

A community-based breast cancer screening program for medically underserved women: its effect on disease stage at diagnosis and on hazard of death

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ABSTRACT

Objective. Earlier studies by this research team found that medically underserved minority women in the Miami-Dade County area of the state of Florida, United States, were in need of breast cancer screening and that there were problems with availability, accessibility, and acceptability of services. In response, a community-based comprehensive breast cancer screening program called the Early Detection Program (EDP) was developed. The specific purpose of this study was to assess the effect that EDP participation had on stage at diagnosis and on hazard of death.

Methods. Existing data from the Florida Cancer Data System (FCDS), a statewide cancer registry, were linked with data from the EDP. In December 1998 we assembled a multiethnic (African-American, black Hispanic, white Hispanic, and white non-Hispanic) retrospective cohort with the following inclusion criteria: all women aged 40 and older with breast cancer diagnosed and staged at University of Miami/Jackson Memorial Medical Center (which is located in the city of Miami, Florida) from January 1987 through December 1997. EDP participants were medically underserved, that is, they resided in lower socioeconomic areas and/or had limited or no health insurance to cover medical costs. Subjects identified as EDP participants were compared to nonparticipants with respect to disease stage at diagnosis and hazard of death. Logistic regression and Cox regression models were used for analysis.

Results. EDP participants were 2.4 times as likely (95% confidence interval = 1.71 to 3.43) to present with a diagnosis of localized cancer as were nonparticipants, even after controlling for race and age at diagnosis. EDP participation was independently associated with both earlier diagnosis and reduced hazard of death.

Conclusions. Participation in the EDP increases the likelihood of early detection of breast cancer and reduces the hazard of death for medically underserved women in the Miami-Dade County area of Florida. Interestingly, white Hispanics showed a better survival than did both African-Americans and white non-Hispanics. Our research also demonstrates the value of utilizing existing cancer registry data to evaluate a community-based program such as the EDP.

Key words

Breast neoplasms, health services accessibility, mammography, survival rate, ethnic groups, Florida.

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In 2002 the American Cancer Society estimated that 203 500 women in the United States of America would be diagnosed with breast cancer that year and that 39 600 women would die as a result of the disease, making it the highest incidence cancer and second leading cause of death among women in the country (1). More specifically, breast cancer is the most common malignancy and the leading cause of deaths attributed to cancer among women of Hispanic origin living in the United States (2–4). According to recent census estimates for the United States, persons of Hispanic descent are the fastest growing ethnic group in the country. Hispanic women, however, are less likely to report utilization of a breast cancer screening program than are other women in the United States (5, 6). Furthermore, first-generation Hispanic Americans in particular have been found to have a relative delay in the timeliness of their cancer diagnosis, prompting investigators to suggest that this group be targeted for interventions designed to increase breast cancer screening (5).

Survival from breast cancer has been reported to be closely related to stage at diagnosis: five-year survival is 97% for women diagnosed with localized breast cancer, 77% for women diagnosed with regional cancer, and only 21% for women diagnosed with distant metastases (1). There is a differential burden, however, of breast cancer mortality by race/ethnicity in the United States: higher age-adjusted mortality occurs among black and Hispanic women than among non-Hispanic whites (2, 4, 7, 8). This growing burden of breast cancer is now also a major public health issue for many developing countries, including ones in Latin America and the Caribbean, with mortality rates from breast cancer steadily increasing over the past two decades (9). For example, the nations of South America now have some 70 000 new cases diagnosed annually, along with 30 000 deaths. Also of concern is the high percentage of late-stage diagnosis, which is due in part to low levels of mammography screening (9–12).

The Early Detection Program (EDP), based at the University of Miami School of Medicine, in the city of Miami, Florida, is a community-based program that provides breast cancer screening for medically underserved women, that is, women who reside in lower socioeconomic areas and/or have limited or no health insurance to cover medical costs. The EDP has covered the Miami-Dade County area since 1987. (Dade County changed its name to Miami-Dade County in 1997. The county includes the city of Miami and a number of other, smaller communities.) In 1990 Dade County had a total population of 1 937 094 persons, including 358 548 residents of the city of Miami (13).

The creation and development of the EDP was guided by the first major data analysis of the Florida Cancer Data System (FCDS), a hospital-based statewide cancer incidence registry capturing more than 90% of all diagnosed cancer cases. These analyses found that late-stage breast cancer diagnosis was a problem, particularly among black women residing in the Miami-Dade County area (14, 15). Further analysis found similar results among Hispanic women (14, 15). These analyses of the cancer data led to the conclusion that black and Hispanic women who were from a lower socioeconomic status and/or had limited health insurance or no coverage at all were in need of breast cancer screening availability, accessibility, and acceptability. In an effort to enhance cancer screening and early detection services in general, and specifically to overcome obstacles to availability, accessibility, and acceptability of these services, the Sylvester Comprehensive Cancer Center and the University of Miami/Jackson Memorial Medical Center (UM/JMMC) implemented the pilot EDP program in 1987, which is now institutionalized.

The Miami-Dade County area is known for its ethnic diversity, even *within* minority groups such as Hispanics (Argentines, Brazilians, Chileans, Colombians, Cubans, Dominicans, Mexicans, Nicaraguans, Panamanians, Puerto Ricans, and Venezuelans are all well represented in Miami, as are many other groups) and blacks (African-

Americans, Bahamians, Haitians, Jamaicans, and Trinidadians are all well represented). In many ways this extensive ethnic diversity makes the area a true microcosm of the Caribbean Basin and South America.

Over the period of January 1987 through December 1997 the EDP provided low-cost mammography services to more than 25 000 women, of whom 56% were Hispanic, 37% were African-American, and 7% were white or “other” race/ethnicity. In comparison, the 1990 distribution for the entire county was: 49.2% Hispanic, 19.1% black non-Hispanic, and 30.2% white non-Hispanic (13).

Through cooperation between primary health care centers and the UM/JMMC, the EDP facilitated referrals to specialists throughout the Miami-Dade County area, but with the majority of the specialists practicing at UM/JMMC. The EDP also facilitated timely intervention by providing continuous data on the program screening service utilization rates to both the county primary health care centers and UM/JMMC providers (13–16). Details on the organization of the EDP have been previously published (14–17).

Screening for breast cancer by mammography can detect the disease at an early stage, thus improving prognosis, increasing survival, and reducing mortality (18–26). The Centers for Disease Control and Prevention of the United States estimate that timely mammography screening could prevent 15%–30% of all deaths from breast cancer occurring among women in the country who are over the age of 40. Despite that knowledge, significant disparities in screening rates across socioeconomic levels continue to exist in the United States (27, 28).

Access to mammography screening services has proved problematic for some medically underserved populations, such as minority women in the United States, due to multiple barriers, including cost, lack of health insurance, and scarcity of available screening services (29–34). In Latin America, only Bolivia, Chile, Cuba, Ecuador, Mexico, and Panama offer mammography services within their health care systems

(12). Information on how mammography is offered in private sector settings in Latin America is not available, but it is likely that only women of high socioeconomic status would have access to these services. Responding to these gaps in access to preventive services, community-based screening programs, including mobile programs, have been successful in expanding access and increasing screening rates in the United States (35–37). Usually housed in a large vehicle such as a trailer or mobile home, mobile programs are capable of serving multiple sites and are equipped with the latest technology. These screening programs have the added benefit of linking clients with a range of other health services. Specific to breast cancer screening, this integration of services has also increased access to follow-up referral visits for women with positive mammography findings (38).

As mentioned earlier, the EDP was developed to provide available, accessible, and acceptable breast cancer screening opportunities for medically underserved black and Hispanic women in the Miami-Dade County area. The aim of the specific analysis contained in this paper was to assess the effect of participation in the EDP on stage at diagnosis and on hazard of death as compared to nonparticipation, given that these measures are effective endpoints for screening programs. To facilitate this assessment, existing data from the Florida Cancer Data System (FCDS), a hospital-based statewide cancer incidence registry capturing over 90% of all diagnosed cancer cases, were linked with data from the EDP among four racial/ethnic groups: white non-Hispanic, white Hispanic, black Hispanic, and African-American.

METHODS

A retrospective cohort was constructed in December 1998 based on data previously collected for the FCDS statewide registry. When determining how to classify, localize, stage, and report breast cancers, that registry fol-

lows cancer registration rules adopted from the SEER (Surveillance, Epidemiology, and End Results) Program Code Manual. The SEER Program of the National Cancer Institute of the United States collects and publishes cancer incidence and survival data from population-based cancer registries within the United States (39).

The inclusion criteria were: all women aged 40 and older with breast cancer diagnosed and staged at UM/JMMC, Miami, Florida, from January 1987 through December 1997.

Data from the FCDS were linked by the UM research team with data from the EDP by using the Social Security number as a unique record identifier for cases that participated in the EDP from January 1987 through December 1997.

Demographic data included age at diagnosis and race/ethnicity. Race/ethnicity was defined as white non-Hispanic, African-American, white Hispanic, and black Hispanic. The clinical variables included cancer stage at diagnosis and vital status at last contact. Cancer stage at diagnosis was defined as in situ, local, regional, and distant.

The final cohort consisted of 1 173 women. Of these, 214 women were identified as participants in the EDP. Follow-up on all cases took place from date of diagnosis until date of last contact with UM/JMMC.

Statistical analysis

Using logistic regression, we modeled stage at diagnosis (local vs. regional/distant) on EDP participation, race/ethnicity (using white non-Hispanic as reference group), and age at diagnosis (years). A Cox regression model of hazard of death was fitted using the PHREG procedure in the SAS software package. The proportionality assumption was verified graphically by plotting the survival function estimates by time for different covariate values. Variables in the model included EDP participation, stage at diagnosis (regional/distant as reference group), race/ethnicity (white non-Hispanic as reference group),

and age at diagnosis (years). Women with in situ stage at diagnosis were excluded from both models. This was based on the fact that five-year survival for women with in situ lesions is almost 100% (1). All analyses were conducted using SAS version 8.02 software (SAS Institute Inc., Cary, North Carolina, United States).

RESULTS

The median follow-up time was 3.8 months; the longest follow-up period was 90 months. There were 218 deaths recorded in this population, 24 among the 214 EDP participants and 194 among the 959 nonparticipants. Table 1 describes the cohort. Overall, almost half of the cases (47.7%) were in situ or local stage disease at diagnosis. EDP participants were more likely to present with in situ or localized cancer diagnoses than nonparticipants ($P < 0.001$). Overall, just over half of the cases were white Hispanics (50.6%); the next largest group was African-American (29.1%), followed by non-Hispanic white (17.2%) and black Hispanic (3.2%). However, EDP participants were more likely to be African-American than non-EDP participants ($P < 0.001$), and Hispanics were equally distributed among EDP and non-EDP groups. The mean age at diagnosis was 57.6 years, with a range of 40.0 to 96.2 years. Age at diagnosis did not differ between the EDP participants and the nonparticipants.

The multivariate logistic model (Table 2) indicates that EDP participants were 2.4 times as likely (95% confidence interval (CI) = 1.71 to 3.43) to present with local diagnosis as were nonparticipants, even after controlling for race and age at diagnosis. African-Americans were significantly less likely than white non-Hispanics were to present with local disease (odds ratio (OR) = 0.3; 95% CI = 0.21 to 0.53). Interaction effects between race/ethnicity and EDP participation were tested, and they were not significant ($P = 0.73$). The odds of presenting with local disease increased 1.03 times for each additional year of age at diagnosis.

TABLE 1. Characteristics of study population, participants and nonparticipants in breast cancer Early Detection Program (EDP), Miami-Dade County, Florida, United States, 1987–1997

Characteristic	All cases (n = 1173)	EDP nonparticipant (n = 959)	EDP participant (n = 214)	P value
Stage at diagnosis (%)				< 0.001 ^a
In situ	8.8	6.5	19.2	
Local	38.9	37.3	45.8	
Regional	37.9	39.7	29.4	
Distant	14.5	16.5	5.6	
Local and in situ ^b	47.7	43.8	65.0	< 0.001 ^a
Race/ethnicity (%)				< 0.001 ^a
White non-Hispanic	17.2	19.6	6.5	
African-American	29.1	26.4	41.1	
White Hispanic	50.6	50.7	50.0	
Black Hispanic	3.2	3.3	2.3	
Age at diagnosis (yr)				0.986 ^c
Mean	57.6	57.6	57.7	
Standard deviation	10.0	10.0	10.2	
Minimum	40.0	40.0	40.3	
Maximum	96.2	96.2	90.8	

^a P value according to chi-square test of independence.

^b Comparison of local and in situ vs. regional and distant.

^c P value according to t test.

The Cox regression model (Table 3) shows that after controlling for stage at diagnosis, race, and age at diagnosis, the hazard of death for EDP participants was 0.645 times (95% CI = 0.418 to 0.998) that of the hazard of death for nonparticipants. The hazard of death for patients diagnosed with local disease was less than one third (hazard ratio (HR) = 0.29; 95% CI = 0.19 to 0.44) the hazard of death for those with more advanced stages of disease. The hazard of death for white Hispanics was 0.62

times (95% CI = 0.42 to 0.91) that of white non-Hispanics. Presented in Figure 1, survival curves of EDP participants versus EDP nonparticipants demonstrate the beneficial effect that EDP participation had on survival.

DISCUSSION

Early Detection Program participation was independently associated with both earlier diagnosis and re-

duced hazard of death. As reduced hazard of death in breast cancer is a function of both early detection and timely referral to high-quality health care, this supports the EDP as being successful in facilitating patient referral from primary health care centers to specialists at UM/JMMC. These findings are consistent with a large literature that reports the same benefits for other breast cancer screening programs (39, 40).

Possible explanations for the survival differences between EDP and non-EDP participants could be length and lead-time biases, which are commonly found in screening studies (40). Similar to other published studies (41), we attempted to partially control for length bias and lead-time bias by excluding in situ breast carcinomas, which would have been less likely to be diagnosed without mammography. This was done based on the fact that the distribution of lead times in a screening program depends in part on the incidence rate and on the distribution of the duration of preclinical disease (42). Even after eliminating all in situ diagnoses, EDP participants still showed a significantly decreased risk of death in comparison to nonparticipants.

There was no information available on method of breast cancer detection in non-EDP participants. From January 1987 through December 1997 the EDP was the only breast cancer screening program specifically targeting minority women in the Miami-Dade County area. Furthermore, if a proportion of nonparticipants were diagnosed through a screening program other than EDP, effects of EDP on stage of diagnosis and hazard of death could have been diluted and reinforced these results.

Information for our study participants on other variables that influence stage at diagnosis and/or survival was not available at the time of the study. These other variables included temporality issues such as time from diagnosis to start of treatment and treatment modality, assurance that EDP participation preceded diagnosis, household income, and medical insurance coverage (43, 44). The fact that all women in

TABLE 2. Logistic model, including odds ratio and confidence interval (CI) for local vs. regional and distant stage at diagnosis, for the Early Detection Program (EDP), Miami-Dade County, Florida, United States, 1987–1997^a

	Estimate	P value	Odds ratio	95% CI
Intercept	-1.659	< 0.0001	—	—
EDP participant	0.885	< 0.0001	2.424	1.712–3.432
Age at diagnosis (yr)	0.029	< 0.0001	1.030	1.016–1.043
African-American	-1.166	< 0.0001	0.312	0.210–0.461
White Hispanic	-0.244	0.163	0.784	0.556–1.104
Black Hispanic	-0.581	0.123	0.559	0.268–1.170

^a For this model the 103 in situ cases were omitted, leaving 1 070 of the original 1 173 cases to be analyzed. The reference groups were EDP nonparticipant and white non-Hispanic.

TABLE 3. Cox regression model of hazard of death for the Early Detection Program (EDP), Miami-Dade County, Florida, United States, 1987–1997^a

	Parameter estimate	P value	Hazard ratio	Hazard ratio 95% confidence limits
EDP participant	-0.438	0.049	0.645	0.418–0.998
Localized cancer	-1.242	< 0.0001	0.289	0.189–0.442
Age at diagnosis (yr)	0.007	0.324	1.007	0.993–1.020
African-American	0.106	0.577	1.112	0.766–1.614
White Hispanic	-0.483	0.014	0.617	0.420–0.906
Black Hispanic	-0.284	0.590	0.753	0.268–2.116

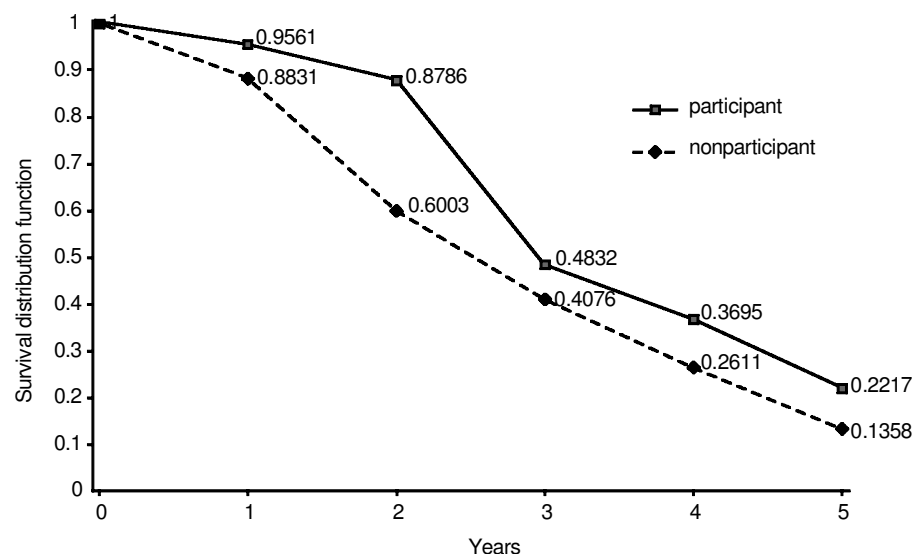
^aFor this model the 103 in situ cases were omitted, leaving 1 070 of the original 1 173 cases to be analyzed. The reference groups were EDP nonparticipant, regional-distant, and white non-Hispanic.

the cohort were diagnosed and staged at the same medical center may have contributed to reduced differences between EDP participants and nonparticipants in some of their medical variables. White non-Hispanic women are recognized to have an earlier diagnosis of breast cancer and better disease prognosis than do minority women in the United States. In our study, white non-Hispanic women accounted for 19.6% of non-EDP participants and only 6.5% of EDP participants. These facts indicate that the better outcomes for EDP participants may have been obtained independently of some socio-demographic variables.

The differences that we found in hazard of death may have been influenced by causes of death other than breast cancer. Future evaluations of EDP outcomes should aim to include the above-mentioned variables (time from diagnosis to start of treatment, treatment modality, assurance that EDP participation preceded diagnosis, household income, and medical insurance coverage), to help with a more comprehensive understanding of the results of the program evaluation.

This study found that being African-American had a negative effect on stage at diagnosis, even after controlling for EDP participation (Table 2).

FIGURE 1. Survival curves of Early Detection Program (EDP) participants versus nonparticipants (in situ omitted), Miami-Dade County, Florida, United States, 1987–1997



This finding is consistent with other studies that report African-American women are more likely to present with later-stage disease and to demonstrate an increased hazard of death (44–47). Although many studies have attributed this race differential to socioeconomic factors, the precise elements that account for the difference—such as health insurance status, education level, and income—have been largely unexplored and warrant further investigation. Other studies have suggested an underlying biological explanation as to why African-American women present with more advanced and aggressive disease at a younger age (47–49).

Future research efforts should examine factors that potentially influence racial/ethnic differences in incidence, clinical presentation, and treatment differentials among the various racial/ethnic groups. For example, the small number of black Hispanics made it difficult to draw any meaningful interpretation of their data, thus justifying further attention to this specific ethnic group. These future research questions underscore the importance of the purposeful selection of the medically underserved minority women as the EDP target population as well as the importance of additional screening efforts in similarly underserved communities.

Increasing age at diagnosis had a favorable effect on stage at diagnosis, even after controlling for EDP participation. Currently, there is some controversy concerning the use of screening mammography for women in their 40s (50). In general, the effect of screening younger women has been slower to appear and less dramatic than the effect among women over 50 years of age. These differences may result from mammographically denser breasts in younger women (leading to reduced sensitivity of mammography), faster spread of some cancers in younger women, or both (51).

Interestingly, white Hispanics showed a better survival than both African-Americans and white non-Hispanics in our study. Previous studies have reported that Hispanic

women are less likely to utilize a breast cancer screening program than are other women in the United States (5, 6). In particular, first-generation Hispanic Americans have been found to have a relative delay in the timeliness of their cancer diagnosis (5). However, a more recent study reported that the stage-adjusted relative risk of breast cancer mortality did not differ between white non-Hispanics and Hispanics and that it was lowest for African-Americans (52). Another recent study found a better five-year survival for Hispanics than for either whites or African-Americans (53). It should also be noted that there are ethno-regional differences in knowledge and attitudes toward cancer and in participation in screening participation among distinct Hispanic populations in different areas of the United States. In particular, Hispanic women of Cuban and Central American origin (who are more commonly found in the area where our study took place) appear to have better knowledge and attitude towards breast cancer screening than do Mexican-American and Puerto Rican women, according to a study of Hispanic women around the United States (54). In any case, our study's findings of more-positive out-

comes for white Hispanic women warrant further research.

This paper also demonstrates the value of utilizing existing cancer registry data to evaluate some components of a community-based program such as the EDP. The use of these data allows a community-based program to compare the health outcomes of its program participants with the health outcomes of persons who did not participate in the community-based program. Long-term follow-up studies with clinical populations are expensive and time-consuming. Therefore, the ability to track individuals through cancer registries represents an attractive and efficient methodology for obtaining timely information on screening programs. That information could be made rapidly available to medical care providers, public health officials, and the community that these programs serve. This approach takes advantage of data already being collected for administrative purposes and avoids the potential criticism associated with self-report data typical of many long-term follow-up studies.

A limiting factor in interpreting the results of this approach is that it starts from cancer cases rather than from screened women and similar

nonscreened women. Still, this approach for evaluating screening program outcomes could prove to be of value in developing countries that lack resources to evaluate community-based screening programs. Furthermore, this approach provides a useful future opportunity to compare interval cancer rates, time to referral and treatment, and other significant program quality standards and goals with guidelines established by the appropriate international agencies or programs. Unfortunately, many developing countries do not yet have cancer registries. In the few developing countries where cancer registries are in place, the capability to link cancer incidence data with cancer mortality data may not exist. However, a number of developing countries, including some in Latin America and the Caribbean, already have breast cancer screening policies, including on mammography, and some of the countries have either national or regional cancer registries (12, 55).

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RESUMEN

Programa basado en la comunidad de tamizaje de cáncer de mama en mujeres médicamente subatendidas: efecto sobre el estadio de la enfermedad en el momento del diagnóstico y el riesgo de muerte

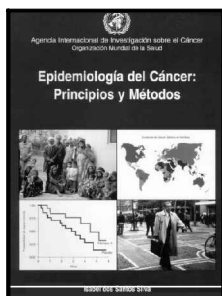
Objetivo. En estudios previos de este colectivo de investigadores se encontró que las mujeres pertenecientes a las minorías subatendidas desde el punto de vista médico en la zona del Condado de Miami-Dade, en el estado de la Florida, Estados Unidos de América, necesitaban someterse a un tamizaje para la detección de cáncer de mama y que la disponibilidad, accesibilidad y aceptación de estos servicios planteaban dificultades. En respuesta a ello se elaboró un programa comunitario integral para el tamizaje del cáncer de mama, denominado Programa de Detección Temprana (PDT). El propósito específico de este estudio fue evaluar el efecto que tuvo la participación en el PDT sobre el estadio de la enfermedad en el momento del diagnóstico y sobre el riesgo de muerte.

Métodos. Los datos existentes en el Sistema de Datos sobre Cáncer de la Florida —un registro de cáncer que abarca a todo el estado— se enlazaron con los datos del PDT. En diciembre de 1998 se conformó una cohorte retrospectiva multiétnica (mujeres afroestadounidenses, hispanas negras, hispanas blancas y blancas no hispanas) según los siguientes criterios de inclusión: mujeres de 40 años de edad o más con cáncer de mama diagnosticado y estadificado en el Jackson Memorial Medical Center (hospital escuela de la Universidad de Miami situado en la ciudad de Miami, Florida) entre enero de 1987 y diciembre de 1997. Las participantes del PDT eran mujeres con necesidades médicas subatendidas, es decir, residían en zonas con malas condiciones socioeconómicas, no tenían un seguro de salud que cubriera los gastos médicos, o tenían un seguro limitado. Se compararon las participantes en el PDT con las mujeres que no participaron en el PDT en cuanto al estadio de la enfermedad en el momento del diagnóstico y el riesgo de muerte. Para el análisis se emplearon modelos de regresión logística y de Cox.

Resultados. Las participantes del PDT tuvieron 2,4 veces más posibilidades de tener un cáncer localizado en el momento del diagnóstico que las mujeres que no participaban (intervalo de confianza de 95%: 1,71 a 3,43), incluso después de ajustar los resultados según la raza y la edad en el momento del diagnóstico. La participación en el PDT estuvo asociada de manera independiente con un diagnóstico más temprano y con un menor riesgo de muerte.

Conclusiones. La participación en el PDT aumenta la probabilidad de detectar tempranamente el cáncer de mama y reduce el riesgo de muerte en mujeres con necesidades médicas subatendidas en la zona del Condado de Miami-Dade, en el estado de la Florida. Las mujeres hispanas de raza blanca mostraron una supervivencia más larga que las afroestadounidenses y que las mujeres blancas no hispanas. Esta investigación también demuestra el valor de usar los datos obtenidos de los registros de cáncer existentes para evaluar programas comunitarios como el PDT.

Epidemiología del cáncer: principios y métodos



Esta obra se dirige principalmente a estudiantes de medicina y salud pública, médicos, profesionales de la salud y cualquiera interesado en entender los principios y métodos aplicados en el estudio de la epidemiología del cáncer. Su objetivo no es formar expertos, sino instruir a los lectores en el empleo de herramientas epidemiológicas básicas y hacerlos capaces de ejercer un juicio crítico cuando evalúan los resultados publicados por otros.

La obra está diseñada para proporcionar —mediante ejemplos ilustrativos y, con frecuencia, datos obtenidos mediante investigaciones— información fácilmente comprensible sobre los conceptos básicos y métodos de investigación usados para estudiar la epidemiología de las enfermedades malignas.

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