Evaluation of Community-Based Projects to Reduce Cancer Disparities among Underrepresented Groups and Participants Satisfaction in Health Disparities Projects

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Abstract Cancer is the second leading cause of death in the United States. The objectives of this study were to evaluate cancer prevention programs and participants satisfaction in 51 disparities projects in Florida. This three-phase evaluation included evaluability assessment, process, immediate outcome and impact evaluation using qualitative assessment, case study, document analysis, face-to-face interviews, and survey. In 2006-2007, a total of 3,165, and in 2008-2009, a total of 1,632 individuals participated in the programs respectively. In breast and cervical cancer prevention programs, change of proportion of African-American and Haitian recruitment significantly increased from 2006-2008 to 2007-2009 (-11.3 to 3.4). Among other services, all means of outreach such as mobile vans, faith-based activities, health fairs, and small-group education sessions also increased by 5.3%, 7.9%, 5.5%, and 9.4% respectively. In participants' satisfaction the majority of respondents (N=231) were 35-54 years old (46.7%), non-Hispanic Black (81.7%), female (70.3%), high school and some college educated (58.8%), and with income less than \$25,000 (65.5%). The majority of the participants were very satisfied with the program staff's training, cultural sensitivity, language skills, resources, education materials, referral system, and changing behavior (mean score: 4.5-4.7) and with the overall project and the project's role in improving their quality of life.

Keywords Cancer Disparities, Program Evaluation, Community-Based Programs, Closing The Gap, Underserved Population

Cancer is the second leading cause of death in the United States, surpassed only by cardiovascular diseases, being responsible for one in every four deaths. The Centers for Disease Control and Prevention (CDC) reported that 567,614 people had died from cancer, and more than 1.48 million people were diagnosed with cancer in 2009 alone¹. Smith estimated that the total projected cancer incidence will increase by approximately 45%, affecting 2.3 million people in the US by the year 2030². The physical, emotional, mental, and spiritual tolls of cancer diagnoses on the survivor, their friends and family are incalculable but financial costs of cancer is overwhelming. The National Institutes of Health (NIH) estimated that cancer has cost the United States approximately \$263.8 billion in medical costs and lost productivity in 2010³.

The National Cancer Institute³ (NCI) estimated that 1,660,290 people in the United States will be diagnosed with and 580,350 will die from cancer of all sites in 2013, narrowing the gap with the first place killer of cardiovascular disease. The Surveillance, Epidemiology and End Results (SEER) Cancer Statistics Review inform us that the national median age at diagnosis for cancer of all sites was 66 years of age from 2006-2010⁴. The age-adjusted incidence rate was 463.0 per 100,000 people per year. The median age at death for cancer of all sites was 72 years of age for the same time period. The age-adjusted death rate was 176.4 per 100,000 people per year.

The prevalence of cancer nationwide is also astonishing with approximately 13,027,914 people affected in 2010. That's over 4.2% of the entire US population diagnosed with cancer. The SEER Program also calculated the lifetime risk of having cancer to be 41.24% based on rates from 2007-2009⁴. This means that 1 in 2 men and women will be diagnosed with some form of cancer at some point during their lifetime. These national trends are also reflected in the

1. Introduction

population in the state of Florida.

The United States Cancer Statistics (USCS) calculates the cancer incidence rate in Florida at 439.5 per 100,000 population and the mortality rate at 165.1 per 100,000¹. In 2009, there were 102,827 new cancer cases diagnosed in Florida and 40,931 deaths from the disease. Even though cancer can affect men and women of all ages, races, and ethnicities, it does not affect all groups equally^{5, 6}. African Americans are more likely to die of cancer than any other race or ethnicity with the age-adjusted death rate for cancer of all sites of 211 per 100,000 population^{7, 8, 9}. Compare that with 175 for whites, 123 for American Indians/Alaska Native, 117 for Hispanics, and 109 for Asians/Pacific Islanders⁹. Since age is the primary risk factor of cancer, elderly people are also more likely to be diagnosed with and die from the disease. Extra measures should be taken in order to protect these at-risk populations.

Cancer was the second leading cause of death in Florida in 2005. In 2004-06, the average number of cancer cases diagnosed was 101,516; the incidence rate was 563 per 100,000¹⁰. According to the same report, 40,140 cancer deaths with an age-adjusted death rate of 162 per 100,000 occurred in 2006-08 in Florida. About 2,600 deaths due to breast cancer and 300 deaths due to cervical cancer occurred in Florida annually¹¹. Cancer-related disparities exist among minorities; Black males had the highest age-adjusted mortality rate for all cancers combined among the four race groups (547.7 per 100,000)^{12, 13}. Prostate cancer mortality rates accounted for much of this difference. Black males had a mortality rate of 54 per 100,000 from prostate cancer,

whereas white males had a rate of 19 per 100,000¹⁴. Cancer puts an enormous economic burden on Floridians, with approximately \$3.8 billion in hospital charges for in-patient hospital care in 2005 for those with a primary diagnosis of cancer. When including patients with a secondary diagnosis of cancer, the total hospital charges are \$19 billion. Hospital charges in 2005 for colorectal cancer were \$557 million; for lung and bronchus \$514 million; for breast, colorectal and cervical cancers combined \$703 million¹⁵.

The elimination of disparities in the burden of cancer is one of the overarching themes of the both government and non-government national institutions (ACS challenge goals). A series of reports published by ACS in the late 1980s documented large disparities in cancer burden by race and ethnicity, socioeconomic factors such as poverty, inadequate education, and lack of health insurance appeared to be far more important than biological differences¹⁶⁻²⁰. American College of Physicians' position paper indicated overwhelming evidence that racial and ethnic minorities are prone to poorer quality health care than white Americans, even when factors such as insurance status are controlled²¹. The cause of these disparities are multifactorial, however, social and economic factors as well as being in underserved communities play a critical role²². Considering these factors, earlier in 2000 the "Reducing Racial and Ethnic Health Disparities: Closing the Gap Act" was enacted in an effort to mobilize underserved communities in Florida to address and eliminate health outcome disparities and promote disease prevention activities²³.

Table 1. Cancer projects received funding in 2006-2009 FY

Applicant	County	Brief Description	Funding Year 06/07	Funding Year 07/08	Funding Year 08/09
YWCA of Greater Miami/Dade	Dade	Targets uninsured and underinsured minority women – Haitian, Hispanic, African-American, and Caribbean Islanders. Provide screenings and follow-up, limited diagnostic, education, referrals, and case management	Yes	Yes	Yes
HIS Great Commission	Palm Beach F/P	Medical mobile unit in a Front Porch and low-income area that provides screenings, case management, and education	Yes	Yes	Yes
Pinellas CHD	Pinellas F/P	Colorectal cancer awareness project to reduce colorectal cancer death rate to minorities	Yes	Yes	Yes

F/P – Front Project

2. Materials and Methods

The cancer projects were evaluated along with all other projects in the area of cardiovascular diseases, diabetes, maternal and infant mortality, HIV/AIDS, adult and child immunization, and oral health care. Two funded projects were intended to focus on breast and cervical cancers, however, due to the demands from underserved communities some colorectal and prostate cancer screening were done. The evaluation was done in three phases. The first phase involved qualitative assessment and a case study approach to evaluate each project's goals, objectives, plans, resources, achievements, needs and other topics that are contextual to each project. Content analysis, telephone interviews and surveys are used in this step to establish process measures²⁴. The second phase included an evaluability assessment for clarifying program designs, exploring program reality, and, if necessary, helping redesign programs to ensure that they meet the criteria such as a) well-defined program goals, objectives, and performance measures, b) plausible program goals and objectives, c) ability to obtain relevant performance data (or use alternative methods to collect data, d) agreement on the evaluation. The third phase included immediate outcome and impact evaluation and actual immediate outcome and impact measures.

The objectives of evaluability assessment were twofold: to delineate whether a program can be meaningfully evaluated and whether evaluation is likely to contribute to improve program performance²⁵. Both qualitative and quantitative

methods are used for an evaluability assessment. Documents analysis, interview, and face-to-face meetings with the program manager, data manager, and previous evaluator were the primary methods to establish evaluability of the program.

3. Results

Process Measures

From 2006 to 2007, a total of 3,165 individuals participated in the cancer prevention programs. Of these, 6 were males and 3,159 were females. As well, 5 were American Indian, 92 were Asian Pacific Islander, 1,701 were Black, and 1,162 were White. Of these, 2,854 participants identified themselves as Latino, and 265 were listed as other ethnic background. From 2007 to 2008, a total of 3,208 individuals participated in the program. Of these, 13 were males and 3,195 were females. As well, 193 were Asian Pacific Islander, 1,363 were Black, and 1,371 were White. Of these, 2,810 identified themselves as Latino, and 320 were listed as other ethnic background. From 2008 to 2009, a total of 1,632 individuals participated in the programs. Of these, 50 were males and 1,582 were females. As well, 6 were Asian Pacific Islander, 749 were Black, and 682 were White. Of these, 1,377 identified themselves as Latino, and 256 were listed as other ethnic background (Table 2).

Table 2. Demographics of Breast and Cervical Cancer Program Participants, 2006 to 2009

Characteristics	2006-2007	2007-2008	2008-2009
Gender			
Male	6	13	50
Female	3159	3195	1582
Total	3165	3208	1632
Race			
American Indian	5	0	0
Asian Pacific Islander	92	193	6
Black (non-Hispanic)	1701	1363	749
White (non-Hispanic)	1162	1371	682
Latino	2854	2810	1377
Other	265	320	256
Total	6079	4764	3070
Insurance			
Medicare	1	3	16
Medicaid	6	2	5
Private	1	9	38
Other	7	3	14
None	3149	3187	1560
Total	3164	3204	1633
Primary Language			
English	279	345	300
Spanish	2660	2594	1215
Creole	212	242	109
Other	17	26	9
Total	3168	3207	1633

* The total number is more than total participants because of the duplication of racial identity.

In breast and cervical cancer prevention programs, change of proportion of African-American or Black recruitment significantly increased from 2006-08 to 2007-09 from -11.3% to 3.4% (Figure 1). Among “other” ethnic groups, Haitian participants increased significantly. Among other services, all means of outreach such as mobile vans, faith-based activities, health fairs, and small-group education sessions also increased—by 5.3%, 7.9%, 5.5%, and 9.4% respectively (Figure 2).

Immediate Outcome and Impact Measures

There was a significant change in the proportion of participants who were screened for breast cancer by clinical breast examination and mammography; for cervical cancer by Pap Smear; and for colon cancer by Fecal Occult Blood Test and Colonoscopy from 2006-2008 to 2007-2009. The change in clinical breast examination was noteworthy

because while there was a 6.2% increase from 2006 to 2008, there was a 30.6% decrease from 2007 to 2009 (Figure 3).

Compared to the 2006-07 funding year, the proportion of participants referred to private non-profit organizations such as Susan Komen Cancer Foundation and Moffitt Cancer center increased in 2007-2008 (Figure 4). However, this trend decreased in the 2008-2009 funding year, and there was a significant proportion increase in referral to health care providers in 2008-2009 (68.5%) (Figure 5).

Overall, breast and cervical cancer programs had mixed success throughout the funding period. Outreach efforts were reasonably successful (Figure 2), and increased referrals to health care providers may have impacted overall quality-of-life-related outcomes; however, due to lack of individual data, this could not be established at this point.

Figure 1. Proportion Changed in Race from 2006-08 to 2007-09

Figure 2. Proportion Changed in Means of Outreach Efforts

Figure 3. Proportion Changed in Screening for Cancer in 2006-08 versus 2007-09

Figure 4. Proportion Changed in Referrals in 2006-07 to 2007-08

Figure 5. Proportion of Participants Referred, 2007-08 to 2008-09

Participants' Satisfaction:

In complex programs that deal with health disparity issues, participants' satisfaction about the outreach efforts, services provided, and self-reported gain in knowledge, skills, and behavior may be considered as immediate outcomes^{26, 27}. To understand participants' satisfaction with different aspects such as program access, staff skills, cultural sensitivity, and overall satisfaction, a survey was conducted among participants through the respective program offices. A 30-item survey instrument (Appendix-1) was developed that

included demographics and satisfaction levels in a 5-point Likert Scale. The survey was distributed among program offices in Florida through the Office of Minority Health, Florida Department of Health. The program offices mailed or electronically sent the survey to the program participants with return instructions. By completing the survey, the participants provided the informed consent to take part in this evaluation research. The survey was approved by the Institutional Review Board (IRB) at the Florida A&M University (FAMU).

Table 3. Indicators/Variables Used to Establish Process and Immediate Impact

Indicators/ Variables	2006-2007	2007-2008	2008-2009
Male	6	13	50
Female	3159	3195	1582
American Indian	5	0	0
Asian Pacific Islander	92	193	6
Black	1701	1363	749
White	1162	1371	682
Latino	2854	2810	1377
Other(Haitian)	265	320	256
Clinical Breast Exam Normal	1381	1601	316
Mammogram Normal	1073	894	360
Pap Smear Normal	976	1078	478
PSA Normal	0	0	
FBOT Normal	3	19	89
Colon Normal	19	6	
Mammogram Abnormal	383	245	63
Breast Cancer Diagnostic	900	883	1
Cervical Cancer Diagnostic	191	346	6
Colorectal Cancer Diagnostic	10	0	1
Mobile Medical Van	346	522	NA
Faith-Based Activity	219	477	NA
Health Fair	247	428	NA
Small Group Education Event	107	411	NA
Others	2877	2792	NA
Referral FL Breast and Cervical Cancer	974	879	NA
Referral Physician	0	0	NA
Referral Local CHD Follow-up Care	1	0	1118
Referral Other	1744	1506	NA
Referral Susan Komen	98	297	NA
Referral Moffit Cancer Center	0	1	NA

Table 4. Demographics and other Characteristics of Participants in Satisfaction Survey

Variables	f (%)
Age	
18-24	9 (4.4)
25-34	33 (15.8)
35-44	42 (20.1)
45-54	56 (26.6)
55-64	32 (15.4)
65+	37 (19.9)
Total	209 (100)
Gender	
Male	61 (29.8)
Female	144 (70.3)
Total	205 (100)
Education	
Less than High School	26 (12.7)
High School	83 (40.7)
Some College	37 (18.1)
College Graduate	37 (18.1)
Graduate School or more	21 (10.3)
Total	204 (100)
Family Income	
Less than \$10,000	58 (29.0)
10, 000-24,999	73 (36.5)
25,000-\$49,000	39 (19.5)
50,000-\$74,999	20 (10.0)
75,000 or more	10 (5.0)
Total	200 (100)
Insurance	
Private	27 (13.1)
HMO	32 (15.5)
Medicare	32 (15.5)
Medicaid	21 (10.2)
Other	31 (15.0)
None	63 (30.0)
Total	206 (100)
Marital Status	
Married	81 (38.8)
Divorced/Separated	51 (24.4)
Widowed	20 (9.6)
Single/Never Married	57 (27.3)
Total	209 (100)
Employment Status	
Working Full time	71 (34.3)
Working Part time	30 (14.5)
Retired	43 (20.8)
Not working now	58 (28.0)
Never worked	4 (1.9)
Total	207 (100)

Table 5. The Program Responding Participants Received[illegible]

Table 6. Participant's Responses to Satisfaction Questions

Question				
	N(Mean)	SD	Minimum	Maximum
The project/program I participated in provided necessary services to me.	209 (4.7)	0.5	2.0	5.0
The project/program I participated in had sufficient staff to provide necessary services.	208 (4.7)	0.6	1	5
The project/program staff was very much sensitive to my culture.	209 (4.7)	0.6	3	5
The project/program staff understood my language and spoke accordingly.	207 (4.7)	0.5	3	5
The project/program staff had necessary training and skills to provide services as needed.	209 (4.7)	0.5	3	5
The project/program I participated in had sufficient resources to provide necessary services.	209 (4.6)	0.6	1	5
The project/program I participated in provided me services that were not available to me from any other project or program.	208 (4.5)	0.8	1	5
I have received helpful educational materials from the project/program.	209 (4.7)	0.7	1	5
I have received necessary referral services whenever needed from the project/program.	206 (4.6)	0.6	3	5
In my opinion, the program/project I attended performed a good job.	207 (4.7)	0.5	3	5
The project/program helped me to adopt a new health-related behavior.	209 (4.6)	0.7	1	5
The project/program helped me to improve my health or quality of life.	209 (4.6)	0.6	1	5
I value the opportunity to participate in this project/program.	209 (4.7)	0.5	3	5
I would like to see the project/program continue in my area.	209 (4.8)	0.4	3	5
Overall I am satisfied with the program/project.	209 (4.8)	0.5	1	5

A total of 231 surveys were returned to the evaluator through the Office of Minority Health. However, in final analysis 19 participants were excluded who responded that their age was less than 18 years. The majority of respondents were 35-54 years old (46.7%), non-Hispanic Black (81.7%), female (70.3%), high school and some college educated (58.8%), and with income less than \$25,000 (65.5%). The demographics of the participants who have completed the survey were further broken down by gender, age, insurance, income, marital and employment status (Table 4).

The majority of the responding participants received services during the 2008-2009 program period (65.6%) and participated in Cardiovascular Diseases and Diabetes programs (37.3% and 30.6%, respectively). The majority of the participants were very satisfied with the program staff's training, cultural sensitivity, language skills, resources, education materials, referral system, and changing behavior (mean score: 4.5-4.7 on a 5-point Likert Scale). The participants were also satisfied with the overall project and the project's role in improving their quality of life. They

valued the programs and wanted them to continue (Table 6).

4. Conclusion

Despite multiple challenges, the 51 Closing the Gap (CTG) programs are making enormous strides in eliminating health disparities in diabetes, cardiovascular diseases, cancer, HIV/AIDS, adult and child immunization, maternal and infant mortality, and oral health in Florida. There are three cancer projects among the Closing the Gap programs (Table 1). The goal of two of the cancer projects is to increase the rate of early detection of breast and cervical cancer among minority women in the front porch communities of Dade and Palm Beach counties. The goal of the third CTG cancer project is to increase the rate of early detection of colorectal cancer in the front porch communities of Pinellas County. Nineteen CTG projects have been serving front porch community members in Palm Beach, Duval, Hillsborough, Escambia, Jackson, Citrus, Lake, Sumter, Marion, St. Lucie,

Broward, Orange, Leon, Gadsden, Jefferson, Taylor, Dade, Lee, Collier, and Alachua counties²³.

5. Discussion

The overall objectives of this evaluation were to establish the immediate impacts and some outcomes of these projects quantitatively. Due to the lack of individual level disaggregated data, a unique methodology was developed to quantify some of these immediate impacts and outcomes. However, since this methodology used an aggregated level of data, conclusions on individual levels may lead to ecological fallacies. Additionally, participants' satisfaction is considered a significant impact/outcome; however, one must consider the fact that in some cases, the participants were comparing project services with the virtually non-existent services that they had previously experienced as the standard of care. In this evaluation, the survey on participants' satisfaction may not be representative to all the program participants since data were nonrandomly selected. Due to inconsistency of data collection some outcome/impacts that were established in 2006-2008 period could not be compared to 2008-2009, which has limited the ability to draw conclusion in continuous form of these evaluation period (2006-2009).

A great deal of qualitative information was generated on the programs' cultural sensitivity, staff communication, community health workers recruitment, different types of barriers, and facilitators of success in the past evaluation²⁴. Along with these factors, health literacy and access to services must be examined. Furthermore, a separate study found that travel impediments may influence access to health care, particularly in cancer screening²⁸. Future programs should consider incorporating these factors in providing services.

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