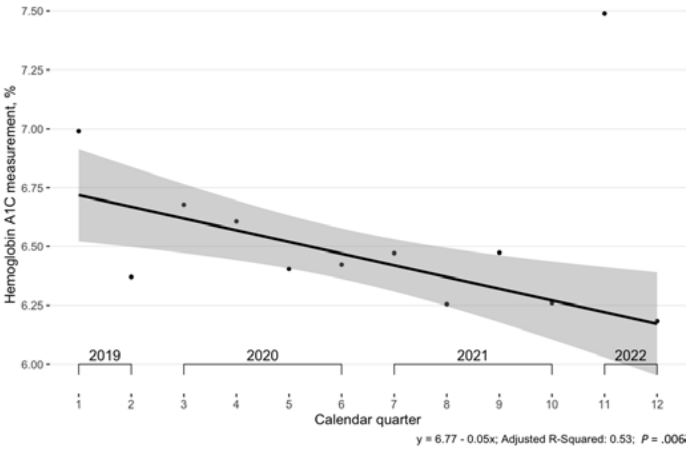

Figure 5. Mean glycosylated hemoglobin A_{1c} (HbA_{1c}) measurements among participants (N = 471) in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap Program, Providence, Rhode Island, July 2019–July 2022. All visits (baseline and follow-up) were used in calculation of means. The regression excluded the outlier found during the Omicron (January 2022) wave of COVID-19. Shading indicates 95% CIs.

Discussion

From 2018 through 2022, the percentage of Rhode Island residents without health insurance ranged from 4.8% to 4.9% despite introduction of low-cost health insurance for residents and state expansion of Medicaid (2,19). This statistic obscures racial and ethnic disparities in health insurance coverage. Hispanic residents of Rhode Island are more likely than non-Hispanic residents to lack health insurance, have no regular primary care physician, and experience financial barriers to seeking care (14). The proportion of non-Hispanic White residents without health insurance decreased from 5.2% in 2018 to 1.5% in 2022, while the proportion of Hispanic residents without health insurance was higher overall and decreased from 24.3% to 21.0% during the same period (19,20).

CEHC was established in 2008 to address the need for primary and preventive health care for people without health insurance, with a focus on culturally competent care for all — and the BTG program aligns with this mission. Most BTG participants in our study cohort self-identified as Hispanic or Latino (91%), similar to the 2016–2017 cohort, in which nearly all identified as non-White Hispanic or Latino (4), and in contrast to the general population of Rhode Island, at 17% Hispanic or Latino (21,22). This difference may be due to the location of CEHC in Olneyville, a neighborhood in which 63.9% of the population is Hispanic (23).

Hispanic people are more likely than non-Hispanic White people in Rhode Island to have diabetes, hypertension, and cardiovascular disease. In 2010, the prevalence of diabetes in the state was almost 2 times higher in the Hispanic population (13%) than in the non-Hispanic White population (6.7%) (21). Hypertension, a major contributor to cardiovascular disease, also disproportionately affects Hispanic people compared with non-Hispanic White people (24). Although evidence is conflicting on cardiovascular disease death rates in the Hispanic population relative to the non-Hispanic White population, the rates of nonfatal myocardial infarction and loss of disability-adjusted life years are higher in the Hispanic population than in the non-Hispanic White population in the US (24,25). These trends are not unique to the Hispanic population in the US, with Black, American Indian, Alaska Native, Native Hawaiian, and Pacific Islander populations also facing similar disparities (26). New interventions to prevent complications from poorly managed chronic disease should focus on these groups.

In 2020, rates of primary care and emergency department use decreased across the nation before slowly rising in demand, even above pre-pandemic levels (27,28). Use of the BTG program mirrored this trend, with sharply decreased numbers of office visits in the early pandemic months and subsequent increases. The BTG cohort in this study consisted of 471 patients during the 24-month enrollment window from July 2019 to July 2021, a rate of 19.6 patients per month. This rate is similar to previously published BTG enrollment rates at CEHC's main clinic in 2018: 805 patients during 41 months (19.6 patients per month) (4). The overall similarity in enrollment rates, despite an initial dip in participation for this study, may have resulted from increased community trust in the BTG program when the clinic began establishing other services, such as free COVID-19 testing, vaccination, and Paxlovid distribution. These services may have raised awareness of CEHC programs.

Participation in BTG activities by women was negatively and disproportionately affected by surges in COVID-19. Overall, 44.7% of BTG participants were women and 55.2% were men. This disproportion may have resulted from increased childcare responsibility caused by closures of childcare facilities and restrictions on children visiting CEHC's main clinic during the pandemic. Addressing childcare needs may be critical to improving health care access for parents of young children.

Improving access to care for people without health insurance may decrease associated costs imposed on the health care system (29). The potential benefits of BTG participation to the local health system are notable. Our previous study found that BTG participants had 61% fewer potentially preventable emergency department visits, resulting in an average annual potential savings to the Rhode Island health care system of $781,122 (4). Better control of chronic diseases through managing blood glucose, normalizing HbA_{1c}, and reducing blood pressure has been estimated at $1,445 to $2,073 per patient (30).

A survey of low-income Hispanic adults with diabetes at clinics in the Southwest and Midwest found that during the pandemic, many Hispanic adults were unable to receive medical care for diabetes and had an increased frequency of hyperglycemia (31). Barriers to health care during the pandemic, such as job-related pressures, transportation needs, and childcare considerations, also affected BTG participants. No-show rates were high for postbaseline office visits, especially in months where new strains of COVID-19 were emerging in Rhode Island. However, despite this, retention in the program improved significantly to 91%, compared with the previous iteration, where 26.1% were lost to follow-up or transferred to other providers (4). This unexpected result could be attributed to telehealth, which has been shown to increase appointment attendance by reducing barriers related to cost and time, particularly benefiting patients who live far from medical providers (32–34). It is also possible that the current iteration of the program increased its outreach and fostered more timely reengagement for all CEHC patients as a result of increased funding for vaccinations and COVID-19 testing.

Across metabolic biomarkers, when we compared patient outcomes at different calendar quarters, we found that most significant improvements occurred during the 2019–2020 period (before the COVID-19 pandemic). During the 2020–2021 period (peak COVID-19), biomarkers also improved from baseline, but with a smaller magnitude, reflecting observed decreases in the number of participants and smaller changes in metabolic values, potentially related to disruptions in clinic schedules and patient attitudes toward clinic access. The Delta surge was officially recognized by the state of Rhode Island in August 2021 (35), followed by the Omicron wave, reported by local news organizations in January 2022 (36). These surges coincided with poorer outcomes in blood glucose levels, HbA_{1c} values, and blood pressure control among study participants. Total cholesterol did not change significantly during the evaluation period, possibly because of the known preference of CEHC health care providers to encourage lifestyle changes first, followed by statin medications.

Limitations

Our study has several potential limitations. First, interpretation of the results may be limited because the cohort was not randomized and the BTG program involved voluntary participation (by motivated participants), which precluded an intent-to-treat analysis. Second, we did not collect information about participants' level of education, which may be a confounder of metabolic outcomes. Third, the data can be generalized only to patients who are willing and able to engage with health education such as that provided by the BTG program, reflecting a potential selection bias such that participants included in this evaluation had the means and will to return for at least 1 follow-up visit. However, sensitivity analysis showed that participants who dropped out appeared to have similar baseline characteristics as those who remained in the study, except for total cholesterol levels, and adding those participants back into data based on their last observation carried forward showed no change in significance. In addition, all BTG participants had a metabolic comorbidity, which does not perfectly reflect real-world populations.

Conclusion

Lack of access to health care contributes to underdiagnosis and undertreatment of chronic diseases and poor continuity of care. Hospitalization of patients without health insurance also has negative financial consequences for patients and health care systems. Innovative programs such as BTG and the associated *Vida Sana* program, tailored to the cultural and linguistic preferences of their communities, are needed to improve access to care populations that lack health insurance and have low literacy levels. Our results reject the null hypothesis. Despite the disruptions of the COVID-19 pandemic, BTG supported continual improvement in participants' metabolic biomarkers. Our study illustrates that access to free health care, continuity of care, and lifestyle education programs have positive effects on the health of people who lack health insurance. With our collective efforts, neighborhood by neighborhood, we may yet bridge the gaping divide of health care disparity.

Acknowledgments

We thank the following people for their contributions: CEHC volunteers Pooja Hindocha, Nita J. Nair, Jennifer L. Pigoga, Katie Barry, and Meghan McCarthy, who initiated the BTG program (with Dr De Groot) in 2015; all pandemic-era CEHC staff members and volunteers from 2020 to today, for their steadfast dedication to community health care work in unprecedented times; and all BTG participants, for their perseverance and commitment to learning about lifestyle interventions and working to improve their individual health, while building a local community of health-minded people.

Funding for the BTG program has been provided by Blue Cross & Blue Shield of Rhode Island, the CharterCare Foundation, the Textron Charitable Trust, the Rhode Island Department of Labor and Training, Integra Healthcare, the Rhode Island Department of Health, the US Department of Housing and Urban Development's Community Development Block Grant program, and the City of Providence. Funding for the DPP at CEHC has been provided by the Rhode Island Department of Health. Funding for the *Vida Sana* program has been provided by the Rhode Island Department of Health, the Well-Integrated Screening and Evaluation for WOMen Across the Nation (WISEWOMAN) program (funded by the Centers for Disease Control and Prevention), Blue Cross & Blue Shield of Rhode Island, the Textron Charitable Trust, the CharterCare Foundation, and Integra Healthcare.

The authors declared no potential conflicts of interest with respect to the research, authorship, or publication of this article. No copyrighted material, surveys, instruments, or tools were used in the research described in this article.

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Table

Table. Paired *t* Tests for Differences in Means Among Participants in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap Program, Providence, Rhode Island, July 2019-July 2021[a]

Measurement	Months from baseline	No. of participants	Baseline mean (SD)	Follow-up mean (SD)	Difference in means	*P* value[b]
HbA_{1c}, %						
All participants	0	386	6.58 (2.19)	—	—	—
	6	96	7.17 (2.71)	6.46 (1.68)	−0.71	.005
	12	56	6.61 (2.42)	6.28 (1.73)	−0.33	.21
	18	23	6.28 (1.86)	6.75 (2.12)	0.47	.27
	21	14	6.29 (1.65)	6.02 (0.72)	−0.27	.38
Participants with diabetes (HbA_{1c} ≥6.5%) or prediabetes (HbA_{1c} 5.7%–6.4%)	0	242	7.46 (2.49)	—	—	—
	6	55	8.18 (2.99)	7.01 (1.94)	−1.17	<.001
	12	26	8.10 (2.90)	7.03 (2.23)	−1.07	.002
	18	13	7.24 (2.64)	6.78 (1.80)	−0.46	.21
	21	8	6.79 (1.82)	6.36 (0.79)	−0.43	.44
Blood glucose, mg/dL						
All participants	0	347	139.5 (82.4)	—	—	—
	6	92	153.3 (102.2)	139.2 (65.6)	-14.05	.27
	12	60	150.8 (93.7)	126.9 (53.2)	-23.93	.09
	18	22	169.9 (114.9)	147.4 (97.7)	-22.5	.49
	21	14	200.4 (143.4)	107.3 (23.6)	-93.07	.03
Participants with diabetes (HbA_{1c} ≥6.5%) or prediabetes (HbA_{1c} 5.7%–6.4%)	0	242	141 (84)	—	—	—
	6	31	206 (130)	160 (77.6)	−45.8	.02
	12	12	242 (121)	189 (85.9)	−53.2	.13
	18	5	308 (125)	233 (82.3)	−75.0	.15
	21	3	244 (111)	108 (22.6)	−136.0	.12
Total cholesterol, mg/dL						
Participants with hyperlipidemia (≥240 mg/dL)	0	183	237.2 (31.2)	—	—	—
	6	34	204.6 (47.1)	204.6 (47.2)	0	.99
	12	25	224.7 (54.7)	221.6 (72.2)	−3.1	.78
	18	4	204.3 (53.7)	184.5 (42.5)	−19.8	.54
	21	6	221.3 (50.9)	226.3 (29.1)	5.0	.82
Systolic blood pressure, mm Hg						
All participants	0	469	133.2 (22.0)	—	—	—
	6	118	135 (21.3)	130 (19.9)	−5	.02
	12	86	134 (22.0)	129 (15.6)	−5	.02

Abbreviation: —, does not apply; HbA_{1c}, glycosylated hemoglobin A_{1c}.

[a] Means in this table were calculated based on months elapsed from baseline, for patients enrolled between 2019 and 2021, within the data evaluation window of 2019 to 2022.

[b] Determined by *t* test; $P < .05$ considered significant.

(continued on next page)

(continued)

Table. Paired *t* Tests for Differences in Means Among Participants in the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap Program, Providence, Rhode Island, July 2019-July 2021[a]

Measurement	Months from baseline	No. of participants	Baseline mean (SD)	Follow-up mean (SD)	Difference in means	*P* value[b]
	18	28	132 (25.1)	124 (18.2)	−8	.11
	21	17	136 (21.4)	134 (21.6)	−2	.58
Participants with hypertension (systolic blood pressure >120 mm Hg)	0	246	140 (19.0)	—	—	—
	6	56	144 (19.5)	137 (17.2)	−7	.01
	12	45	144 (20.5)	135 (13.6)	−9	.006
	18	15	143 (28.2)	132 (18.6)	−11	.23
	21	13	142 (21.0)	140 (21.3)	−2	.80
Diastolic blood pressure, mm Hg						
All participants	0	469	83 (13.3)	—	—	—
	6	118	82 (13.0)	80 (11.6)	−2	.04
	12	86	83 (12.1)	79 (9.9)	−4	.01
	18	28	82 (13.2)	78 (10.7)	−4	.16
	21	17	85 (11.4)	77 (12.5)	−8	.02
Participants with hypertension (diastolic blood pressure >80 mm Hg)	0	223	94 (10.6)	—	—	—
	6	13	89 (14.7)	88 (10.3)	−1	.90
	12	10	88 (6.33)	79 (7.8)	−9	.01
	18	5	84 (11.2)	76 (3.6)	−8	.28
	21	6	83 (8.0)	81 (17.1)	−2	.85

Abbreviation: —, does not apply; HbA_{1c}, glycosylated hemoglobin A_{1c}.

[a] Means in this table were calculated based on months elapsed from baseline, for patients enrolled between 2019 and 2021, within the data evaluation window of 2019 to 2022.

[b] Determined by *t* test; *P* < .05 considered significant.

Appendix. Supplemental Table

Comparison of Baseline Measurements Between Participants Lost to Follow-Up and Participants Included in Analysis, by Sex, Year of Data Collection, and Type of Measurement (Baseline or Follow-Up), the Clínica Esperanza/Hope Clinic Bridging the [Health Equity] Gap Program, Providence, Rhode Island, July 2019-July 2022

Metabolic indicator	Patients lost to follow-up, mean (SD)	Participants with 1 or more follow-up visits, mean (SD)	*P* value[a]
Systolic blood pressure, mm Hg	137.1 (22.3)	134.5 (22)	.10
Diastolic blood pressure, mm Hg	82.7 (12.9)	83.7 (13.6)	.20
Hemoglobin A_{1c}, %	6.48 (2.1)	6.696 (2.3)	.18
Blood glucose, mg/dL	144.0 (87.9)	136.0 (78.2)	.18
Body mass index, kg/m^2	31.2 (5.3)	31.6 (5.6)	.18
Total cholesterol, mg/dL	213.0 (5.6)	202.0 (43.1)	.01

Abbreviation: HbA_{1c}, glycosylated hemoglobin A_{1c}.
[a] Determined by *t* test; $P < .05$ considered significant.

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY
Volume 21, E74 SEPTEMBER 2024

SYSTEMATIC REVIEW

Outpatient Follow-Up Visits to Reduce 30-Day All-Cause Readmissions for Heart Failure, COPD, Myocardial Infarction, and Stroke: A Systematic Review and Meta-Analysis

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Accessible Version: www.cdc.gov/pcd/issues/2024/24_0138.htm

Suggested citation for this article: Bilicki DJ, Reeves MJ. Outpatient Follow-Up Visits to Reduce 30-Day All-Cause Readmissions for Heart Failure, COPD, Myocardial Infarction, and Stroke: A Systematic Review and Meta-Analysis. Prev Chronic Dis 2024;21:240138. DOI: https://doi.org/10.5888/pcd21.240138.

PEER REVIEWED

Summary

What is already known on this topic?

Outpatient follow-up visits soon after discharge may help prevent hospital readmissions.

What is added by this report?

The pooled adjusted effect of outpatient follow-up visits reduced 30-day all-cause readmissions by 21%, but between-study variability was high (I^2 = 92.7%).

What are the implications for public health practice?

Health care systems should continue to encourage the scheduling of outpatient follow-up visits, but more high-quality research studies are needed.

Abstract

Introduction

Hospital readmissions is an important public health problem that US hospitals are responsible for reducing. One strategy for preventing readmissions is to schedule an outpatient follow-up visit before discharge. The objective of this study was to determine whether outpatient follow-up visits are an effective method to reduce 30-day all-cause readmissions for patients discharged from US hospitals with heart failure, chronic obstructive pulmonary disease (COPD), acute myocardial infarction (AMI), or stroke.

Methods

We conducted a systematic review and meta-analysis to identify relevant articles published from 2013 through 2023. We searched PubMed, CINAHL, and Cochrane. Eligible studies were those that assessed the effect of postdischarge outpatient follow-up visits on 30-day all-cause readmission. We used random effect meta-analyses to generate pooled adjusted effect estimates and 95% CIs.

Results

We initially identified 2,256 articles. Of these, 32 articles underwent full-text review and 15 met inclusion criteria. Seven studies addressed heart failure, 3 COPD, 2 AMI, and 3 stroke. Ten articles provided sufficient information for meta-analysis. The pooled adjusted effect measure was 0.79 (95% CI, 0.69–0.91), indicating that outpatient follow-up visits were associated with a 21% lower risk of readmission. However, we found a high degree of between-study heterogeneity ($Q = 122.78$; $P < .001$; I^2 = 92.7%). Subgroup analyses indicated that study quality, disease condition, and particularly whether a time-dependent analysis method was used, explained much of the heterogeneity.

Conclusion

Outpatient follow-up visits are a potentially effective way to reduce 30-day all-cause readmissions for patients discharged with heart failure or stroke, but evidence of benefit was lacking for COPD and we found no studies for assessing AMI. Our results emphasize the importance of study quality.

Introduction

Hospital readmissions are a serious public health problem and are associated with increased illness, death, and health care costs (1). An estimated 3.8 million readmissions occurred in the US in 2018 with an average cost of $15,200 per readmission (1,2). Heart failure, chronic obstructive pulmonary disease (COPD), acute myocardial infarction (AMI), and stroke are 4 highly prevalent conditions in the top 20 leading causes of readmissions. In 2018, some 1 million index heart failure admissions resulted in 233,000 readmissions and cost $3.49 billion (1). Similarly, in that year, COPD, AMI, and stroke accounted for 78,000, 74,300, and 53,000 readmissions, respectively, with readmission rates ranging from 10% to 20% (1,2). Patients who are readmitted also have poorer outcomes, including lower survival rates and poorer quality of life (3–5), when compared with patients discharged with the same disease who are not readmitted.

In 2013, the Hospital Readmissions Reduction Program (HRRP) began offering incentives to hospitals with low readmission rates and enforcing penalties on hospitals with high readmission rates (6,7). The HRRP targets heart failure, COPD, and AMI. Stroke was proposed for inclusion, but controversy over the importance of stroke severity led to its exclusion (8). Controversy remains regarding the effectiveness of HRRP in reducing readmissions (9,10).

Studies on transitional care services aimed at reducing readmissions showed promising results (11–13), but uncertainty about their effectiveness remains (14–16), in part due to barriers such as insufficient administrative support, lack of resources, and lack of staff buy-in (17). A previous meta-analysis of randomized trials that focused on reducing heart failure readmissions included various interventions, such as patient education, telephone support, nurse home visits, and outpatient follow-up visits (11). The meta-analysis concluded that nurse home visits and outpatient follow-up visits were effective in reducing readmissions, but because each trial tested at least 2 interventions bundled together, it was difficult to isolate the effect of any single strategy. The objective of this study was to quantify the singular effect of outpatient follow-up visits on reducing 30-day all-cause readmissions in patients with heart failure, COPD, AMI, or stroke discharged from US acute care hospitals from 2013 through 2023.

Methods

We conducted this systematic review and meta-analysis according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (18). Briefly, we searched 3 databases (PubMed, CINAHL, and Cochrane) by using a combination of terms that included but was not limited to heart failure, COPD, AMI, stroke, readmission, rehospitalization, outpatient, office, follow-up, post discharge, and visit. The search was completed on June 14, 2023, and included all studies published on or after January 1, 2013 (ie, approximately 10.5 years). Both authors independently screened the titles and abstracts of the initial list of citations, identifying potentially eligible articles for full-text review. We conducted an additional review of the bibliographies of 7 related meta-analyses identified by our search. We resolved disagreements on initial and final study selection by consensus.

Study selection

Eligible studies were those that 1) included patients aged 18 years or older, who were discharged from US hospitals with an index hospitalization for heart failure, COPD, AMI, or stroke, 2) identified the presence or absence of an outpatient follow-up visit within 30 days of discharge as the primary exposure variable, 3) used 30-day all-cause readmission as the primary outcome, and 4) studied either the direct effect of receiving an outpatient follow-up visit within 30 days of discharge or assessed the effect of scheduling an appointment for an outpatient follow-up visit before discharge. We limited outpatient follow-up visits to those occurring in a traditional ambulatory setting with either a primary care or specialist physician, physician's assistant, or nurse practitioner. We included all types of study designs, including retrospective cohorts, case-control studies, clinical trials, and quality improvement projects that used a pre–post comparative design. We did not include studies that assessed outpatient follow-up visits that had to occur at 1 specific outpatient clinic (eg, a clinic at the discharging hospital) or those that examined the effect of outpatient follow-up visits that only involved a pharmacist. However, we included studies that included pharmacists as part of a multidisciplinary team. We also excluded studies with sample sizes less than 100, editorials, and abstracts.

Data extraction

For studies that underwent full-text review and met all eligibility criteria, we extracted data on the following study-level characteristics: study design, condition or diagnosis, geographic location (ie, city, state, region), objective of the study, data source (electronic medical record, administrative data, disease registry), sample size, time frame of case enrollment, discharge destinations (various combinations of home, home health, skilled nursing facility, acute rehabilitation, hospice, other), description of exposure (type of provider, timing postdischarge), outcome (30-day readmission), whether the analysis was conducted at the patient or hospital level, prevalence of outpatient follow-up, crude readmission rate, adjusted effect measure (either an odds ratio [OR] or hazard ratio [HR]), 95% CIs, and *P* values. Data were extracted in duplicate by both authors, and differences were resolved by consensus.

To assess study quality, we modified the Newcastle-Ottawa Scale, which assesses the quality of nonrandomized studies (19). We made 2 modifications: we assessed whether the study adequately controlled for demographic variables (age, race, sex, socioeconomic status), and we added a new item referred to as "time-dependent bias." We added this item to address a common problem associated with readmission studies (20), whereby subjects who have a readmission soon after discharge do not have the opportunity to have an outpatient follow-up visit, so they remain "unexposed." Our modified scale had 8 binary (yes or no) quality criteria and a total score ranging from 0 to 8. We used 3 criteria (representativeness of exposed cohort [whether the study population was broadly representative of the US population in terms of age, sex, ethnicity, and socioeconomic status], selection of nonexposed cohort, and ascertainment of exposure) to assess selection of study participants, 3 criteria (control for demographics, control for severity of disease or readmission risk, and time-dependent bias) to assess comparability of exposure groups, and 2 criteria (assessment of outcome and adequacy of follow-up of cohorts) to assess outcomes. We used scores of less than 6 to define low-quality studies.

We generated descriptive statistics to describe the characteristics of the included studies. For the studies that provided an adjusted effect measure (OR or HR) that quantified the effect of outpatient follow-up visits on 30-day readmission risk at the patient level, we conducted a random-effect (DerSimonian–Laird) meta-analysis using the meta command in Stata version 16 (StataCorp LLC). We categorized these reports as Tier 1 studies. We combined individual adjusted ORs or HRs without further manipulation to create a pooled adjusted effect estimate (labeled OR/HR), and calculated 95% CIs. We used the Cochrane Q statistic to test for between-study heterogeneity and the I^2 statistic to quantify the magnitude of between-study heterogeneity. A Q statistic with an associated P value less than .05 indicates a significant amount of between-study heterogeneity. An I^2 statistic greater than 30% indicates a moderate degree of between-study heterogeneity, and an I^2 statistic greater than 75% indicates a high degree of heterogeneity. Prespecified subgroup analyses included study quality (score of ≥6 [high] vs <6 [low]), adequate control of time-dependent bias (controlled or not controlled), and diagnosis (heart failure, COPD, AMI, stroke). We conducted these subgroup analyses to determine whether these study-level characteristics influenced the effect of outpatient follow-up visits in reducing the risk of 30-day all-cause readmission. Quality improvement projects did not provide an adjusted effect measure for outpatient follow-up visits and were, therefore, not included in the meta-analysis. Similarly, comparative studies that presented results aggregated at the hospital level rather than at the patient level were also not included in the meta-analysis. We categorized these 2 types of reports as Tier 2 studies and reviewed them qualitatively.

Results

Our search of the 3 databases yielded 2,830 citations, which after removing 574 duplicates yielded 2,256 unique citations (Figure 1). After applying exclusion criteria, 32 studies underwent full-text review, and 15 articles were included in our final review (Table 1); 10 articles were Tier 1 studies, and 5 articles were Tier 2 studies.

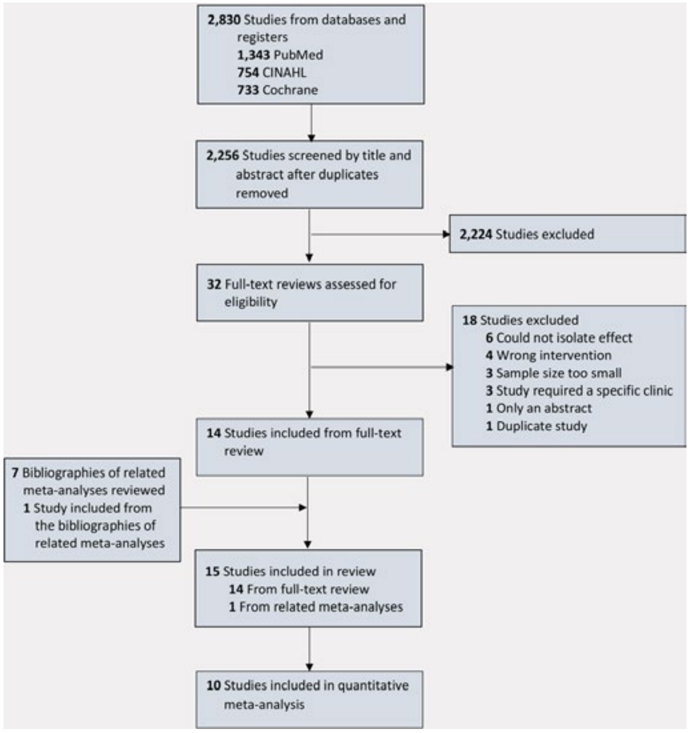

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) flow diagram of systematic review of US studies of outpatient follow-up visits and reduction of 30-day all-cause readmissions among patients with heart failure, chronic obstructive pulmonary disease, acute myocardial infarction, or stroke. Abbreviation: CINAHL, Cumulative Index to Nursing and Allied Health Literature.

Tier 1 studies

Nine of 10 Tier 1 studies used a retrospective cohort design; one used a case-control design (Table 1). Tier 1 studies had a wide range of sample sizes, from 839 to 78,345 participants. Every Tier 1 study defined the exposure as an outpatient follow-up visit with a primary care physician or a specialist physician (cardiologist, pulmonologist, geriatrician, neurologist), or a nurse practitioner within 30 days of discharge. We found significant differences in geographic location. Three studies used national data (either large claims-based or fee-for-service Medicare data); the remaining 7 studies used electronic medical records from health systems of various sizes (range, 1 to 26 hospitals). We also found differences in the combination of hospital discharge destinations used to select eligible participants. Every study included home with or without home health as a discharge destination, but varied in whether they included other destinations such as skilled nursing facilities or long-term care hospitals.

Meta analysis

The random effects meta-analysis conducted on the 10 Tier 1 studies (Figure 2) found a significant overall pooled adjusted relative effect (OR/HR = 0.79; 95% CI, 0.69–0.91). However, we found a high degree of between-study heterogeneity ($Q = 122.78$; $P < .001$; $I^2 = 92.7\%$).

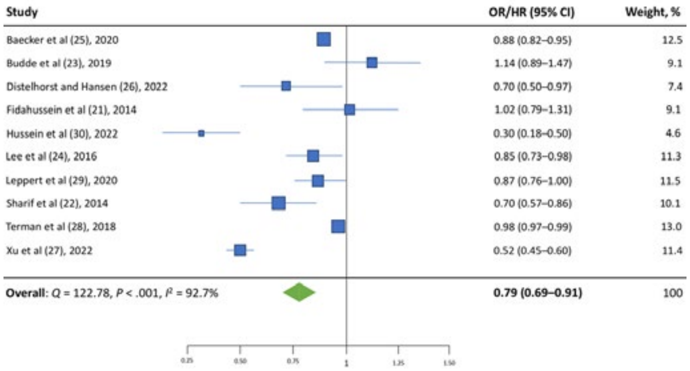

Figure 2. Random effect meta-analysis showing the pooled summary estimate of all 10 Tier 1 studies. The size of the data markers (squares) corresponds to the weight of the study in the meta-analysis. Abbreviations: HR, hazard ratio; OR, odds ratio.

Quality assessment

Total scores for the 10 Tier 1 studies ranged from 4 to 8, with a median of 6 (Table 2). Three studies (22,23,30) were deemed low-quality (score <6). Studies scored poorly on 2 criteria in particular: representativeness of the exposed cohort and time-dependent bias. Only 2 studies (24,25) scored well in representativeness, and both were conducted in California using Kaiser Permanente health system data. The 3 studies (22,28,29) that used national databases did not have proportions of age, sex, ethnicity, and socioeconomic status close enough to the national averages to warrant a positive score in representativeness.

Only 4 studies scored well on addressing time-dependent bias by using a method to ensure that the exposure (outpatient follow-up visit) occurred before the outcome (readmission). One study (24) did this at the study design phase by individually matching cases and controls on the duration of follow-up time available. The other 3 studies (25,28,29) controlled time-dependent bias at the analysis stage by defining the exposure as a time-dependent variable in a Cox regression model.

Subgroup analyses

The pooled adjusted effect of outpatient follow-up visits was smaller in the 7 high-quality studies (OR/HR = 0.82; 95% CI, 0.71–0.95; $P = .008$) than in the 3 low-quality studies (OR/HR = 0.65; 95% CI, 0.37–1.15; $P = .14$), although only the former was significant (Figure 3). Both subgroups showed high levels of between-study heterogeneity (high quality: $Q = 91.49$, $P <.01$, $I^2 = 93.44\%$; low quality: $Q = 22.82$, $P <.01$, $I^2 = 91.23\%$).

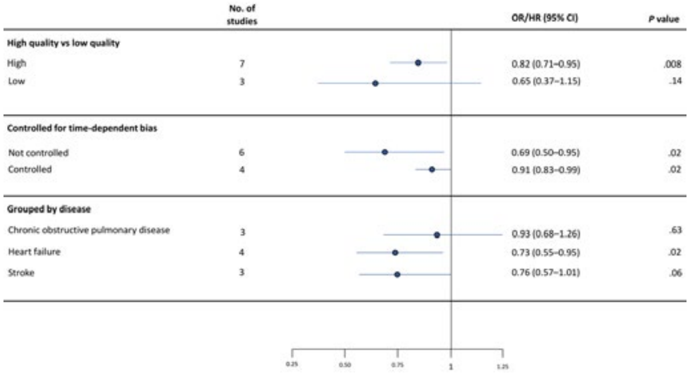

Figure 3. Random effect meta-analysis showing the pooled effect estimates for 3 subgroups.

The 4 studies that adequately controlled for time-dependent bias demonstrated a smaller pooled effect and narrower 95% CIs (OR/HR = 0.91; 95% CI, 0.83–0.99; $P = .03$) than the 6 studies that did not control for this bias (OR/HR = 0.69; 95% CI, 0.50–0.95; $P = .02$) (Figure). Both subgroups demonstrated high levels of between-study heterogeneity (not controlled for bias: $Q = 49.32$, $P <.01$, $I^2 = 89.86\%$; controlled for bias: $Q = 14.11$, $P <.01$, $I^2 = 78.74\%$).

When we grouped studies by disease condition, the 4 heart failure studies showed a significant 27% reduction in readmission risk (OR/HR = 0.73; 95% CI, 0.55–0.95; $P = .02$) (Figure). The pooled adjusted effect among the 3 stroke studies was similar in magnitude but the confidence interval slightly exceeded the null value (OR/HR = 0.76; 95% CI, 0.57–1.01; $P = .06$). The pooled adjusted effect of the 3 COPD studies was smaller and not significant (OR/HR = 0.93; 95% CI, 0.68–1.26; $P = .62$). All 3 subgroups still showed high levels of between-study heterogeneity (heart failure: $Q = 41.97$, $P < .01$, $I^2 = 92.85\%$; stroke: $Q = 22.70$, $P < .01$, $I^2 = 91.19\%$; COPD: $Q = 10.26$, $P = .01$, $I^2 = 80.51\%$).

Description of Tier 2 studies

Five Tier 2 studies were not included in the meta-analysis. Two were retrospective cohort designs that included only AMI patients; both presented aggregated hospital-level data stratified by outpatient follow-up rates divided into quartiles. One (31) used Medicare claims data from 288 hospitals from a national registry and found that hospitals in the highest quartile for outpatient follow-up rates had similar readmission risk compared with the bottom quartile (OR = 0.99). The other retrospective cohort study (32) used national Medicare claims data from 1,088 hospitals and found that hospitals in the lowest quartile for outpatient follow-up rates had slightly higher risk of readmission (RR = 1.07) compared with the highest quartile of hospitals.

The 3 remaining studies (33–35) were quality improvement projects that used a pre–post design to measure the effectiveness of enhanced discharge planning strategies on increasing outpatient follow-up visits and decreasing 30-day all-cause readmissions in heart failure patients. All 3 projects were conducted at the regional or state level and had sample sizes ranging from 261 (35) to 56,072 patients (34). Two reports (33,35) were single-center studies, and the third (34) included 20 Michigan hospitals. The quality improvement interventions increased the frequency of outpatient follow-up visits from as low as 3.3% (34) to as high as 27.3% (33). The net impact of these studies on readmission risk showed similarly wide variation; one study (34) found only a modest decline of readmissions (1.7%), although because of the large study size this effect was significant. Dev et al (35) found a 9% decrease in readmissions postintervention, and Ryan et al (33) observed the largest decline in readmission risk (30%).

Discussion

This systematic review included 15 US-based studies published since 2013 that reported on the effect of outpatient follow-up visits on the risk of 30-day all-cause readmission for heart failure, COPD, AMI, and stroke patients. The overall results of the meta-analysis that included 10 of these studies indicated a modest but significant 21% reduction in risk of readmission when heart failure, COPD, and stroke patients had an outpatient follow-up visit shortly after hospital discharge. However, when the effect of outpatient follow-up visits was stratified by disease condition, we observed a significant reduction in readmission only for heart failure and stroke. We found a relative risk reduction of 27% in heart failure patients that was similar in magnitude to another meta-analysis of heart failure patients that found a 20% reduction in readmission risk (RR = 0.80; 95% CI, 0.67–0.97) with the use of multiple interventions that included outpatient follow-up visits (11). We observed a similar risk reduction in stroke patients (24%), but we are not aware of any other meta-analyses conducted among stroke patients that report on the efficacy of outpatient follow-up visits in reducing readmission risk. Our systematic review did not yield any Tier 1 studies conducted among AMI patients; thus, AMI was not included in the meta-analysis. We hypothesize that the lack of studies examining outpatient follow-up visits among AMI patients may be due to the greater focus on cardiac rehabilitation in this population.

The estimated risk reduction in COPD patients who received an outpatient follow-up visit (7%) was noticeably smaller in magnitude than the estimated risk reduction for heart failure and stroke patients. The effect was also smaller than a previous meta-analysis that reported a 20% reduction in readmission risk for COPD patients exposed to bundled discharge interventions that included outpatient follow-up visits (RR = 0.80; 95% CI, 0.65–0.99) (36). However, we believe that the lack of an effect for COPD patients observed in our meta-analysis is best explained by the poor quality of the 3 COPD studies, none of which controlled for time-dependent bias (21–23).

Time-dependent bias (20,31) (also known as “survival bias” [20] or “immortal-time bias” [37,38]) occurs in studies that assess the effect of an exposure on an outcome when the classification of exposed participants requires that the participant remain event-free until they are exposed (20). Thus, in readmission studies, patients who are readmitted shortly after discharge may not have had an opportunity to complete their scheduled outpatient follow-up visit (and to become “exposed”), and therefore remain “unexposed,” resulting in a bias where the readmission rate is inflated in the group that did not have an outpatient follow-up visit. Time-dependent bias is common in observational studies (38,39) and is important to control for because the highest readmission rates observed in patients with COPD occurs in the first 72 hours after hospital discharge (40), which is likely to occur before an outpatient follow-up visit can be completed. A study by Zhou (20) and colleagues compared 5 methods of controlling for time-dependent bias and concluded that “exposure time matching” implemented during the design phase or defining the exposure as a “time-dependent variable” in the statistical analysis phase were the 2 best ways to control for time-dependent bias (20). These authors also found that ignoring the bias could almost double the effect estimate of the exposure (HR = 0.62 for no control vs HR = 0.80 when either of the above 2 methods were used). In our study, of the 4 Tier 1 articles that controlled for time-dependent bias, one (24) used the exposure-time–matching method during the design phase, and the other 3 (25,28,29) used a time-dependent variable in their statistical model. We observed similar findings to Zhou (20) and colleagues: our subgroup analysis showed that articles that ignored time-dependent bias estimated a 31% reduction in readmission risk, while the 4 articles that controlled time-dependent bias demonstrated only a 9% reduction in risk and a much narrower 95% CI.

Outpatient follow-up visits represent an important opportunity for hospitals and providers to prevent readmissions and improve patient outcomes (41), especially for heart failure and stroke patients. Scheduling outpatient follow-up visits at the time of discharge is a logical intervention for hospitals to use to reduce the risk of readmission for patients. However, while simple in theory, its implementation is often complicated when navigating the US health care system. Challenges related to lack of insurance, lack of a regular health care provider, costs, health literacy, and travel are just a few of the many barriers to implementing outpatient follow-up visits effectively (16,42). Beyond reducing readmissions, outpatient follow-up visits can present an opportunity for reconciling medications, building self-management skills, and ordering further medical testing (43). While outpatient follow-up visits show promising results, it is unlikely that a single intervention can fix the problems of readmissions on its own. Many studies have included outpatient follow-up visits as a part of a comprehensive set of interventions designed to reduce readmission risk (12–14,44,45), which have also been a focus of some meta-analyses (11).

Strengths and limitations

The main strength of this systematic review is that the source studies used similar designs and had consistent definitions for exposures and outcomes. This allowed us to conduct a meta-analysis on our 10 Tier 1 studies and report an overall pooled adjusted effect measure across 3 prevalent diseases that quantifies the effectiveness of outpatient follow-up visits in reducing readmissions. Our subgroup analyses identified that study quality, disease condition, and time-dependent bias contributed to between-study heterogeneity, which illustrates the clinical complexity of addressing readmissions and highlights that the effectiveness of outpatient follow-up visits is likely affected by a myriad of patient, clinical, and system-level factors.

Our findings have some limitations. Our analysis was limited to adult patients discharged from a US hospital with heart failure, COPD, AMI, or stroke. We focused on outpatient follow-up visits that occurred in typical ambulatory settings with a physician or nurse practitioner. We excluded outpatient follow-up visits that used a designated outpatient follow-up clinic because these require organizational and financial resources beyond what is typically available to most hospitals. However, we found only 3 studies that used a dedicated outpatient follow-up clinic (46–48), all of which were conducted at a single center and had small sample sizes. Individual studies used either ORs or HRs as effect estimates, but we chose not to convert ORs to relative risks because of the limitations of the proposed methods (49–52). Individual studies varied in their range of discharge destinations, in their geographical locations (within the US), and in demographic characteristics. All these factors likely limit the generalizability of our findings. In light of these limitations, we emphasize the need for more high-quality studies that control for time-dependent bias to further elucidate the individual effect of outpatient follow-up visits on reducing 30-day all-cause readmissions.

Conclusion

Across multiple diseases, preventing readmissions can improve the quality of life of patients and reduce illness, death, and costs (1,3–5). At a system level, reducing readmissions could increase funding to public hospitals that have received a disproportionate level of penalties from HRRP (53,54). We identified the effectiveness of outpatient follow-up visits in reducing 30-day all-cause readmissions for US patients discharged with heart failure and stroke, but found insufficient data on outpatient follow-up visits for AMI patients. Although our findings do not support the use of outpatient follow-up visits among COPD patients, these results may be related to the design and quality of these studies rather than the disease itself.

Acknowledgments

The following materials are available from the corresponding author in a supplement: 1) a full description of search terms used and the results obtained; 2) operational definitions of each study-level variable, 3) a summary of all extracted data, 4) details of the operational definitions of the 8 quality criteria and scoring examples, 5) details on prevalence of outpatient follow-up visits and crude readmission rates, and 6) all meta-analysis results for each subgroup.

The authors declare no potential conflicts of interest with respect to the research, authorship, or publication of this article. The authors received no external financial support for the research, authorship, or publication of this article. No copyrighted material, surveys, instruments, or tools were used in the research in this article. We thank Iris Kovar-Gough, MLIS, Michigan State University Libraries, for her contributions to our data search, and Garrett Reichle, MS, University of Michigan Medical School, for his contributions to the development of our abstraction tools and our modified Newcastle-Ottawa Scale.

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Tables

Table 1. Systematic Review of US Studies of Outpatient Follow-Up Visits and Reduction of 30-Day All-Cause Readmissions Among Patients With Heart Failure, COPD, Acute Myocardial Infarction, or Stroke: January 1, 2013–June 14, 2023

Study, date of publication	Disease	Sample size	Study design	Exposure	Location (study period)	Data source	Discharge destination
Tier 1 studies[a]							
Fidahussein et al (21), 2014	COPD	839	Retrospective cohort	Visit with a PCP or pulmonologist within 30 days of discharge	Olmsted County, Minnesota (2004–2011)	Mayo Clinic EMR	Home; skilled nursing facility
Sharif et al (22), 2014	COPD	8,263	Retrospective cohort	Visit with a PCP, pulmonologist, or both within 30 days of discharge	US (2009–2011)	Optum Insight, a national claims database	Anywhere but long-term care health center
Budde et al (23), 2019	COPD	2,653	Retrospective cohort	Visit with a PCP within 10 days of discharge	New York City (2011–2016)	Mount Sinai Hospital EMR	Anywhere but hospice
Lee et al (24), 2016	Heart failure	11,985	Case control study	Visit with a PCP or cardiologist within 7 days of discharge	Northern California (2006–2013)	Kaiser Permanente EMR	Home
Baecker et al (25), 2020	Heart failure	26,128	Retrospective cohort	Visit with a PCP or nurse practitioner within 7 days of discharge	Southern California (2013–2018)	Kaiser Permanente EMR	Home; home health care
Distelhorst and Hansen (26), 2022	Heart failure	1,280	Retrospective cohort	Visit with a PCP within 14 days of discharge	Ohio (2017–2019)	Cleveland Clinic Health System EMR	Home
Xu et al (27), 2022	Heart failure	6,918	Retrospective cohort	Visit with a PCP, geriatrician, or cardiologist within 14 days of discharge	Duke University Health System, North Carolina (2020–2021)	Duke University Health System EMR	Home; home health care
Terman et al (28), 2018	Stroke	78,345	Retrospective cohort	Visit with a PCP or neurologist within 30 days of discharge	US (2012)	Fee-for-service Medicare claims	Home
Leppert et al (29), 2020	Stroke	14,630	Retrospective cohort	Visit with a PCP or neurologist within 30 days of discharge	US (2009–2015)	PharMetrics, a national claims database	Home
Hussein et al (30), 2022	Stroke	872	Retrospective cohort	Visit with a PCP within 30 days of discharge prestroke and poststroke	Twin Cities, Minnesota (2015–2018)	University of Minnesota hospital EMR	Home; home health care; skilled nursing facility; long-term care health center
Tier 2 studies[b]							
Hess et al (31), 2013	Acute myocardial infarction	228 hospitals	Retrospective cohort	Visit with any physician within 7 days of discharge, measured at the hospital level	US (2003–2006)	CRUSADE registry data linked to Medicare fee-for-service claims	Home
Brown et al (32), 2014	Acute myocardial infarction	1,088 hospitals	Retrospective cohort	Visit with a PCP within 14 days of discharge, measured at the hospital level	US (2008–2009)	MedPAR, a national database	Home; home health care

Abbreviations: COPD, chronic obstructive pulmonary disease; CRUSADE, Can Rapid Risk Stratification of Unstable Angina Patients Suppress Adverse Outcomes with Early Implementation of the ACC/AHA Guidelines; EMR, electronic medical record; MedPAR, Medicare Provider Analysis and Review; PCP, primary care physician.

[a] Studies that provided an adjusted effect measure (odds ratio or hazard ratio) that quantified the effect of outpatient follow-up visits on 30-day readmission risk at the patient level were categorized as Tier 1 studies.

[b] Quality improvement projects that did not provide an adjusted effect measure for outpatient follow-up visits and comparative studies and presented results aggregated at the hospital level rather than at the patient level were categorized as Tier 2 studies.

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Table 1. Systematic Review of US Studies of Outpatient Follow-Up Visits and Reduction of 30-Day All-Cause Readmissions Among Patients With Heart Failure, COPD, Acute Myocardial Infarction, or Stroke: January 1, 2013–June 14, 2023

Study, date of publication	Disease	Sample size	Study design	Exposure	Location (study period)	Data source	Discharge destination
Ryan et al (33), 2013	Heart failure	398 patients, 1 hospital	Quality improvement project	Visit with a cardiologist within 7 days of discharge, patients identified as preintervention or postintervention	Connecticut (2008–2011)	Fee-for-service Medicare claims	Not reported
Baker et al (34), 2015	Heart failure	56,072 patients, 20 hospitals	Quality improvement project	Visit with any physician within 7 days of discharge, patients identified as preintervention or postintervention	Southeastern Michigan (2011–2013	Fee-for-service Medicare claims	Home
Dev et al (35), 2021	Heart failure	261 patients, 1 hospital	Quality improvement project	Visit with a cardiologist within 7 to 14 days of discharge, patients identified as preintervention or postintervention	Phoenix, Arizona (2010–2013)	Phoenix Veterans' Administration Medical Center EMR	Home; home health care

Abbreviations: COPD, chronic obstructive pulmonary disease; CRUSADE, Can Rapid Risk Stratification of Unstable Angina Patients Suppress Adverse Outcomes with Early Implementation of the ACC/AHA Guidelines; EMR, electronic medical record; MedPAR, Medicare Provider Analysis and Review; PCP, primary care physician.

[a] Studies that provided an adjusted effect measure (odds ratio or hazard ratio) that quantified the effect of outpatient follow-up visits on 30-day readmission risk at the patient level were categorized as Tier 1 studies.

[b] Quality improvement projects that did not provide an adjusted effect measure for outpatient follow-up visits and comparative studies and presented results aggregated at the hospital level rather than at the patient level were categorized as Tier 2 studies.

Table 2. Results of Application of Modified Newcastle-Ottawa Scale for Assessing the Quality of Nonrandomized Studies in a Systematic Review of Published US Studies of Outpatient Follow-Up Visits and Reduction of 30-Day All-Cause Readmissions Among Patients With Heart Failure, COPD, Acute Myocardial Infarction, or Stroke[a]: January 1, 2013–June 14, 2023

	Selection of study population			Comparability between exposure groups, control of confounding			Outcome		
Study (date of publication)	Representativeness of exposed cohort	Selection of non-exposed cohort	Ascertainment of exposure	Control for demographic characteristics	Control for severity of disease or readmission risk	Time-dependent bias	Assessment of outcome	Adequacy of follow-up of cohorts	Score[b]
Fidahussein et al (21), 2014		♦	♦	♦	♦		♦	♦	6
Sharif et al (22), 2014		♦	♦		♦		♦	♦	5
Budde et al (23), 2019		♦		♦	♦			♦	4
Lee et al (24), 2016	♦	♦	♦	♦	♦	♦	♦	♦	8
Baecker et al (25), 2020	♦	♦	♦	♦	♦	♦	♦	♦	8
Distelhorst and Hansen (26), 2022		♦	♦	♦	♦		♦	♦	6
Xu et al (27), 2022		♦	♦	♦	♦		♦	♦	6
Terman et al (28), 2018		♦	♦	♦	♦	♦	♦	♦	7
Leppert et al (29), 2020		♦	♦	♦	♦	♦	♦	♦	7
Hussein et al (30), 2022		♦	♦	♦			♦	♦	5

Abbreviation: ♦, study included this element.

[a] Only articles included in the meta-analysis (Tier 1 studies) were assessed for quality. Studies that provided an adjusted effect measure (odds ratio or hazard ratio) that quantified the effect of outpatient follow-up visits on 30-day readmission risk at the patient level were categorized as Tier 1 studies.

[b] Modified scale had 8 binary quality criteria and a total score ranging from 0 to 8. A score of <6 was considered low quality; a score of ≥6 was considered high quality.

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