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Preventing premature deaths from breast and cervical cancer among underserved women in the United States: insights gained from a national cancer screening program

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Abstract

This commentary highlights some of the valuable insights gained from a special collection of papers that utilized data from the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and appear in this special issue. The data and experiences of the NBCCEDP can inform the identification of new opportunities and directions for meeting the cancer screening needs of underserved women in a complex and changing health care environment.

Keywords

Early detection of cancer; Healthcare disparities; Vulnerable populations; Mammography; Papanicolaou test; Medically uninsured

For more than two decades, the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) has provided access to breast and cervical cancer screening and diagnostic services to more than 4 million low-income, underinsured, and uninsured women in the USA [1]. The NBCCEDP is implemented by the Centers for Disease Control and Prevention (CDC) through cooperative agreements awarded to health departments in all 50 states and the District of Columbia as well as selected tribes, tribal organizations, and US territories. The NBCCEDP is the largest organized cancer screening program in the nation and, by design, reaches women who are underserved and not well represented in other healthcare systems. Of the funds provided to grantees under the NBCCEDP, a small proportion is used to process data submitted by providers on demographic characteristics and clinical outcomes for the women they serve [2]. Known as the Minimum Data Elements (MDEs), these standardized data (without personal identifiers) are used by CDC to monitor and evaluate program performance [3-5]. Although not designed for research, the data collected through the NBCCEDP can be used to examine some of the practical challenges to ensuring that low-income women in the USA benefit from the promise of early detection of

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breast and cervical cancer. The findings from such analyses can inform future efforts to improve the provision of preventive health services for low-income women and the impact of such services on death rates for breast and cervical cancer. This commentary highlights some of the valuable insights gained from a collection of papers that utilized data from the NBCCEDP and appear in this special issue.

Serving priority populations

Given the level of resources available to NBCCEDP grantees relative to the unmet needs for screening services, effective utilization of program resources is essential. A key component to effective public health program implementation is managing performance, and this requires accurate and timely information systems [6]. In 2006, the NBCCEDP implemented a performance management system including 11 priority indicators based on the MDEs [7]. Two of the indicators emphasize priority populations: At least 20 % of newly enrolled women receiving cervical cancer screening must be rarely or never before screened and at least 75 % of the women receiving mammograms must be 50 years of age or older. Analyses of recent data on clinical outcomes demonstrate that cancer detection rates were higher for these priority populations compared to other women who were screened through the NBCCEDP. Benard et al. [8] report that among women 40 years and older, those who had rarely or never been screened for cervical cancer had higher percentages of abnormal Pap tests and invasive disease compared to women who reported having a Pap test within the last 5 years. In addition, regardless of whether the mammogram was conducted for screening or diagnosis, White et al. [9] found that breast cancer detection was higher among women 50 years and older compared to younger women. These findings lend support to the NBCCEDP's focus on priority populations where disease is more evident.

The limits to what increased program efficiency can achieve

The articles by Tangka et al. [10] and Howard et al. [11] show that although the NBCCEDP has national scope, women receiving services represent only a small fraction of the women who met NBCCEDP eligibility criteria based on age, income, and health insurance status. For cervical cancer screening, 6.5 % of eligible women 18–64 years old received Pap tests through the NBCCEDP [10]. This proportion is higher for women 40–64 years old, but still fairly small at 16.5 % [10]. An estimated one-third of all eligible women were not screened for cervical cancer, either within or outside the NBCCEDP. For mammography, 10.6 % of eligible women 40–64 years old received a mammogram through the NBCCEDP within a 2-year period [11]. An estimated 30 % of eligible women received a mammogram outside of the NBCCEDP, and about 60 % of all eligible women were not screened for breast cancer [11].

Some state grantees provided Pap tests and mammograms to a larger proportion of eligible women than other states [10, 11]. Subramanian et al. [12] examined the factors associated with this variability and identified several program and state-level characteristics as important. A larger number of eligible women, a higher average cost of screening (which includes the cost of screening and diagnostic evaluation and cost of program operations), and a greater proportion of women in urban areas all were associated with a lower

proportion of eligible women being screened. An earlier analysis of program data revealed strong evidence that the average cost of providing screening services declines with larger numbers of women screened [13]. Thus, in addition to limited funds, some of the factors that are restraining the ability of grantees to serve more women are structural and not easily modified by NBCCEDP grantees.

A window into the experiences of vulnerable women and their providers

Some of the women who received services through the NBCCEDP had symptoms or had been referred to the NBCCEDP because of an abnormal screening test performed elsewhere. For both breast and cervical cancer, the articles by White et al. [9] and Benard et al. [8] show that these referrals were more common among younger women. Ryerson et al. [14] reported that the most common breast symptoms were pain or tenderness and breast lump. Although low, the proportion of women with symptoms who received a diagnosis of invasive breast cancer was substantially elevated compared to asymptomatic women, especially if they reported a breast lump or inflammation or changes to the skin or nipple. Most women who received mammograms through the NBCCEDP reported no symptoms. Wu et al. [15] analyzed cancer registry data for women enrolled in the NBCCEDP. Compared to other women with breast cancer, women whose breast cancer had been diagnosed through the NBCCEDP had a poorer stage distribution of breast cancer. Miller et al. [16] further examined stage of diagnosis for women served by the NBCCEDP. Distant stage breast cancers were more common among older women, black women, and those whose mammograms were regarded as diagnostic; distant stage cervical cancer was more common among older women and those who had not been screened within the last 5 years. These findings indicate that the NBCCEDP continues to reach women who are medically underserved.

The network of primary care physicians who serve women through the NBCCEDP is established locally by the grantee. These providers are willing to serve low-income women at the Medicare reimbursement rate as required by the NBCCEDP's authorizing legislation (The Breast and Cervical Cancer Mortality Prevention Act of 1990); typically, these providers also see low-income women in their communities who are not NBCCEDP participants. Based on the results from a national sample of primary care providers from 2006 to 2007, providers who participated in the NBCCEDP were found to report beliefs and screening practices similar to those of providers who were not NBCCEDP participants [17]. Watson et al. [18] analyzed recent MDE data to examine the quality of follow-up when the Pap test results were equivocal. Most of these women were followed with the HPV test and received recommended management if they were found to be HPV positive. Thus, NBCCEDP providers appeared to be changing their practices to be consistent with changing screening guidelines.

Innovative approaches to building the evidence base

Innovation is another essential component to effective program implementation [6], and the NBCCEDP has fostered innovative approaches to recruit and serve often hardto-reach populations. Programs are encouraged to use interventions that have been formally

evaluated and demonstrated to be effective at increasing screening for breast and cervical cancer [19]. To date, limited evidence exists for all but a few proven strategies, such as one-onone education and client reminders. For example, special events such as health fairs are fairly common, but the evidence is insufficient to demonstrate their effectiveness at increasing cancer screening [20].

In addition to research studies, the rigorous evaluation of strong programs can contribute to the evidence base in support of specific intervention strategies. DeGroff et al. [21] described an effort to identify promising practices within the NBCCEDP. While few promising practices were found, a bundled payment model used by the Colorado program was identified and underwent a rigorous evaluation. This study also identified important problems in the implementation of non-screening activities related to dose and fidelity. As a result, increased attention was given to improving grantee capacity in program planning, implementation, and evaluation. Hall et al. [22] reported on a recent pilot study in Georgia to increase mammography use among African American women. A multimedia campaign that included black radio was shown to increase awareness of the program among eligible African American women. Program data were used to evaluate the impact of the intervention [22]. The evidence-based AMIGAS educational program to increase cervical cancer screening, targeting Hispanic women who have rarely or never had a Pap test, is another example of an innovative approach to reaching underserved women [23]. With increased attention to logic modeling for program planning and evaluation among NBCCEDP grantees, more promising practices can be tested and evaluated.

Cancer screening for underserved women after age 64

About one-third of all cervical cancer deaths and well over half of all breast cancer deaths in the USA occur among women aged 65 years and older [24]. The USPSTF recommends biennial screening mammography for women aged 50–74 years [25], up to 10 years later than the upper age eligibility for the NBCCEDP. Although the USPSTF does not recommend routine screening for cervical cancer for average risk women older than age 65 years with adequate prior testing, screening may be indicated for older women with limited access to care, minority women, and other women who are less likely to meet the criteria for adequate prior screening [26]. In addition, the recommendation to not screen for cervical cancer after age 65 does not apply to women with a prior history of high-grade precancerous cervical lesions or cervical cancer, in utero exposure to diethylstilbestrol (DES), or HIV infection [26]. Thus, the need for cancer screening services continues after women age out of eligibility for the NBCCEDP and become eligible for Medicare.

For low-income women under the age of 65 years, being underinsured may serve as a barrier to screening. The Affordable Care Act requires that screening for breast and cervical cancer be provided without cost sharing for women enrolled in non-grandfathered private insurance plans, including all plans purchased through the Health Insurance Marketplace and beneficiaries newly eligible for Medicaid through the expansion. However, for these women, cost sharing is not eliminated for recommended diagnostic follow-up tests resulting from abnormal screening tests. Even after women become eligible for Medicare, many may remain medically underserved because of similar limitations in coverage. Although

Medicare Part B covers Pap tests and screening mammograms at no cost if the doctor accepts Medicare, women may have to pay some or all of the costs associated with recommendations for the follow-up of abnormal test results (www. medicare/gov/coverage). Some women may remain underinsured because they cannot afford the premiums for Medicare Part B or the premiums for supplemental insurance to cover the significant cost sharing involved with traditional fee-for-service Medicare. Adams et al. [27] examined women who recently had become eligible for Medicare in Georgia. These women were far less likely to receive a mammogram within 18 months of enrollment if they had non-continuous Medicare Part B coverage or only Medicare Part A.

In this same study by Adams et al. [27], women who had participated in the Georgia Breast and Cervical Cancer Program were more likely to be rescreened by mammography after enrollment in Medicare than non-participants. In addition, a larger percentage of the breast cancers detected among previous program participants were diagnosed at in situ or localized disease stage compared to all breast cancer cases reported to the Georgia cancer registry. These findings suggest that educational and support components of the program may have established a practice of regular screening that persists once women age out of program eligibility.

Going forward

The NBCCEDP has developed a nationwide organized cancer screening program that effectively utilizes limited resources to reach medically underserved women and provide access to priority populations. The NBCCEDP is grounded in current evidence-based screening and intervention recommendations, innovation, and the continuous monitoring of quality to inform program improvements. This has resulted in a strong infrastructure built on experience that will be essential in navigating today's rapidly changing healthcare environment to increase cancer screening rates.

Population-based efforts aimed at increasing access to services and reducing disparities are projected to be essential for the achievement of Healthy People 2020 objectives for cancer screening [28]. Despite the successes of the NBCCEDP, serious challenges remain to meeting the cancer screening needs of underserved women. Of all US women aged 40–64 years who met NBCCEDP eligibility criteria, it was estimated that nearly six out of ten women had not received a mammogram within the last 2 years [11], and four out of ten had not received a Pap test within the last 3 years [10], even when sources for screening services outside the NBCCEDP were considered. These discouraging findings point to the need for more targeted outreach and population-based activities to reach a greater number of underserved women, regardless of the payer. Expanded efforts also are needed to make screening services available and affordable to a larger number of underserved women.

Implementation of the Affordable Care Act provides new access to cancer screening for millions of people who were previously uninsured. It also offers new opportunities for the NBCCEDP to expand its role with health systems partners such as Federally Qualified Health Centers (FQHCs) or health plans; payers such as Medicaid or Medicare; and purchasers such as employers, as well as community partners to increase cancer screening

on a population level [29]. Partnerships to systematically improve organized approaches to cancer screening through the use of evidence-based interventions and to effectively address non-screening barriers such as language and cultural barriers, lack of awareness and knowledge about screening, lack of transportation or child care, lack of paid sick leave, or similar barriers will help to address the continuing disparities found in cancer screening [29, 30]. Scientific research can shape these efforts and identify new approaches to meet national goals to eliminate health disparities [31]. The use of program data could be expanded through linkages with other data sources, such as cancer registries [32].

This unique collection of timely papers based on the data and experiences of the NBCCEDP enhances our understanding of the challenges and opportunities for meeting the cancer screening needs of underserved women. Together, the papers in this special issue provide a baseline against which future progress toward meeting these needs can be assessed.

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