Cancer Screening and Barriers to Screening Among Unhoused Individuals in Rhode Island

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ABSTRACT

INTRODUCTION: Unhoused individuals have higher mortality from cancer than the overall population. We aimed to determine cancer screening uptake and the barriers to screening faced by unhoused individuals in Rhode Island.

METHODS: Surveys focused on cancer screenings. Logistic regressions were used to identify interactions between having undergone screening and demographic characteristics. Responses to open-ended questions were analyzed to inform the findings.

RESULTS: Amongst 502 participants, the screening rates for breast, cervical and colorectal cancer were 27%, 58%, and 39%, all below the national averages. Cancer risk factors such as smoking and alcohol were highly prevalent. Not having a primary care provider (PCP), lack of transportation, fear and logistical issues were among the most self-identified barriers to cancer screening. There was a statistically significant interaction between sex and access to PCP (P=.03) with regards to having up to date colorectal cancer screening. Specifically, unhoused men with a PCP were significantly more likely to be screened for colorectal cancer than those without PCP (52% vs 18%, P<.0001).

CONCLUSIONS: Improving cancer screening among unhoused communities is critical. Access to PCP and health insurance can be leveraged to improve uptake of screening recommendations.

KEYWORDS: Cancer; screening; unhoused

INTRODUCTION

Homelessness is a rising public health crisis in the United States, affecting more than 3.5 million individuals.[1,2] In Rhode Island, the unhoused population increased by 35% between 2023 and 2024, with more than 2,400 individuals accounted for in early 2024.[3] Unhoused individuals are twice as likely to die from cancer relative to the general population.[4-6] While the reasons underlying these disparities are undoubtedly complex, low rates of cancer screening are recognized factors.[7] Unhoused individuals are nearly half as likely as the general population to undergo screening for colorectal, breast, and cervical cancers, among others as recommended by the U.S. Preventive Service Task Force (USPSTF).[6-12] More recent studies show that screening gaps may have been exacerbated by the COVID-19 pandemic.[13] Even when unhoused individuals are willing to undergo cancer screening, the inadequate healthcare infrastructure, lack of social support, and complex care logistics deter them from completing screening and having appropriate follow-up.[8-10] Additionally, unhoused individuals may face stigma and discrimination from healthcare institutions and providers, leading to a reluctance to seek care exacerbating this disparity.[14] This underscores the important role that primary care providers (PCPs) and community clinics have in ensuring trustworthy longstanding relationships with this population.[15] This study attempts to identify the screening rates and barriers to cancer screening among unhoused individuals in Providence, Rhode Island by conducting structured surveys focused on screening and system level barriers to screening.

METHODS

Study design and data collection

This cross-sectional study gathered quantitative data via a structured survey which included several open-ended, semi-structured questions. Surveys were conducted with adult unhoused individuals 18 years of age or older, from the metropolitan area of Providence, Rhode Island and nearby areas. The survey consisted of 46 items and was conducted from September 2023 to April 2024. The survey queried 1) basic demographics; 2) housing history; 3) basic medical information; 4) cancer risk factors; 5) cancer screenings; and 6) barriers to cancer screening. The open-ended items included questions about barriers to completing cancer screening. These items were verbally administered by the interviewers who took notes capturing the participants' open-ended responses. The surveys were administered by social scientists (PJ, MS), and were conducted at soup kitchens, shelters, on the street, and at other community events supporting unhoused individuals. Participants were identified via snowball sampling. Surveys were conducted using the participants' preferred language (English or Spanish) with the use of a certified Spanish interpreter when needed. Complete survey items are available in **Figure 1**.

Figure 1. Survey questions

What is your age?
What is your sex/gender?
What is your race or ethnicity?
Where do you sleep at night?
How long have you been sleeping there?
How long have you been unhoused?
What were the factors that led you to homelessness?
What is your highest level of education?
What language do you speak most of the time?
Have you ever had cancer? If so, what type?
Do you have any family history of cancer? If yes, who and what type?
Do you smoke cigarettes?
Have you ever smoked cigarettes?
If yes, how many cigarettes do you smoke?
If yes, how long have you smoked?
Do you drink alcohol?
Have you ever drank alcohol?
If yes, how often and how much alcohol do you drink?
Do you use sun block?
Do you use any intravenous drugs?
Have you been screened for HIV?
Have you been screened for hepatitis C?
Have you ever had a mammogram?
If yes, when was the last mammogram?
If not, why have you not had one yet?
Have you ever had a pap smear?
If yes, when was the last pap smear?
If not, why have you not had one yet?
Have you ever been screened for colorectal cancer?
If yes, when was the last colonoscopy or FIT test?
If not, why not?
Have you ever had a CT scan screening on your lungs for lung cancer?
If yes, when was the last screening?
If not and they smoke and are over 50, why not?
Have you ever had a prostate cancer screening?
If yes, when was the last screening?
If not and they are over 50, why not?
Have you ever had a skin cancer screening?
If yes, when was the last screening?
If not, why have you not had one yet?
Is there anything that is stopping/preventing you from getting cancer screening?
Do you have health insurance?
If yes, what type of health insurance do you have?
Do you have a primary care doctor or practice?

Having up-to-date cancer screening was defined by USPSTF recommendations for the average risk adult.[12] For breast cancer, that is having completed a mammogram between the last year for participants with breasts between ages 40 and 74; for cervical cancer, having completed a pap smear within the last 3 years for participants with cervix between ages 21 and 65, and for colorectal cancer, having completed a colonoscopy within the last 10 years for participants of any sex between ages 45 and 75.

Statistical analysis

Descriptive statistics for the quantitative data were generated using SAS version 9.4 (The SAS Institute, Cary, NC). Logistic regressions including terms for a) whether they were sheltered, b) had a primary care provider, c) race, and d) sex, as well as all 2-, 3-, and the 4-way interaction in order to highlight any sparsity in the sample, and avoid averaging across potentially important higher-order effects. Firth's penalized maximum likelihood estimation was used to reduce bias in the parameter estimates associated with separability arising from 100% of participants having the same response. Rather than having equal coefficients across classifications, coefficients were structured to be proportional to the size of the observed margins. In this way, estimates were more reflective of raw percentages.

Analysis of open-ended items

Participants' answers to open-ended survey questions were summarized by the interviewer and entered into the data tracking system. If relevant, participants were asked what got in the way of getting any cancer screening. All answers were reviewed by the study team and coded to identify common barriers to screening. As these were open-ended items, participants could offer as many barriers as were personally relevant. In addition to organizing coded responses into the types of barriers experienced, we also sorted those barriers by sex and by whether participants had a primary care provider (PCP), to explore how those contexts shape the barriers participants identified.

Ethics

The study was approved by the Brown University Health Institutional Review Board. Local community leader (KS) provided feedback on the study design and logistics. A research member (PJ, MS) approached potential participants and invited them to voluntarily participate in the study. All individuals who participated in the study provided verbal informed consent. Participants were given a $5 food gift card and a list of local healthcare resources following participation. This study was supported by a Health Equity Grant from Genentech Inc. The sponsor had no role in study design, data collection, analysis, or manuscript writing.

RESULTS

Participants demographics

A total of 502 unhoused individuals participated in the survey. Demographic characteristics of the survey participants are presented in **Table 1**.

Table 2 describes the up-to-date screening rates among eligible participants for breast, cervical, and colorectal cancers. Out of 125 eligible participants for breast cancer screening, only 34 (27%) reported having up-to-date screening. Regarding cervical cancer screening, from 133 eligible participants, only 77 (58%) had up-to-date screening. With regards to colorectal cancer screening, from 359 eligible participants, only 140 (39%) had up-to-date screening. When these results were disaggregated by access to a PCP, participants with a PCP were more likely to have up-to-date colorectal cancer screening, and had a trend toward higher rates of screening for breast and cervical cancer. In terms of lung cancer screening, 226 (70%) participants were eligible for screening at the time of the study, however only 18 participants reported having received screening with a computed tomography; the remaining eligible participants were unsure if they had ever been screened for lung cancer. Similarly, 223 male participants were eligible for prostate cancer screening at the time of the survey; however, most of them were unsure if they had received a PSA test. Regarding hepatitis C screening, the majority of the participants were unsure of having been screened. Given the reported low rates of lung, prostate and hepatitis C screening, these were not disaggregated by access to PCP or included in further analysis.

In the exploratory analysis using logistic regressions, to understand the relationship between different demographics and up-to-date cancer screenings, there was a statistically significantly larger effect of having a PCP on colorectal cancer screening and sex. [adj. P=.0246; **Figure 2**]. This was largely driven by the fact that men with a PCP were more likely to have been screened for colorectal cancer than those without a PCP (adj. P<.0001); while this effect was attenuated in females (adj. P=.8952). In contrast, unhoused female participants with PCP access did not differ from those without for colorectal cancer screening (35% vs 32%, P=.8213). Further, the rates of colorectal cancer screening in females were higher than males without PCP prior to but not after adjustment for multiplicity (33% vs 18% P=.0291, adj. P=.0582), and lower than males with a PCP (33% vs 52% P=.0093, adj. P=.0280). Regarding breast and cervical cancer screening, the rates in women did not differ by access to PCP in the multivariate analysis.

Barriers to cancer screening

Among all study participants, when asked "Is there anything that is stopping/preventing you from getting cancer screening" 212 answered "yes" and 254 participants answered "no". From their open-ended responses to the question, these participants identified 273 total barriers.

Table 1. Participant Demographics

Demographics	n (%) N=502
Sex	
Male	357 (71.1)
Female	143 (28.5)
Age - median (IQR)	53 (44 – 61)
Race/Ethnicity	
Non-Hispanic White	271(54.2)
Non-Hispanic Black	94 (18.8)
Hispanic/Latino	72 (14.4)
Other	63 (12.6)
Access to a PCP (y/n)	334 (66.5)
History of cancer (y/n)	48 (9.6)
Smoking (current)	355 (70.7)
Alcohol (current)	226 (45.0)
Active health insurance (y/n)	460 (92.0)
Shelter arrangements (y/n)	359 (71.5)

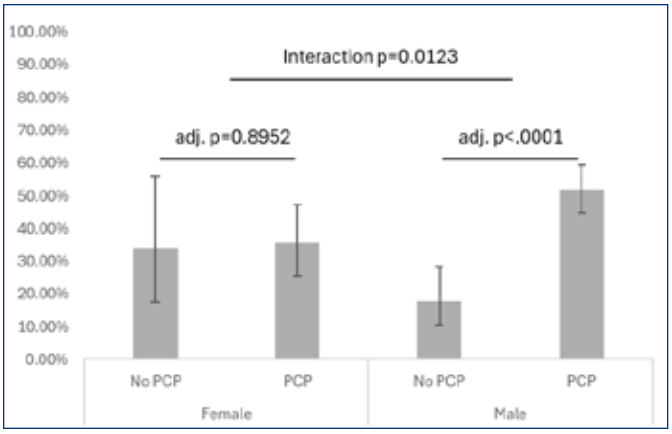
PCP: primary care provider.

Table 2. Rates of Up-to-Date Screening for Breast, Cervical, and Colorectal Cancer among Screening-Eligible Participants

Screening (eligible)	Overall Screened (% of eligible)	Participants with Access to PCP	Participants without PCP Access	Diff (95% CI)
Breast (n=125)	34 (27.2%)	27/90 (30.0%)	7/35 (20.0%)	10.0 (-6.3–26.3)
Cervical (n=133)	77 (57.9%)	58/92 (63.0%)	19/41 (46.3%)	16.7 (-1.5–34.9)
Colorectal (n=359)*	140 (39.0%)	119/253 (47.0%)	21/106 (19.9%)	27.2 (17.5–36.9)†

PCP: primary care provider. Data presented as n (%).
*Many participants were unsure of having had a prostate, lung, and/or hepatitis C screening, therefore were not included in the table.
†P value <.001.

Figure 2. Percent of Unhoused Screened for Colorectal Cancer



Any participant could identify multiple barriers. The most common barriers being lack of transportation, lack of PCP, fear, lack of information on screening, and lack of health insurance [**Table 3**].

Among female participants citing barriers, transportation was most discussed (n= 26; 46%) with lack of PCP and fear tied for second most noted barrier (n= 10; 18% each). Among male participants who discussed barriers to cancer screening, transportation was again the most noted (n=59; 38%) and lack of PCP was the second most noted barrier (n=32; 21%). Among the participants who discussed barriers to cancer screening, 123 indicated they had a PCP. Transportation was also the most cited barrier among these participants (n=49; 40%). Similarly, of the 89 participants who both discussed barriers and indicated they did not have a PCP, transportation was again the most common barrier (n=36; 40%). Of note, lack of health insurance was more commonly cited by male participants (n=18; 12%) than by female participants (n=3; 5%) who identified barriers to cancer screening. Being undocumented was not commonly cited; females did not note this as a barrier and only five men (3%) noted it. Ability to prepare for tests was cited by only one female and one male participant (n= 2% and 1% respectively).

Table 3. Self-identified Barriers to Cancer Screening

Barrier	Count (%)
Transportation	85 (40%)
Lack of primary care provider	42 (20%)
Fear	28 (13%)
No knowledge of services/lack of information	24 (11%)
Lack of insurance/underinsured	21 (10%)
Situation of homelessness	17 (8%)
Mental health, anxiety, and/or stress;	16 (8%)
Distrust of doctors/medical treatment	8 (4%)
Other	33 (14%)

n=212, participants who identified a barrier.

Table 4. Reasons for delayed colorectal cancer screening

Reason	Count (%)
Fear, uncomfortable with test	36 (24%)
Unaware of need or doctor hadn't ordered	35 (23%)
Knows they need one but hasn't been able to go	27 (18%)
No primary care provider (PCP)	26 (17%)
Does not feel they need one	10 (7%)
Medical issues prevent them from going or having test	4 (3%)
Difficulty preparing for test	4 (3%)
Other	8 (5%)

(N=150, participants age 45 to 75 who provided a reason as to why they have not had a colonoscopy)

If participants were eligible to have received colorectal cancer screening based on their age (between 45 and 75) and reported not having been screened, they were asked why they had not been screened. A total of 150 participants provided 150 open-ended responses. The most common responses are included in **Table 4**, fear of the test and not being aware of the need for screening were the most cited.

DISCUSSION

This cross-sectional study highlights significant gaps in early cancer detection for unhoused individuals, specifically for breast, cervical, and colorectal cancer, and negligible awareness in regards to screening for lung, prostate, and liver cancer. Additionally, it provides information on the self-perceived barriers of the unhoused to cancer screening, which can inform the design and implementation of initiatives and programs to address these gaps.

For breast cancer, the percentage of eligible unhoused female participants reporting being up-to-date with mammograms was around 27.2%, compared to 79.8% nationally in 2023.[16] This very low rate is consistent with findings from similar studies with unhoused populations in the U.S.[8,10] These findings call for the adoption of programs informed by unhoused individuals to reduce these disparities, including addressing transportation challenges, utilization of mobile mammography clinics, reducing fear of tests by incentivizing screening, counseling, and educational initiatives; as well as addressing logistical barriers assisting individuals with scheduling appointments and timely and appropriate follow ups.

For cervical cancer, only 57.9% of eligible participants in our study were up-to-date with cervical cancer screening compared to the national average of 75.8% in 2023.[16] In addition to addressing transportation challenges, interventions to increase awareness about cervical cancer and HPV screening, and assessing the feasibility of self testing should be assessed.

For colorectal cancer, only 39.0% of the participants in our study were up-to-date with screening recommendations, and to our knowledge, none of the participants had completed a stool based screening essay. By comparison, the U.S. national average for colorectal cancer screening in 2023 was 72.6%.[16] Our findings highlight the underutilization of colonoscopy for cancer screening in this population and the challenges that unhoused individuals face for colorectal cancer screening. The most commonly identified barriers by the participants included fear of the colonoscopy and/or the results, followed by lack of information or being unaware of the need, barriers to attending a colonoscopy appointment, and not having a PCP. The design of multifaceted and culturally appropriate interventions aimed at increasing knowledge and reducing fear; partnerships with PCPs and community practices to strengthen referral networks; and exploring the

feasibility of using fecal based screenings are deeply needed. Additionally, collaboration with shelters and other community organizations to provide respite and private bathrooms to allow comfortable colonoscopy preparation for unhoused individuals would be important. Furthermore, logistics for transportation, patient accompaniment, and adequate follow up can be addressed through patient care navigation. Using patient care navigators with prior experience of unhousing could be pivotal for decreasing fear and gaining trust among unhoused individuals. To our knowledge, this is the first study to report the positive effect of access to PCP on up-to-date colorectal cancer screening among unhoused men. This finding comes at a crucial time for primary care provision in the U.S. where workforce shortages are widespread,[17] and where local and federal policies to address provider shortages are urgently needed. Future research should focus on understanding facilitators for PCP access in this population, best practices to connect unhoused individuals to PCPs, and the important role of PCP engagement in screening initiatives for this population. Similarly, a better understanding of the roadblocks and facilitators that PCPs face when obtaining colorectal cancer screening for unhoused individuals is necessary. A recent study conducted in the province of Ontario, Canada, found that working in interprofessional practices, using trauma-informed care models, and adaptive care approaches can facilitate screening uptake.[15]

Increasing lung cancer screening is important in this community, because 71% of survey participants were current smokers, compared to 12% for the U.S. general population.[18] In our study, the majority of participants were unsure if they had undergone lung cancer screening. These low rates of lung cancer screening are similar to those found in other underserved communities in the U.S.[19,20] Our results also highlight the need for increased adoption of lung cancer screening recommendations for the overall population, given the national average of only 16% of eligible individuals being screened annually.[16] Partnerships with PCPs, tobacco cessation programs, and the use of patient care navigators could be strategies to overcoming barriers to lung cancer screening in this population[19,21]; similar efforts are currently being utilized in Rhode Island.[22]

Regarding prostate cancer, the majority of eligible participants were unsure if they had undergone screening. Our results are similar to those of a recent study of medical records of a metropolitan healthcare system in Ohio, in which the rates of prostate cancer screening with PSA among unhoused individuals was low.[23] The prostate cancer screening rate they found and the rate we found in our participants are both way below the 38% national average.[16] Together, these results underscore the need for increasing awareness among the unhoused population and providers and for the design of targeted interventions.

With respect to barriers to screening, lack of transportation has been identified both in our study and by others as one of the most prevalent barriers to complete cancer screening.[24,25] A recently published study similarly identified lack of transportation and lack of access to or awareness of screening among the most cited barriers in an unhoused population in Michigan.[26] The study also identified "low prioritization of health compared to other insecurities faced while being homeless" as an important barrier. The study, with 143 participants, sorted data by willingness to be screened and whether the participant was due for screening. The data from our current study amplifies these findings with data from our much larger sample and adds to the experienced barriers the important role of PCP engagement. Identifying facilitators to PCP engagement and supportive environments are important.[15] It has been recognized that PCPs experience moral distress when screening patients who may not be able to undergo appropriate treatment due to social factors.[27] The establishment of patient referral networks and partnerships between primary clinics and oncology centers are important to ensure appropriate follow-up and treatment. Lack of transportation is also a barrier addressable by public policy and dedicated local government funding, therefore partnerships with stakeholders could be fundamental.

In our study, 92% of the unhoused participants had health insurance which was almost always Medicaid, which suggests that undergoing screening may be feasible for this population. However, we fear that with recent funding cuts to Medicare and Medicaid programs,[28] many unhoused individuals may lose or will not be able to renew their healthcare coverage and therefore impact their ability to complete cancer screenings. Continuing funding for state Medicaid and Medicare programs is crucial for efforts to improve cancer screening in this and other disadvantaged populations.

Our study has several notable strengths. First, through collaboration with local community organizations, we were able to survey a significant number of unhoused individuals in the Providence, RI area. Second, our study contributes to the literature on cancer screening and barriers that this population faces. To our knowledge this is the first study to report the positive impacts of access to PCP on colorectal cancer screening in the U.S. unhoused population. Furthermore, the participants in our study were willing to discuss cancer screening, including answering open-ended questions about their reasons for not engaging in screening and identifying how barriers to cancer screening intersect with their housing experiences. This willingness suggests that future research might consider a qualitative study to learn more about how unhoused individuals think these existing barriers to cancer screening could be addressed, and to develop interventions that target their particular needs and housing context, including best practices to connect them with PCPs, ways to ensure they are able to attend their health visits and cancer screening appointments, address concerns and transportation needs. Furthermore, it is important to recognize that some participants identified the stresses of

being unhoused and regarded a higher priority to accessing food and shelter than to undergoing cancer screening.

There are several limitations of this study. First, this was a cross-sectional study, it is possible that access to PCPs or access to adequate housing may evolve or change over time. We did not account for the length of time being unhoused and the willingness to undergo screening in our study. The validity of self-reported responses is additionally an issue for our study. We noted a trend to higher up-to-date screening for cervical and breast cancer among unhoused female individuals with a PCP, but due to the small sample size of women in our study we were not able to reach a conclusion. Efforts are underway to better characterize the perceptions and barriers to cancer screening among unhoused female individuals. Although our study identified high risk cancer behaviors in this population, the self-reported data on lung cancer, hepatitis C, and prostate cancer screening was not enough to conduct rigorous analysis. Future research should aim to address these questions. Answers to our open-ended questions were entered as notes by survey administrators, therefore it was not possible to infer the meaning of some responses. Our study contributes to the lack of cancer screening data in marginalized populations; however, our results may not be generalizable to unhoused populations beyond Providence, RI. Finally, while we have outlined several suggestions to improve the experience and outcomes of unhoused patients regarding cancer screening, efforts to improve housing and healthcare access in this community are needed, it is of utmost importance to continue to address the fundamental causes of unhousing, and to support programs to improve access to shelter, food, and other basic needs for this community.

CONCLUSIONS

Unhoused individuals have high rates of cancer risk factors, however, important gaps in cancer screening remain. Unhoused individuals face significant barriers to cancer screening, yet access to PCP is associated with higher uptake of colorectal cancer screening. The most common self-identified barriers to cancer screening were lack of transportation, fear of the testing or results, and lack of information. We have outlined suggestions to improve cancer screening in the unhoused population, but more research is needed for the development of interventions to address these disparities.

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