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Breast and cervical cancers diagnosed and stage at diagnosis among women served through the National Breast and Cervical Cancer Early Detection Program

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Abstract

Purpose—To assess cancers diagnosed and the stage of cancer at the time of diagnosis among low-income, underinsured, or uninsured women who received services through the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

Methods—Using the NBCCEDP database, we examined the number and percent of women diagnosed during 2009–2011 with in situ breast cancer, invasive breast cancer, and invasive cervical cancer by demographic and clinical characteristics, including age, race and ethnicity, test indication (screening or diagnostic), symptoms (for breast cancer), and screening history (for cervical cancer). We examined these characteristics by stage at diagnosis, a new variable included in the database obtained by linking with state-based central cancer registries.

Results—There were 11,569 women diagnosed with invasive breast cancer, 1,988 with in situ breast cancer, and 583 with invasive cervical cancer through the NBCCEDP. Women who reported breast symptoms or who had diagnostic mammography were more likely to be diagnosed with breast cancer, and at a later stage, than those who did not have symptoms or who had screening mammography. Women who had been rarely or never screened for cervical cancer were more likely to be diagnosed with cervical cancer, and at a later stage, than women who received regular screenings.

Conclusions—Women served through the NBCCEDP who have not had prior screening or who have symptoms were more often diagnosed with late-stage disease.

Keywords

Breast cancer; Cervical cancer; Cancer stage; Cancer screening

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The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Conflict of interest

All authors are federal government employees. The authors have no conflicts of interest to disclose.

Introduction

Stage of cancer at the time of diagnosis represents one of the most important predictors of cancer morbidity and long-term survival [1]. Cancer stage represents the extent of the cancer and is used along with other tumor characteristics to help determine what type of treatment is needed [2]. To stage cancer, doctors look at the size of the tumor and whether it has spread to other areas in the body. They use a systematic measurement known as the tumor nodes metastasis (TNM) system which was developed in the late 1940s [3, 4]. This system has three basic components: (1) size of primary tumor (T), (2) involvement in local and regional lymph nodes (N), and (3) whether the cancer has spread to distant organs, also called metastasis (M).

Population-based data on cancer stage are collected through cancer registries such as the National Program for Cancer Registries administered through the Centers for Disease Control and Prevention (CDC) [5] and the Surveillance, Epidemiology, and End Result (SEER) Program administered through the National Cancer Institute [6]. These data provide critically important information used for monitoring cancer rates and trends, planning cancer control and prevention efforts, and evaluating screening programs. Healthy People 2020 objectives monitor specific outcomes regarding reducing invasive cervical cancer incidence rates to 7.1 per 100,000 women and late-stage female breast cancer rates to 41.0 per 100,000 women [7]. A recent study using cancer registry data representing 97 % of the US population found that these targets were not met; in 2010, the invasive cervical cancer rate was 7.5 per 100,000 women and the late-stage female breast cancer rate was 41.7 per 100,000 women [8].

Screening is one way to find female breast and cervical cancers at earlier stages when treatment is most effective and to identify precancerous changes of the cells before they become malignant [9–12]. In response to the burden of breast and cervical cancer, the CDC was authorized by Congress to establish the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in 1990 to provide breast and cervical cancer screening and diagnostic services to low-income, under- and uninsured women who would otherwise have no access to these services. Details on the implementation of the NBCCEDP have been published elsewhere [13]. The NBCCEDP specifically aims to provide services to women who are not getting routine screening. From 1991 to 2012, NBCCEDP grantees served more than 4.5 million women and diagnosed more than 65,000 breast and cervical cancers and 160,000 premalignant cervical lesions [14].

Research has shown that 5-year survival is much higher when cancer is diagnosed at an early stage than at a distant stage [15]. The relative 5-year survival for breast cancer is 99 % when diagnosed at a local stage, compared with 25 % when diagnosed at a distant stage; similarly, the relative 5-year survival for cervical cancer is 91 % when diagnosed at a local stage and 16 % at a distant stage. A previous report on the stage of diagnosis among women diagnosed with cancer through the NBCCEDP from 1991 to 2002 found that 74 % of breast cancers and 53 % of cervical cancers were found at early stage [16]. At that time, the stage of disease was not standardized to a single classification system and was primarily based on the clinical presentation at the time of initial tissue diagnosis and not on the final stage after

surgery and additional tests. In 2009, the NBCCEDP began linking cancer cases diagnosed in the program with data from state-based central cancer registries in order to obtain registry-standardized cancer stage information. This paper is the first description of the stage of cancer at the time of diagnosis using the NBCCEDP linked registry data among women diagnosed through funded grantees across the United States.

Methods

Data source

The NBCCEDP collects a standardized set of data elements for all breast and cervical cancer screening and diagnostic services provided by the grantees, known as minimum data elements (MDEs). The dataset contains variables on each clinical encounter including date of service, patient age, race, ethnicity, screening history, symptoms, indication for test, examination received, examination results, and final diagnosis. Demographics include age, race, and ethnicity. Age was categorized into groups of 40–49, 50–59, 60–64, and 65 or older for breast cancer and 18–29, 30–49, and 50 or older for cervical cancer. Race and ethnicity was categorized as white non-Hispanic, black non-Hispanic, other non-Hispanic (which included American Indian/ Alaska Native (AI/AN), Asian–Pacific Islander (API), and multiracial due to small sample sizes), Hispanic, and unknown race/ethnicity. Indication for test was categorized as screening or diagnostic, based on the reported indication for the initial mammogram or Papanicolaou (Pap) test just prior to the diagnosis, symptoms, or a previous abnormal examination. Screening indication included routine examination among women who did not present with symptoms, whereas diagnostic indication included women with symptoms or previous abnormal examinations. Symptoms reported were included as a separate category because frequently the clinical examination and report of symptoms were obtained after the screening test had been completed.

To supplement information on cancers detected, the NBCCEDP also collects registry-standardized data through routine data linkages with state-based central cancer registries. Grantees linked data for women diagnosed from 2004 through 2011, the most recent year of complete registry data available. Stage at diagnosis was based on the SEER Summary Stage 2000 which characterizes cancers as localized, regional, distant, or unknown stage as this is the data consistently available from all the central cancer registries through the data linkage [3].

Study population

The NBCCEDP population consists of low-income woman at or below 250 % of the federal poverty level who do not have health-care coverage for breast and cervical cancer screening services. Of those undergoing breast cancer screening, 48 % are non-Hispanic white women, followed by 25 % Hispanic women, and over half are aged 50–59 years old. Among those receiving cervical cancer screening, 50 % are non-Hispanic white women, followed by 23 % Hispanic women, and majority are between the ages of 40 and 59 years old (68 %) [17].

This analysis was restricted to years from 2009 through 2011 due to the availability of MDE data on indication for service (whose collection started in 2009) and availability of stage

data acquired through registry linkages through 2011. The study population consisted of 17,340 women who were diagnosed with breast or cervical cancer through the NBCCEDP from 1 January 2009 through 31 December 2011. There were 3,200 women excluded from this analysis because of the following reasons: missing registry data in the MDE (2,794), primary cancer site was not breast or cervical (70), cancer was classified as lymphoma (4), discrepancy between invasive and carcinoma in situ classification (136), or a previous diagnosis of breast or cervical cancer (196). Although data were excluded from 3,200 women, these women were not characteristically different from the study population. Missing registry data were uniform across several states that had not completed their data linkage with cancer registries. Cervical carcinoma in situ was not included in this study because it is not collected in cancer registries. After all exclusions, our final study population consisted of 11,569 women diagnosed with invasive breast cancer, 1,988 with breast carcinoma in situ, and 583 with invasive cervical cancer.

Data analysis

The number of women diagnosed with breast carcinoma in situ, invasive breast cancer, and invasive cervical cancer was calculated by age group, race and ethnicity, indication for test (screening or diagnostic), symptoms (for breast cancer), and screening history (for cervical cancer). The proportion of local, regional, and distant stage invasive breast and cervical cancer were also calculated by patient characteristics. Due to small cell sizes, we tested that patient characteristics were significant for differences in stage using the Monte Carlo simulation exact p values with significance at p value < 0.01 . Using logistic regression modeling, adjusted odds ratios (aORs) and corresponding 95 % confidence intervals (CIs) for each characteristic were estimated for women diagnosed with cancer. Models were adjusted for age, race/ethnicity, indication for test, breast symptoms (breast cancer analysis only), and screening history (cervical cancer analysis only). All analyses were performed using SAS software version 9.2 (SAS Institute, Cary, North Carolina).

Results

During 2009–2011, 1,988 women were diagnosed with breast carcinoma in situ through the NBCCEDP (Table 1). Although the odds of being diagnosed with breast carcinoma in situ were higher among women aged 50–64 years, about half of cases were among women aged 50–59 years, and half were among non-Hispanic white women. One-third of the women diagnosed with carcinoma in situ were reportedly being tested for diagnostic reasons, and 64 % reported breast symptoms.

During the study period, 11,569 women were diagnosed with invasive breast cancer through the NBCCEDP (Table 2). Similar to breast carcinoma in situ, about half of the women diagnosed with invasive breast cancer were aged 50–59 years and the odds of having breast cancer were higher for older women. While 60 % of the women with invasive breast cancer were non-Hispanic white women, the odds of having invasive breast cancer were the same among non-Hispanic white and black women, but lower among “other” non-Hispanic women (i.e., AI/AN, API, and multiracial women) and Hispanic women. Approximately 62 % of the women with invasive breast cancer were tested for a diagnostic indication. While

only one-third reported breast symptoms, these women had much higher odds of being diagnosed with invasive breast cancer than those who did not report symptoms. By stage at the time of breast cancer diagnosis, 48 % had local disease, 39 % had regional disease, and only 7 % had distant disease (Table 3). Age at diagnosis, race/ethnicity, and indication for test was independently associated with stage at the time of breast cancer diagnosis (p value < 0.0001). Women 40–59 years had a higher proportion of regional stage breast cancer compared to women 60 years or older. Regional and distant stage breast cancer was more common among non-Hispanic black women than among women of other racial/ethnic groups. By test indication, 61 % of women with screening indication more often presented with local breast cancer compared to 42 % of women who had a diagnostic indication. Similarly, 62 % of women who did not report breast symptoms presented with local disease compared to 41 % of women who did.

During 2009–2011, 583 women were diagnosed with invasive cervical cancer through the NBCCEDP (Table 4). Very few women (4 %) diagnosed with invasive cervical cancer were under the age of 30 years. “Other” non-Hispanic women and Hispanic women had lower odds of being diagnosed with invasive cervical cancer. Most women (64 %) with invasive cervical cancer were tested for a screening indication, but women who were tested for a diagnostic indication had higher odds of cervical cancer. Women who had rarely or never been screened for cervical cancer had higher odds of cervical cancer than those who were screened within the past 5 years. By stage at the time of cervical cancer diagnosis, 36 % had local disease, 41 % had regional disease, and 12 % had distant disease (Table 5). Stage at the time of cervical cancer diagnosis did not statistically differ by age, race/ethnicity groups, screening history, and test indication.

Discussion

This paper describes the first report of the new cancer registry data elements in the NBCCEDP database collected from linkages with state-based central cancer registries. This provides a more standardized description of cancer stage than the previous process where data were based on initial cancer detection rather than final staging procedures.

This study finds that slightly less than half of women diagnosed with invasive breast cancer in the NBCCEDP were diagnosed at an early stage and more than one-third at a regional stage. During 2004–2006, 62 % of women aged 50 years or older in the United States were diagnosed with breast cancer at an early stage and 28 % at a regional stage [18]. Compared to the general population, Wu et al. [19] showed that women enrolled in the NBCCEDP were more likely to have later stage breast disease than matched women not enrolled in the NBCCEDP. This is consistent with the fact that women served in the NBCCEDP may not receive regular mammograms and present with symptoms, indicating breast cancer is already present.

Our study found that more than half of women diagnosed with cervical cancer in the NBCCEDP had late-stage (regional or distant) disease. During 2004–2006, 36 % of women in the United States were diagnosed with cervical cancer at regional stage [18]. Similar to breast cancer, a higher proportion of women in the NBCCEDP present with regional disease

at the time of diagnosis than in the general population. This may not be surprising as the NBCCEDP focuses efforts for cervical cancer screening on women who have never been screened or who have not been screened within the previous 5 years. These women are more likely to present with late-stage disease [20]. Studies have shown that 60 % of women diagnosed with invasive cervical cancer have never been screened or not screened in the past 5 years [21].

Our findings are subject to several limitations. First, registry data elements were missing for 15 % of women with breast cancer and 30 % of women with cervical cancer. Therefore, these cases were not included in the analysis. Second, the stage of cancer at the time of diagnosis was unknown for approximately 6 % of breast cancer cases and 12 % of cervical cancer cases; however, this is consistent with other studies using registry data [18]. Third, the indication for test may have been misclassified in some cases; for example, some women were recorded as receiving a screening (not diagnostic) mammogram, but their records showed that they had an abnormal clinical breast examination prior to the mammogram or that the woman reported breast symptoms. Fourth, screening history for cervical cancer cases was self-reported and was not verified through medical records review. Last, because the NBCCEDP serves a very small percentage of the eligible population [22, 23], the findings of this evaluation cannot be generalized to all low-income women in the United States.

Even though the goal of cancer screening is to find cancer in early stages with the highest survival rates or to prevent cancer, many women served through the NBCCEDP were diagnosed at later stages. This is not surprising since the NBCCEDP only serves low-income women who do not have access to screening services or routine health care. Many of these women served actually required diagnostic services rather than true screening services. Others have reported that women who are symptomatic have been found to have later stage disease [24]. Also the women served through the NBCCEDP typically do not get routine preventive health care or have a primary source of health care which may be related to the missed opportunity at finding breast cancer early or preventing development of invasive cervical cancer [25]. For many women, the NBCCEDP provides the only source of access for breast and cervical cancer detection and treatment services [13].

While the NBCCEDP has served millions of women, more work is needed in states to identify, educate, provide community outreach services through community health workers and patient navigation, and provide appropriate screening services to women who are at the highest risk for developing breast and cervical cancer. Continued assessment of the women diagnosed with cancer within and outside of the NBCCEDP can help the program improve its targeted efforts and work with other organizations such as employers, health insurers, and health-care systems to improve screening, diagnostic, and treatment services among all women in the United States [17]. These efforts are important factors in working toward the Healthy People 2020 goals of reducing female breast cancer death rates (C-3), reducing cervical cancer death rates (C-4), reducing invasive cervical cancer (C-10), and reducing late-stage female breast cancer (C-11) [7].

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Table 1

Characteristics and adjusted odds ratios^a of women diagnosed with breast carcinoma in situ through the National Breast and Cervical Cancer Early Detection Program, 2009–2011

Characteristics	n (%)	OR (95 % CI)
Overall	1,988 (100.0)	N/A
Age group		
40–49 years	616 (31.0)	Referent
50–59 years	946 (47.6)	1.24 (1.12–1.38)
60–64 years	394 (19.8)	1.42 (1.25–1.61)
65 years	32 (1.6)	1.45 (1.00–2.05)
Race/ethnicity		
White, non-Hispanic	1,078 (54.2)	Referent
Black, non-Hispanic	385 (19.4)	0.99 (0.88–1.12)
Hispanic	341 (17.2)	0.62 (0.55–0.70)
Other, non-Hispanic	152 (7.6)	0.79 (0.66–0.93)
Unknown	32 (1.6)	0.76 (0.52–1.07)
Indication for test		
Screening	1,229 (61.8)	Referent
Diagnostic	660 (33.2)	1.31 (1.18–1.45)
Unknown	99 (5.0)	2.76 (2.23–3.38)
Breast symptoms		
No	486 (24.4)	Referent
Yes	1,271 (63.9)	3.04 (2.71–3.40)
Unknown	231 (11.6)	1.94 (1.68–2.23)

^a Adjusted for age, race/ ethnicity, indication for test, and breast symptoms

Table 2

Characteristics and adjusted odds ratios^a of women diagnosed with invasive breast cancer through the National Breast and Cervical Cancer Early Detection Program, 2009–2011

Characteristics	n (%)	OR (95 % CI)
Overall	11,569 (100.0)	N/A
Age group		
40–49 years	3,403 (29.4)	Referent
50–59 years	5,408 (46.7)	1.75 (1.67–1.83)
60–64 years	2,587 (22.4)	2.59 (2.45–2.73)
65 years	171 (1.5)	2.44 (2.07–2.85)
Race/ethnicity		
White, non-Hispanic	6,912 (59.7)	Referent
Black, non-Hispanic	2,168 (18.7)	0.95 (0.91–1.00)
Hispanic	1,552 (13.4)	0.48 (0.45–0.51)
Other, non-Hispanic	701 (6.1)	0.72 (0.67–0.78)
Unknown	236 (2.0)	0.96 (0.83–1.09)
Indication for test		
Screening	3,889 (33.6)	Referent
Diagnostic	7,224 (62.4)	3.07 (2.94–3.20)
Unknown	456 (3.9)	3.73 (3.36–4.12)
Breast symptoms		
No	6,803 (58.8)	Referent
Yes	3,775 (32.6)	11.25 (10.76–11.77)
Unknown	991 (8.6)	2.61 (2.43–2.80)

^a Adjusted for age, race/ ethnicity, indication for test, and breast symptoms

Table 3
 Stage at diagnosis of invasive breast cancer among women through the National Breast and Cervical Cancer Early Detection Program by patient characteristics, 2009–2011

Characteristics	Local n (%)	Regional n (%)	Distant n (%)	Unknown n (%)	p value ^a
Overall	5,598 (48.4)	4,508 (39.0)	760 (6.6)	703 (6.1)	N/A
Age at diagnosis					
40–49 years	1,590 (46.7)	1,405 (41.3)	198 (5.8)	210 (6.2)	0.00
50–59 years	2,552 (47.2)	2,167 (40.1)	377 (7.0)	312 (5.8)	
60–64 years	1,370 (53.0)	882 (34.1)	171 (6.6)	164 (6.3)	
65 years	86 (50.3)	54 (31.6)	14 (8.2)	17 (9.9)	
Race/ethnicity					
White, non-Hispanic	3,373 (48.8)	2,646 (38.3)	460 (6.7)	433 (6.3)	0.00
Black, non-Hispanic	1,014 (46.8)	921 (42.5)	162 (7.5)	71 (3.3)	
Hispanic	775 (49.9)	578 (37.2)	87 (5.6)	112 (7.2)	
Other, non-Hispanic	330 (47.1)	264 (37.7)	39 (5.6)	68 (9.7)	
Unknown, non-Hispanic	106 (44.9)	99 (41.9)	12 (5.1)	19 (8.1)	
Indication for test					
Screening	2,380 (61.2)	1,150 (29.6)	143 (3.7)	216 (5.6)	0.00
Diagnostic	3,000 (41.5)	3,168 (43.9)	600 (8.3)	456 (6.3)	
Unknown	218 (47.8)	190 (41.7)	17 (3.7)	31 (6.8)	
Breast symptoms					
Yes	2,782 (40.9)	3,055 (44.9)	566 (8.3)	400 (5.9)	0.00
No	2,328 (61.7)	1,135 (30.1)	120 (3.2)	192 (5.1)	
Unknown	488 (49.2)	318 (32.1)	74 (7.5)	111 (11.2)	

^aMonte Carlo estimation for exact test

Table 4

Characteristics and adjusted odds ratios^a of women diagnosed with invasive cervical cancer through the National Breast and Cervical Cancer Early Detection Program, 2009–2011

Characteristics	n (%)	OR (95 % CI)
Overall	583 (100.0)	N/A
Age group		
18–29 years	23 (3.9)	Referent
30–49 years	295 (50.6)	7.78 (5.13–12.37)
50 years	265 (45.5)	7.71 (5.02–12.41)
Race/ethnicity		
White, non-Hispanic	334 (57.3)	Referent
Black, non-Hispanic	78 (13.4)	0.83 (0.64–1.05)
Hispanic	124 (21.3)	0.58 (0.47–0.72)
Other, non-Hispanic	37 (6.3)	0.53 (0.37–0.73)
Unknown	10 (1.7)	0.68 (0.34–1.23)
Indication for test		
Screening	375 (64.3)	Referent
Diagnostic	184 (31.6)	13.59 (11.19–16.46)
Unknown	24 (4.1)	2.47 (1.58–3.67)
Screening history		
Screened within past 5 years	242 (41.5)	Referent
Rarely/never screened	221 (37.9)	3.59 (2.97–4.32)
Unknown	120 (20.6)	3.92 (3.13–4.89)

^aAdjusted for age, race/ ethnicity, indication for test, and screening history

Table 5
 Stage at diagnosis of invasive cervical cancer among women through the National Breast and Cervical Cancer Early Detection Program by patient characteristics, 2009–2011

Characteristics	Local n (%)	Regional n (%)	Distant n (%)	Unknown n (%)	p value ^a
Overall	212 (36.4)	236 (40.5)	68 (11.7)	67 (11.5)	N/A
Age at diagnosis					
18–29 years	11 (47.8)	10 (43.5)	0 (0.0)	2 (8.7)	0.02
30–49 years	121 (41.0)	110 (37.3)	27 (9.2)	37 (12.5)	
50 years	80 (30.2)	116 (43.8)	41 (15.5)	28 (10.6)	
Race/ethnicity					
White, non-Hispanic	118 (35.3)	133 (39.8)	44 (13.2)	39 (11.7)	0.13
Black, non-Hispanic	26 (33.3)	38 (48.7)	8 (10.3)	6 (7.7)	
Hispanic	56 (45.2)	47 (37.9)	9 (7.3)	12 (9.7)	
Other, non-Hispanic	9 (24.3)	13 (35.1)	7 (18.9)	8 (21.6)	
Unknown, non-Hispanic	3 (30.0)	5 (50.0)	0 (0.0)	2 (20.0)	
Indication for test					
Screening	139 (37.1)	158 (42.1)	39 (10.4)	39 (10.4)	0.63
Diagnostic	63 (34.2)	69 (37.5)	26 (14.1)	26 (14.1)	
Unknown	10 (41.7)	9 (37.5)	3 (12.5)	2 (8.3)	
Screening history					
Screened within past 5 years	89 (36.8)	88 (36.4)	29 (12.0)	36 (14.9)	0.17
Rarely/never screened	75 (33.9)	99 (44.8)	29 (13.1)	18 (8.1)	
Unknown	48 (40.0)	49 (40.8)	10 (8.3)	13 (10.8)	

^aMonte Carlo estimation for exact test