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Cervical cancer screening among homeless women of New York City shelters

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Abstract

Introduction—Homeless persons have minimal opportunities to complete recommended cancer screening. The rates and predictors of cervical cancer screening are understudied among homeless women in the US.

Methods—We enrolled 297 homeless women 21–65 years old residing in 6 major New York City shelters from 2012 to 2014. We used a validated national survey to determine the proportion and predictors of cervical cancer screening using cytology (Pap test).

Results—Mean age was 44.72 (± 11.96) years. Majority was Black, heterosexual, single, with high school or lower education; 50.9% were smokers and 41.7% were homeless more than a year. Despite a 76.5% proportion of self-reported Pap test within the past 3 years, 65% of women assumed their Pap test results were normal or did not get proper follow up after abnormal results.

Conflict of Interest

To the best of our knowledge, no conflict of interest, financial or other, exists.

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Forty-five-point-nine percent of women did not know about frequency of Pap test or causes of cervical cancer. Lower proportion of up-to-date Pap test was associated with lack of knowledge of recommended Pap test frequency ($p<0.01$) and relationship between HPV and an abnormal Pap test ($p<0.01$).

Conclusions—Self-reported Pap testing in homeless women was similar to a national sample. However, the majority of women surveyed were not aware of their results, received limited if any follow up and had significant education gaps about cervical cancer screening. We recommend improved counseling and patient education, patient navigators to close screening loops, and consideration of alternative test-and-treat modalities to improve effective screening.

Keywords

cervical cancer; screening; homeless; cancer disparities

Introduction

Cervical cancer is the second leading cause of cancer deaths in women worldwide. In the United States, it cost \$1.6 billion in 2010 to provide cervical cancer care, from the initial year after diagnosis, last year of life, and the period between (National Cancer Institute (NCI), 2010). Human Papillomavirus (HPV) infection is the cause for 70% of cervical cancers and is the most common sexually transmitted infection (STI) in the US (Dunne et al., 2007). In the past 30 years, cervical cancer incidence and mortality have dramatically declined, nearly 50%, due to extensive preventive and treatment strategies (NCI, 2010). Pap tests screening for cervical cancer is widely integrated into basic women's health care. However, disparities exist in accessing cervical cancer screening among socioeconomically disadvantaged populations and minorities in the United States (US) (American Cancer Society, 2011).

One special population often overlooked in cancer research is the homeless population. An estimated 3.5 million Americans experience homelessness each year and around 630,000 experience homelessness each night; 15% are chronically homeless (National Alliance to End Homelessness, 2013; National Coalition for the Homeless, 2013; US Department of Housing and Urban Development, 2012). New York City (NYC) has a high level of homelessness with around 28,000 adults sleeping in the municipal shelter system (Markee, 2013; Metraux, 2012). High level of mental illness and poor access to primary care have been documented among homeless (Kushel, 2012; Khandor et al., 2011). Furthermore, past experiences of discrimination and unwelcomeness in the health care settings limits access to available preventive or therapeutic services (Khandor et al., 2011; Wen, Hudak, and Hwand, 2007). History of childhood sexual abuse, early sexual activity, alcohol or substance abuse, and lack of connectedness to family and health systems may increase homeless women's risk for STIs (Rotheram-Borus et al., 1996).

Little is known about cervical cancer screening practices in the homeless population and limited previous research has shown Pap test rates around 54–55% among homeless women (Chau et al., 2002; Lebrun-Harris et al., 2013). To better understand barriers to cervical cancer screening among homeless women in New York City (NYC), with one of the largest

homeless populations in the US, we evaluated the proportion and predictors of completing a Pap test within the past 3 years among homeless women in NYC's shelters.

Methods

Setting and Design

The Community Medicine Program of Lutheran Family Health Centers offers clinical services to the homeless population at multiple locations in New York City in collaboration with non-governmental organizations that operate shelters. This cross-sectional study was conducted in 6 shelters and/or shelter-based clinics during 2012–2014. Shelter-clinics also serve the homeless who primarily live on the streets. Inclusion criteria included currently homeless women age 21 to 65 years who resided in New York City's shelters. The age range reflected the US Preventive Services Task Force (USPSTF) recommendations for cervical cancer screening (USPSTF, 2012). Exclusion criteria included women who were non-English/Spanish speaking, unable to consent or answer questions, had a hysterectomy with removal of cervix, and had a prior diagnosis of cervical cancer that needed a different screening schedule. Each week randomly selected days were scheduled to visit shelters and enroll participants. We approached participants in the community room of the shelters or waiting rooms of the shelter-based clinics, described the study, and assessed eligibility. Subsequently a trained female research assistant took participants to a private room, obtained consent and administered the survey face-to-face and recorded responses. An interpreter was used when needed.

Participants were asked to recall their latest Pap test and its result (normal versus abnormal) as well as the last Pap test prior to the most recent one. A calendar was used to assist women to recall approximate dates. Knowledge, attitude, and practices regarding Pap test were assessed using a validated survey, the National Cancer Institute, Health Information National Trends Survey (HINTS) (National Institute of Health, 2012), which was also translated into Spanish. Data on age, race/ethnicity, education, length of homelessness, marital status, sexual orientation, contraception methods, smoking history and number of cigarettes smoked per day were also collected. All data including homeless status and duration of homelessness were self-reported. Pap test status and its result were self-reported. Pap test was considered up-to-date if it was performed within the past three years of the survey date (USPSTF, 2012). The survey took approximately 30 minutes to complete. Participants were notified during the consent process that no one outside of the study team would see their responses or have access to any study data. All participants were assigned a unique study identification code. No biologic samples were obtained. All women needing Pap test were referred to a provider in the shelter-based clinics. The Institutional Review Board at the Lutheran Family Health Centers approved this study.

Outcomes and Analyses

Primary outcome was the proportion of women who had Pap test within the past 3 years. Secondary outcomes were attitudes and practices regarding Pap test, proportion of contraception users, STI prevention methods, and results of latest Pap test (normal vs. abnormal, and if any treatment received). The main predictor/independent variable was the

length of homelessness (categorical). Others included age, race, education, smoking history, marital status, sexual orientation, and provider counseling. Data on HIV status or incarceration were not obtained due to their sensitive nature. Dependent variables are dichotomous/categorical (Pap test within past three years, questions evaluating current knowledge, attitude and practices in regard to Pap test, latest Pap test normal or abnormal, and current contraception and STI prevention methods). We calculated the proportions with 95% Confidence Interval (CI) for primary and secondary outcomes. Descriptive statistics, univariate and bivariate analysis using X^2 , t test, and analysis of variance as well as multivariable logistic regression were performed where indicated. We calculated proportions for primary and secondary outcomes and presented results in total numbers and percentages. We used multivariable logistic regression model and calculated adjusted odd ratios (95% CI) for associations between study outcomes and independent variables to detect predictors and to control for potential confounders. Variables were included into the models when bivariate analysis showed significance level of $p < 0.1$, and/or when clinically sensible and plausible. SPSS Version 20.0 was used for data analysis. Based on original limited literature regarding proportions of Pap test among ethnic and racial minorities, and results of preceding pilot study with 88 participants (73% proportion of women with up-to-date Pap test within 3 years; not published separately), we hypothesized that proportion of Pap test among homeless women in New York City is at least 75% (Lebrun-Harris et al., 2013; Centers for Disease Control and Prevention (CDC), 2010). We calculated a sample size of 288 (two-sided $\alpha = 0.05$, power = 0.8, and 0.05 precision around mean).

Results

Demographics

Up to 400 homeless women were approached of whom close to 77% accepted to participate in the study and met inclusion and exclusion criteria (less than 3% were excluded due to exclusion criteria). Demographics of those who were excluded were not different from the study population. Data from 297 women who met the inclusion and exclusion criteria were analyzed. The mean age of participants was 44.7 years (Standard Deviation (SD) ± 11.9 years). Patients were mostly English speaking. Forty-one percent were homeless for more than 1 year. Fifty-point-five percent were Black; 86.6% heterosexual; and 50.5% current smokers. Socio-demographics of women in our sample were consistent with those of women residing in the study sites. There was no association between duration of homelessness and age, race/ethnicity, and current smoking. Single women were more likely to be homeless less than a year ($p < 0.03$). Women who were homeless more than a year were more likely to have lower education at the level of high school or less ($p < 0.02$). Table 1 summarizes socio-demographics and corresponding data from bivariate analyses in regards to Pap test.

Study Outcomes

Pap screening—Overall 76.3% of women were up to date with the USPSTF recommendations for Pap test. However, 65% did not know the results or did not follow up on the results and assumed it was normal, 61 (27%) had normal results, and 7.8% had abnormal results. In their lifetime, 88% reported having had a Pap test at least once. Forty-

nine percent of women did not know the recommendation about Pap test frequency (either 1-year or 3-year intervals). Only 41.2% knew about the association between HPV and cervical cancer. Only 30.6% were current contraceptive users; 26.2% of all women surveyed used condoms. In bivariate analysis, there was no significant association between duration of homelessness and the knowledge of recommended Pap test frequency, being up-to-date for Pap test, ever having a Pap, or contraception use. The proportions of Pap test and its associated factors, contraception use and results of bivariate analyses regarding up-to-date Pap test are presented in table 2.

Logistic regression—In multiple logistic regression when race, age, sexual orientation, marital status, level of education, duration of homelessness and cigarette smoking were in the model, none had any significant association with being up-to-date for Pap test. Results are presented in table 3.

Discussion

In our study, the overall proportions of up to date or lifetime Pap test among homeless women were comparable to the national averages (National Institute of Health, 2012). The proportions of screening by race and ethnicity were also comparable to the national averages of 74.9% for White, 80.1% for Black, and 75.4% for Hispanic or Latina women (CDC, 2010). However, studies have shown that self-reported Pap testing is less valid than most other self-reported health data and varies by the socioeconomic status (SES); with women of lower SES or minorities being more likely to over-report being Pap tested (up to 36%) (Lofters et al., 2014). Therefore our findings of nationally comparable proportions of Pap test should be interpreted cautiously with potential over-reporting in mind.

Additionally, a considerable number of homeless women were unaware of their Pap results, simply assumed it was normal, or did not follow up with abnormal results. Multiple factors may have contributed to these findings including that: the homeless are a mobile population which makes it difficult for traditional health system to provide feedback or arrange follow ups; health literacy in regards to Pap test and subsequent necessary steps may have been inadequate among the homeless; the homeless face multiple competing social conditions interfering with proper follow-ups and keeping clinical appointments. Furthermore, the homeless generally lack or have inconsistent health insurances and often experience stigma and discrimination within the health system discouraging them from continuing to seek care (Wen, Hudak, and Hwang, 2007).

Lack of a follow-up after Pap tests reflects on an important gap in effective screening highlighting that the intended endpoints are often not achieved and subsequent necessary next steps that are instrumental part of effective screening programs are often missed in the homeless. The homeless women may be more at risk of cervical dysplasia due to risk factors such as smoking, early sexual activities or multiple partners, and unprotected sex (Rotheram-Borus, 1996; Zlotnick and Zerger, 2008) and it is even more important to close loops in screening as it will be unlikely the homeless can afford cancer care after a delayed diagnosis.

Limited data from previous studies in the homeless regarding cancer screening are consistent with our study findings (Chau et al., 2002; Lebrun-Harris et al., 2013). A 2009 survey published in 2013 showed 87.3% were up to date with Pap test within the past 3 years but included more Whites and less Hispanics, and also people living in transitional centers, hotels or other accommodations besides shelters (Lebrun-Harris et al., 2013). An older study from Los Angeles that had similar average duration of homelessness to our study population documented 55% up to date Pap test rates (Chau et al., 2002). Percentage of smokers in our study, though very high compared to the national average, was comparable with the previous studies (Lebrun-Harris et al., 2013).

Among homeless women, the knowledge of recommended Pap test frequency was considerably lower compared to the national average (54.1% vs. 76%) and was associated with less up to date Pap test. Limited number of women had the knowledge of HPV and its relationship to abnormal Pap test (41.9%) compared to the national average of 78% (National Institute of Health, 2012; CDC, 2010). This knowledge gap may be related to inadequate provider counseling and health education during clinical encounters where often the focus is on addressing the acute issues neglecting preventive care especially cancer screening. There is health system discrimination, whether perceived or actual, providers implicit biases, and subtle prejudice against the minorities and homeless and their medical needs (Wen, Hudak, and Hwang, 2007; Devine et al., 2012; Cooper et al., 2012; Hausmann et al., 2011) which might influence the homeless' decision to seek out healthcare further affecting preventive or cancer screening behavior (Wen, Hudak, and Hwang, 2007).

There is clearly a lack of an efficient and effective cancer screening strategy in the shelter-based or federally funded clinics where the homeless seek care. While there are valuable national initiatives such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to provide low-income, uninsured, and underinsured women access to cancer screening (CDC, 2014; Miller, Plescia, and Ekwueme, 2014), providing free services does not assure access to screening. Targeted strategies to address specific barriers among homeless and outreach and education are paramount and need to be systematically implemented in places where the homeless seek care. Barriers to completion of screening process are often not addressed systematically and issues of navigating a complex health system continue to exist while patients are not well informed to make educated health choices (Asgary et al., 2014; Asgary et al., 2014; Asgary et al., 2015).

However, there are opportunities to address these concerns. The homeless, in general, stay in the shelter system for long time which provides an ideal opportunity for cancer screening and follow up during homelessness. Patient educators or peer educators could serve as vehicles to offer more effective health education to the homeless in the shelters or shelter-based clinics. At shelters, already assigned case managers/workers generally make social service referrals and bring the homeless and medical providers together to complete shelter medical evaluation package, which is mandatory for housing process. This system could be utilized to improve proper follow-ups after cancer screening. Additionally, patient navigator strategies have shown sustained improvement in cancer screening among the minorities (Glick et al., 2012; Sabatino et al., 2012), and as models could be adapted to mitigate specific system, provider, and patient level barriers for the homeless. Navigators can provide

tailored education for screening methods and processes, address individuals' misconception, help with scheduling and reminding, and obtain results and make follow-up appointments.

Provider's education to offer cancer counseling to all patients irrespective of their social conditions may help with discrimination and minimizing provider's assumptions about patients' priorities. Systematic and targeted trainings, reflection sessions, online materials, and workshops and conferences targeting biases with providing cultural competency and communication skills could have added values (Devine et al., 2012; Peel et al., 2012; Teal et al., 2010). Training and education that cover barriers specific to the homeless and incorporate strategies to overcome those barriers are instrumental to improve overall cancer counseling.

All these potential strategies are fully compatible with the National Cancer Institute's Center to Reduce Cancer Health Disparities vision and mission to improve cancer screening and cancer equity and decrease cancer disparities among the underserved. They are also consistent with the Affordable Care Act (Title IV; sections 4302 and 4106) seeking to improve access to preventive services for adults on Medicaid.

In this study with direct input from the homeless, and almost 12 years after the only other cross-sectional study in the US (Chau et al., 2002), we collected comprehensive relevant data regarding Pap test using a validated national survey (National Institute of Health, 2012), and compared it with the national proportions. We enrolled homeless women who reside in the shelters or on the streets and were able to obtain a good sample size from multiple shelters in NYC, a city with one of largest populations of the homeless in the country, which makes our data more generalizable.

Limitations

Our study, however, is not without limitations. There may be inherent differences between women who participated versus the ones who refused, considering the psychosocial burden in this population. We assessed only English/Spanish speakers. However, this reflects 90% of our patient population in the NYC's shelters or shelter clinics. The study was a cross-sectional study that utilized self-reported data on Pap test, which could be prone to biases including recall bias, social desirability and over-reporting. Pap test results could also be prone to participant's understanding of "normal" versus "abnormal". We did not collect data on parity, history of substance abuse or mental health problems, which may have been relevant. However, we used a validated reliable national survey to collect data. Although we did not collect direct information regarding other common barriers to Pap test in the general population; including not having a primary care physician or health insurance, recent immigration, modesty, embarrassment, fear of cancer or low perceived risk; we hypothesize that homeless women share these barriers, which should be incorporated in targeted education and services.

Conclusions

Interventions need to be implemented in settings where the homeless seek care to improve effective Pap test and knowledge and practice regarding cervical cancer, thereby closing

gaps in the screening process. We recommend provider counseling and health education at all clinical encounters, employing patient or peer educators, as well as targeting reading materials in the shelters to address misconceptions and improve cervical cancer health literacy. Educational information on cancer prevention should be tailored to the demographic of homeless patients, accounting for health literacy, health belief, and social support. To navigate a complex health system, employing case workers/managers, community health workers, or patient navigators are effective strategies that should be considered. They can provide health education, schedule appointments and ensure that patients keep appointments, send reminders, and help obtain test results.

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Significance

What is already known on this subject? The homeless women are at higher risk for cervical cancer and often have limited access to cancer screening including cervical cancer.

What does this study add? While the proportion of self-reported Pap tests in the homeless was comparable to the national average, an important gap in effective screening exists. The majority of homeless women are not aware of the results of their Pap test, receive limited or no follow-ups, and experience significant education gaps about cervical cancer screening.

Table 1

Socio-demographics by cervical cancer screening status among homeless women from New York City shelters, 2013–2014

Indicators n=297	N (%)	Up to Date Pap 221/289	Not Up to Date Pap 68/289	p value
Age (years)	Mean 44.72 (SD=11.96) Range: 21–64	Mean 44.58 (SD=11.94)	Mean 45.10 (SD=13.30)	0.75
Years of Homelessness (n=295)				0.18
1 yr	172 (58.3)	126/220 (57)	42/67 (63)	
> 1 but 3 yrs	63 (21.4)	51/220 (23)	10/67 (15)	
> 3 yrs but 5 yrs	25 (8.5)	17/220 (8)	8/67 (12)	
> 5 yrs	34 (11.5)	26/220 (19)	7/67 (11)	
Level of Years of Homelessness				
3 vs > 3 yrs				0.6
1 vs > 1 yr				0.56
Marital Status (n=296)				0.4
Single	190 (64.0)	136/221 (62)	49/68 (72)	
Married	30 (10.1)	26/221 (12)	4/68 (6)	
Divorced, separated, widowed	76 (25.6)	59/221 (27)	15/68 (22)	
Level of Education (n=294)				0.88
High School	184 (62.6)	140/221 (63)	41/66 (62)	
Some college or college	110 (37.4)	81/221 (37)	25/66 (38)	
Race Categories (n=295)				0.23
White	45 (15.2)	27/221 (12)	14/66 (21)	
Black	149 (50.5)	118/221 (53)	28/66 (42)	
Hispanic	66 (22.4)	50/221 (23)	15/66 (23)	
Asian, native American, others	35 (11.9)	26/221 (12)	9/66 (14)	
Sexual Orientation (n=284)				0.64
Heterosexual	246 (86.6)	182/213 (85)	58/64 (90)	
Homosexual	17 (6)	14/213 (7)	2/64 (3)	
Bisexual	21 (7.4)	17/213 (8)	4/64 (6)	
Current Cigarette Smoking (n=218)	111 (50.9)	83/160 (52)	24/51 (47)	0.63
Number of Current Cig. Per Day (n=51)	6.13 (SD=4.07) R:1–20	5.67 (SD=3.74)	8 (SD=5.01)	0.1
Years of Cigarette Smoking (n=52)	21.54 (SD=13.25) R: 0–50	20.52 (SD=12.94)	25.82 (SD=14.41)	0.26
Past Cig. Smoking (n=55)	17 (30.9)	14/42 (33)	2/10 (20)	0.48

* Significance level

N for Pap test is 289 due to some missing data regarding Pap test

R=Range

Table 2

Pap test data with bivariate analysis among homeless women from New York City shelters, 2013–2014

Indicators n=297	N (%)	Up to Date Pap 221/289	Not Up to Date Pap 68/289	p value
Current Contraception Use (n=297)	91 (30.6)	71/221 (32)	20/68 (29)	0.67
Condoms	71 (78)			
Oral Contraception	17 (18)			
Sterilization	8 (8)			
Other	3(3)			
Last Pap Test (n=289)				
3 yrs	221 (76.5)			
> 3 yrs	53 (18.3)			
Never had Pap	15 (5.2)			
Results of Last Pap Test (n=102)				0.88
Normal	84 (81.6)	69/84 (82)	14/18 (78)	
Abnormal	8 (7.8)	6/84 (7)	2/18 (11)	
Don't know	11 (10.7)	9/84 (11)	2/18 (11)	
Last Pap Test Prior to the Most Recent One (n=275)				0.00 *
1 yr	90 (32.7)	86/212 (40)	5/59 (8)	
> 1 yr but 3 yrs	82 (29.8)	70/212 (33)	12/59 (20)	
> 3 yrs but 5 yrs	27 (29.8)	23/212 (11)	4/59 (7)	
> 5 yrs	42 (15.2)	27/212 (13)	13/59 (22)	
Last Pap was the first	19 (6.9)	6/212 (3)	11/59 (19)	
Never had Pap	14 (5.1)	0/212 (0)	14/59 (24)	
Reason for Last Pap Test (n=278)				0.05 *
Routine	232 (82.9)	187/220 (85)	41/67 (61)	
Last Pap was abnormal	3 (1.1)	3/220 (1)	0/67 (0)	
A problem, pregnancy, or other	43 (15.4)	30/220 (14)	12/67 (18)	
Knowledge of Recommended Pap Test Frequency (n=294)				0.005 *
Don't know or other frequency	135 (45.9)	90/219 (41)	42/67 (63)	
Once a year	143 (48.6)	114/219 (52)	24/67 (36)	
Every 3 years	16 (5.4)	15/219 (7)	1/67 (1)	
Does HPV Cause Cancer (n=296)				0.68
Yes	122 (41.2)	94/221 (43)	27/68 (40)	
Don't know or no	47 (16.6)	36/221 (16)	9/68 (13)	
Never heard of HPV	127 (42.2)	91/221 (4)	32/68 (47)	
Been Told Has HPV Infection (n= 296)				0.43

Indicators n=297	N (%)	Up to Date Pap 221/289	Not Up to Date Pap 68/289	p value
Yes	16 (5.4)	14/221 (6)	2/68 (3)	
No or don't know	155 (52.4)	118/221 (53)	34/68 (50)	
Never heard of HPV	125 (42.2)	89/221 (40)	32/68 (47)	
Heard New Info Regarding Frequency of Pap (n=294)	56 (19)	46/221 (21)	10/66 (15)	0.37
Agrees to Do Pap Every 3 years if Recommended (n=295)	236 (80)	174/217 (80)	55/65 985)	0.47

* Significance level

Table 3

Result of logistic regression analysis of independent variables and Pap test (dichotomous) among homeless women of New York City shelters, 2013–2014

	Up-to-date Pap		
Predictor* (n=297)	Adjusted Odds ratio	95% CI	Significance level (p value)
Age (continuous)	1.005	0.97 to 1.03	0.72
Years of Homelessness (continuous)	0.63	0.17 to 2.32	0.49
Race (categorical)	1.25	0.84 to 1.87	0.25
Marital Status (categorical)	1.18	0.77 to 1.80	0.43
Level of Education (categorical)	0.76	0.38 to 1.52	0.44
Smoking (dichotomous)	1.07	0.54 to 2.09	0.83

* Definition and categories used are presented in table 1.