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Research Article

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# The Detroit Research on Cancer Survivors (ROCS) Pilot Study: A Focus on Outcomes after Cancer in a Racially Diverse Patient Population

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## Abstract

**Background:** African Americans are often diagnosed with advanced stage cancer and experience higher mortality compared with whites in the United States. Contributing factors, like differences in access to medical care and the prevalence of comorbidities, do not entirely explain racial differences in outcomes.

**Methods:** The Detroit Research on Cancer Survivors (ROCS) pilot study was conducted to investigate factors related to short- and long-term outcomes among patients with cancer. Participants completed web-based surveys, and mailed saliva specimens were collected for future genetic studies.

**Results:** We recruited 1,000 participants with an overall response rate of 68%. Thirty-one percent completed the survey without any interviewer support and the remaining participated in an interviewer-administered survey. Seventy-four percent provided a saliva specimen and 64% consented for tumor tissue retrieval. African American survivors required more interviewer support ($P < 0.001$); however, their response rate (69.6%) was higher than non-Hispanic whites (65.4%). African Americans reported poorer overall cancer-related quality of life compared with non-Hispanic whites, measured by FACT-G score ($P < 0.001$), however, this relationship was reversed after controlling for socioeconomic factors, marital status, and the presence of comorbidities.

**Conclusions:** In this pilot study, we demonstrated that a web-based survey supplemented with telephone interviews and mailed saliva kits are cost-effective methods to collect patient-reported data and DNA for large studies of cancer survivors with a high proportion of minority patients. The preliminary data collected reinforces differences by race in factors affecting cancer outcomes. Our efforts continue as we expand this unique cohort to include more than 5,000 African American cancer survivors.

**Impact:** Formal investigation of factors influencing adverse outcomes among African American cancer survivors will be critical in closing the racial gap in morbidity and mortality.

## Introduction

Although we continue to make progress in reducing the incidence and mortality for most cancers in the United States, African Americans continue to experience disproportionately higher cancer incidence rates, are more likely to be diagnosed with advanced stage disease, and have poorer survival than other populations (1, 2). The determinants of cancer progression, recurrence, mortality, and quality of life in African American cancer survivors are not well understood, but contributors include individual patient-related factors, the quality of health care provided, and the health care system, as well as factors endemic to the local communities. African Americans are less likely than whites to adhere to cancer screening and treatment guidelines, which is partially explained by cultural factors, medical mistrust, and perceived discrimination (3–10). Studies also show that compared with white cancer survivors, African American cancer survivors report more cancer-related health problems and worse health-related quality of life (QOL; refs. 11–14). Many of the behavioral, physical, and psychosocial risk factors that adversely impact QOL are more prevalent in African American than white cancer survivors. African American cancer survivors have been shown to have poorer self-reported health status, higher body mass index (BMI), are disproportionately affected with comorbid conditions, and have lower levels of physical activity than white cancer survivors (15–19).

These cancer health disparities have remained constant or even worsened over time, but very few cancer cohorts include a substantial number of African American participants (20). It has been reported that of survivorship research currently being conducted at National Cancer Institute designated Comprehensive Cancer Centers (NCI-CCC), only 4% of completed research and 7% of ongoing research includes a focus on minorities (21). This is a serious limitation of existing data sources that inhibits our ability to identify potential mechanisms and points of intervention to improve both short- and long-term outcomes after a cancer diagnosis among African Americans.

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**Note:** Supplementary data for this article are available at Cancer Epidemiology, Biomarkers & Prevention Online (http://cebp.aacrjournals.org/).

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In Metropolitan Detroit, a tri-county area in southeast Michigan including Wayne, Oakland, and Macomb counties, older African Americans have high rates of poverty, comorbid medical conditions, and are likely to be medically underserved. Southeast Michigan is home to 70% of Michigan's African American population and 41% of the state's below poverty population (22). Of the 24,500 invasive cancers reported annually among residents of the tri-county area, approximately 25% are diagnosed among African Americans (23). Thus, this region provides a uniquely important context for studying determinants of cancer outcomes in this population.

The goals of the Detroit **R**esearch **O**n **C**ancer **S**urvivors (or ROCS) Pilot Study are to (i) provide data on the feasibility of collecting epidemiologic and QOL data using a self-administered, web-based survey; (ii) determine the achievability of using an at-home saliva collection kit for future genetic investigations; and (iii) provide important preliminary data characterizing the target patient population. The Detroit ROCS Pilot was limited to 1,000 patients and was designed to inform the larger Detroit ROCS cohort study which is currently enrolling more than 5,000 African American cancer survivors in Metropolitan Detroit. Both Detroit ROCS and the Detroit ROCS Pilot focus specifically on patients diagnosed with lung, breast, prostate, and colorectal cancers. These cancers were selected because they contribute greatly to overall cancer burden, occur at the highest frequency in African Americans, and also represent cancers with a range in length of survival and severity of disease.

## Materials and Methods

Eligible patients for the Detroit ROCS Pilot Study were initially identified through the Metropolitan Detroit Cancer Surveillance System (MDCSS), or the Detroit Surveillance, Epidemiology and End Results (SEER) registry as having been diagnosed and/or treated at the Karmanos Cancer Institute (KCI), an NCI-CCC with histopathologically confirmed, first primary lung, female breast, prostate, or colorectal cancer. All patients were diagnosed on or after January 1, 2013, and between the ages of 20 and 79 years at time of diagnosis. Patients self-identified as either non-Hispanic white or African American at the time of consent and baseline interview. In addition to the initial case identification, MDCSS provides relevant clinical data on participating cases including, but not limited to, histologic type, histologic grade, date and tumor stage at diagnosis, primary treatment (surgery and/or radiation), tumor prognostic markers (e.g. estrogen and progestin receptor and HER2 status) and will provide follow-up information on vital status and cause of death.

For all potentially eligible cases identified through the registry, a notification letter was sent to the treating physician of record. The letter explained the study and asked if there was any reason patient contact was ill advised. KCI requires only passive physician notification for contact of patients; therefore, no response from a physician implies study contact is permissible. Physicians indicated study contact was ill advised for approximately 1% of the cases. After physician notification, each patient was mailed an introductory brochure and instructions for completing the baseline survey online and a study phone number if they preferred interviewer assistance. All potential participants who did not complete the baseline survey on their own within two weeks of receiving the introductory brochure were contacted by interviewing staff by telephone. We attempted to contact each potential participant with up to nine calls at varying times and days of the week including weekends. Informed consent, either online or verbal using a research information sheet, was obtained from all participants when they accessed the link to the online survey or completed the survey over the phone. Participants were assured that participation in the study was entirely voluntary, and refusal to participate would not affect their medical care. The study protocol, survey, and all documents were approved by the Institutional Review Board at Wayne State University (Detroit, MI).

The survey, approximately 30–45 minutes in length, included information on sociodemographic factors and financial hardship, medical history and medication use, family history of cancer, behavioral risk factors (tobacco and alcohol use, diet and physical activity), cancer treatment history, and cancer screening practices. Patient reported outcomes were captured using the Functional Assessment of Cancer Therapy (FACT) questionnaire that was tailored to address cancer site–specific concerns, and evaluates QOL including physical, emotional, functional, and social well-being (24). At completion of the baseline survey participants received a $25 gift card and were asked for informed written consent to collect a saliva sample for DNA, consent for study access to medical records and archived tissue (if available), and permission to be recontacted for annual follow-up for up to four years. Each subject was also asked for consent to allow for future contact for other studies, and for sharing of biospecimens to promote more widespread access to data and biospecimens for research purposes. Participants were informed that they could withdraw their consent to use their survey responses and biospecimens at any time. All consenting participants were then mailed an Oragene Saliva collection kit with instructions for collection and two written copies of the informed consent document and asked to return the specimen with one signed consent document within 24 hours of collection using a postage-paid envelope. Those returning saliva kits received an additional $25 gift card. DNA was extracted from saliva specimens using the manufacturer's protocol, evaluated for yield and concentration, and stored at −80°C.

### Statistical analysis

All statistical analyses were performed using SAS v 9.4 and graphs were created using the R statistical software package. Response rates for study participation were calculated for the overall study population and stratified by patient self-reported race. The distribution of self-reported participant demographics (age at diagnosis, sex, education, marital status, employment status, and income), health behaviors (cigarette smoking, alcohol consumption, daily consumption of fruit/vegetables, physical activity to improve health), current body mass index, and family history of cancer were summarized overall and compared by race using $\chi^2$ tests for categorical variables and Cochran–Armitage tests for ordinal variables. Clinical characteristics (AJCC stage and cancer site-specific characteristics) and first course treatment as recorded by the Detroit SEER registry database were evaluated by cancer site and differences in the distribution by race were compared using $\chi^2$ and Cochran–Armitage tests. For comorbid conditions with a prevalence of more than 5%, the proportion of participants reporting the condition was graphed by cancer site and race, including any significant $P$ value from a $\chi^2$ comparison. The mean FACT overall score and subscale scores were calculated by race, cancer site, and comorbidity score, and differences in scores were assessed using the Wilcoxon rank sum test. Racial

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**Table 1.** Response rates for all eligible patients contacted as part of the Detroit ROCS Pilot

| | All patients | Non-Hispanic white | African American |
|---|---|---|---|
| Number of eligible participants identified | 1,475 | 633 | 842 |
| Study outcome, *N* (%) | | | |
| Completed interview | 1,000 (67.8%) | 414 (65.4%) | 586 (69.6%) |
| Refusal | 347 (23.5%) | 162 (25.6%) | 185 (22.0%) |
| Unable to reach | 91 (6.2%) | 40 (6.3%) | 51 (6.1%) |
| Unable to locate | 28 (1.9%) | 12 (1.9%) | 16 (1.9%) |
| Physician recommended against contact | 9 (0.6%) | 5 (0.8%) | 4 (0.5%) |
| Response rates, *N* interviewed (%) | | | |
| Sex | | | |
| Men | 384 (64.4%) | 154 (65.0%) | 230 (64.1%) |
| Women | 616 (70.1%) | 260 (65.7%) | 356 (73.7%) |
| Cancer site | | | |
| Breast | 439 (70.2%) | 174 (67.2%) | 265 (72.4%) |
| Colorectal | 101 (66.4%) | 51 (64.6%) | 50 (68.5%) |
| Lung | 197 (70.6%) | 101 (65.2%) | 96 (77.4%) |
| Prostate | 263 (62.8%) | 88 (62.9%) | 175 (62.7%) |
| SEER summary stage | | | |
| Local or regional | 822 (67.7%) | 323 (65.0%) | 499 (69.6%) |
| Distant | 178 (68.2%) | 91 (66.9%) | 87 (69.6%) |
| Among interview respondents, *N* (%) | | | |
| Method of completion | | | |
| Online | 307 (30.7%) | 218 (52.7%) | 89 (15.2%) |
| Telephone | 693 (69.3%) | 196 (47.3%) | 497 (84.8%) |
| Saliva sample obtained | | | |
| No | 259 (25.9%) | 102 (24.6%) | 157 (26.8%) |
| Yes | 741 (74.1%) | 312 (75.4%) | 429 (73.2%) |
| Tumor tissue consent | | | |
| No | 362 (36.2%) | 130 (31.4%) | 232 (39.6%) |
| Yes | 638 (63.8%) | 284 (68.6%) | 354 (60.4%) |

differences in overall FACT scores were further evaluated using multivariate ANOVA adjusting for demographic variables that significantly varied in the study population (education, marital status, employment, and income), comorbidity score, and treatment status. The impact of these variables was evaluated individually as well as in a fully adjusted model, and least squares means by race was calculated for each model.

## Results

In our effort to recruit 1,000 eligible cancer cases, we sent recruitment letters to 1,475 survivors for an overall response rate of 67.8% (Table 1). Twenty-four percent of cases refused to participate while another 8% did not respond to study contact or could not be located. The response rate among African American survivors was slightly higher than non-Hispanic whites (69.6% vs. 65.4%, respectively; $P = 0.088$). Higher rates were also observed in women (70.1%) compared with men (64.4%, $P = 0.022$), for lung and breast cancer cases (70.6% and 70.2%) compared with colorectal (66.4%) and prostate cancer cases (62.8%, $P = 0.053$). Response rates were similar by stage at diagnosis (local/regional versus distant SEER summary stage, $P = 0.878$) and age at diagnosis (age <60 years vs. ≥60 years, $P = 0.190$).

Overall, approximately 30% of participants completed the baseline survey online, while 70% of participants required an interviewer-administered survey. However, there were substantial differences in the method of completion by race, with 52.7% of non-Hispanic whites completing the survey on their own compared with just 15.2% of African Americans. Differences in method of survey completion were associated with age, education, income, and marital status, with younger, more highly educated and those with higher incomes completing the survey without interviewer support within both racial groups (Supplementary Table S1). There was no difference in survey completion by method (96% of all questions answered for on-line respondents vs. 97% for phone interviews). Nearly 90% of participants who completed the baseline interview also indicated a willingness to provide a saliva specimen with 74.1% of participants actually returning a sample, with no difference by race. The median time between diagnosis and interview was 17.6 months, and this did not vary by race (18.0 months for non-Hispanic white vs. 17.5 months for African Americans, $P = 0.786$)

Select demographic and behavioral characteristics of the 1,000 cancer cases participating in the Detroit ROCS Pilot Study are summarized in Table 2. The median age at time of diagnosis of participants was 60 years (range 27–79 years) and just over 60% were female. The majority of respondents were married, retired at the time of the baseline survey, and most reported at least some college education. However, African American participants were less likely to be married, and reported lower educational attainment and income compared with white participants. African American participants were more likely to report that they were smoking and less likely to report consuming alcohol at the time of survey compared with their non-Hispanic white counterparts. No differences were observed in number of daily servings of fruits or vegetables by race, but African Americans were less likely to participate in physical activity for fitness ($P < 0.001$) and more likely to be obese [BMI $\geq 30$ kg/m$^2$; $P = 0.017$] than non-Hispanic whites. Approximately 75% of pilot participants reported having a family history of any cancer among first-degree relatives and/or grandparents; this percentage was higher in non-Hispanic whites (81.2%) than in African Americans (70.0%). Twenty-eight percent of patients reported a positive family history of the same cancer among these relatives, with no difference by race.

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**Table 2.** Select subject demographics, health behaviors, and family history of cancer for patients who participated in the Detroit ROCS Pilot

| | All patients *N* (%) | Non-Hispanic white *N* (%) | African American *N* (%) | *P*-value* |
|---|---|---|---|---|
| Total | 1,000 | 414 | 586 | |
| **Demographics** | | | | |
| Age at diagnosis | | | | 0.348 |
| <50 | 110 (11.0%) | 51 (12.3%) | 59 (10.1%) | |
| 50–59 | 376 (37.6%) | 141 (34.1%) | 235 (40.1%) | |
| 60–69 | 376 (37.6%) | 156 (37.7%) | 220 (37.5%) | |
| 70–79 | 138 (13.8%) | 66 (15.9%) | 72 (12.3%) | |
| Median | 60 | 60 | 59 | |
| Range | 27–79 | 27–79 | 27–79 | |
| Sex | | | | 0.496 |
| Male | 382 (38.2%) | 153 (37.0%) | 229 (39.1%) | |
| Female | 618 (61.8%) | 261 (63.0%) | 357 (60.9%) | |
| Education | | | | <0.001 |
| Less than high school | 116 (11.6%) | 24 (5.8%) | 92 (15.7%) | |
| High school/GED | 299 (29.9%) | 98 (23.7%) | 201 (34.3%) | |
| Some college/2-year college degree | 346 (34.6%) | 134 (32.4%) | 212 (36.2%) | |
| Four-year college degree | 104 (10.4%) | 76 (18.4%) | 28 (4.8%) | |
| Graduate/professional degree | 128 (12.8%) | 82 (19.8%) | 46 (7.8%) | |
| Not reported | 7 (0.7%) | 0 (0.0%) | 7 (1.2%) | |
| Marital status | | | | <0.001 |
| Married or equivalent | 461 (46.1%) | 300 (72.5%) | 161 (27.5%) | |
| Widowed, divorced, separated | 336 (33.6%) | 89 (21.5%) | 247 (42.2%) | |
| Never married | 196 (19.6%) | 22 (5.3%) | 174 (29.7%) | |
| Not reported | 7 (0.7%) | 3 (0.7%) | 4 (0.7%) | |
| Employment status | | | | <0.001 |
| Full or part time | 275 (27.5%) | 169 (40.8%) | 106 (18.1%) | |
| Homemaker | 37 (3.7%) | 17 (4.1%) | 20 (3.4%) | |
| Unemployed | 84 (8.4%) | 20 (4.8%) | 64 (10.9%) | |
| Retired | 368 (36.8%) | 155 (37.4%) | 213 (36.3%) | |
| Disability | 15 (1.5%) | 46 (11.1%) | 167 (28.5%) | |
| Other | 213 (21.3%) | 5 (1.2%) | 10 (1.7%) | |
| Not reported | 8 (0.8%) | 2 (0.5%) | 6 (1.0%) | |
| Income | | | | <0.001 |
| <$20,000 | 395 (39.5%) | 58 (14.0%) | 337 (57.5%) | |
| $20,000–39,999 | 170 (17.0%) | 68 (16.4%) | 102 (17.4%) | |
| $40,000–59,999 | 114 (11.4%) | 61 (14.7%) | 53 (9.0%) | |
| $60,000–79,999 | 69 (6.9%) | 37 (8.9%) | 32 (5.5%) | |
| ≥$80,000 | 185 (18.5%) | 155 (37.4%) | 30 (5.1%) | |
| Not reported | 67 (6.7%) | 35 (8.5%) | 32 (5.5%) | |
| **Health behaviors** | | | | |
| Cigarette smoking | | | | <0.001 |
| Never | 394 (39.4%) | 178 (43.0%) | 216 (36.9%) | |
| Former | 443 (44.3%) | 200 (48.3%) | 243 (41.5%) | |
| Current | 163 (16.3%) | 36 (8.7%) | 127 (21.7%) | |
| Alcohol consumption in past month | | | | 0.001 |
| Yes | 498 (49.8%) | 233 (56.3%) | 265 (45.2%) | |
| No | 498 (49.8%) | 179 (43.2%) | 319 (54.4%) | |
| Not reported | 4 (0.4%) | 2 (0.5%) | 2 (0.3%) | |
| Servings of fruit per day | | | | 0.061 |
| 0 or less than 1 per day | 252 (25.2%) | 86 (20.8%) | 166 (28.3%) | |
| 1 per day | 347 (34.7%) | 153 (37.0%) | 194 (33.1%) | |
| 2 per day | 227 (22.7%) | 101 (24.4%) | 126 (21.5%) | |
| 3 per day | 114 (11.4%) | 52 (12.6%) | 62 (10.6%) | |
| 4 or more per day | 56 (5.6%) | 20 (4.8%) | 36 (6.1%) | |
| Not reported | 4 (0.4%) | 2 (0.5%) | 2 (0.3%) | |
| Servings of vegetables per day | | | | 0.426 |
| 0 or less than 1 per day | 135 (13.5%) | 49 (11.8%) | 86 (14.7%) | |
| 1 per day | 380 (38.0%) | 165 (39.9%) | 215 (36.7%) | |
| 2 per day | 287 (28.7%) | 117 (28.3%) | 170 (29.0%) | |
| 3 per day | 115 (11.5%) | 45 (10.9%) | 70 (11.9%) | |
| 4 or more per day | 70 (7.0%) | 34 (8.2%) | 36 (6.1%) | |
| Not reported | 13 (1.3%) | 4 (1.0%) | 9 (1.5%) | |
| Physical activity to improve health | | | | <0.001 |
| Yes | 640 (64.0%) | 320 (77.3%) | 320 (54.6%) | |
| No | 358 (35.8%) | 93 (22.5%) | 265 (45.2%) | |
| Not reported | 2 (0.2%) | 1 (0.2%) | 1 (0.2%) | |

*(Continued on the following page)*

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**Table 2.** Select subject demographics, health behaviors, and family history of cancer for patients who participated in the Detroit ROCS Pilot (Cont'd)

| | All patients *N* (%) | Non-Hispanic white *N* (%) | African American *N* (%) | *P*-value* |
|---|---|---|---|---|
| **BMI** | | | | |
| Current BMI categories | | | | 0.017 |
| Underweight or normal | 259 (25.9%) | 116 (28.0%) | 143 (24.4%) | |
| Overweight | 350 (35.0%) | 157 (37.9%) | 193 (32.9%) | |
| Obese | 391 (39.1%) | 141 (34.1%) | 250 (42.7%) | |
| **Family history of cancer** | | | | |
| Any family history | | | | <0.001 |
| No | 254 (25.4%) | 78 (18.8%) | 176 (30.0%) | |
| Yes | 746 (74.6%) | 336 (81.2%) | 410 (70.0%) | |
| Family history of same cancer | | | | 0.056 |
| No | 723 (72.3%) | 286 (69.1%) | 437 (74.6%) | |
| Yes | 277 (27.7%) | 128 (30.9%) | 149 (25.4%) | |

*$P$ value calculation does not include the "not reported" category. Cochran–Armitage $\chi^2$ reported for ordinal variables (age group, education, income, and BMI) and $\chi^2$ for categorical.

The clinical characteristics of participants and elected treatment by tumor type are summarized in Table 3. Among 439 breast cancer cases, the majority (78.4%) were diagnosed with AJCC stage I or II disease and lumpectomy with radiation was the most commonly elected first course of treatment. Most patients were diagnosed with $ER^+/PR^+$ tumors, yet 16.9% had triple negative ($ER^-$, $PR^-$, $HER2^-$) disease. Almost 20% of African American breast cancer survivors were diagnosed with triple-negative breast cancer compared with only 12.6% of white breast cancer survivors. Among 101 colorectal cancer cases, most were diagnosed with AJCC stage III or IV disease with approximately 60% diagnosed in the distal colon. Segmental resection with adjuvant therapy was the most common first course of treatment. Among 197 lung cancer cases, 43.1% were AJCC stage IV at time of diagnosis. Chemotherapy was the most commonly reported treatment, either coupled with radiation (38.1%) or alone (23.9%). Finally, among 263 prostate cancer cases, the majority (52.9%) were diagnosed with AJCC stage II and Gleason grade (3+4) and higher disease. Radiotherapy was the most common first course treatment elected, either with (17.5%) or without hormone therapy (24.3%), followed by radical prostatectomy (30.0%). There were few differences by race in elected treatment with the exception of prostate cancer where non-Hispanic whites were more likely to undergo radical prostatectomy than African Americans. Stage at diagnosis was similar by race for patients with breast and colorectal cancer, while non-Hispanic white patients with lung and prostate cancer were more likely to be diagnosed at advanced stage, reflecting the patient mix diagnosed and/or treated at KCI.

There were significant racial differences in the prevalence and distribution of comorbid conditions between African Americans and non-Hispanic white cancer cases (Fig. 1). African American patients were significantly more likely to report diagnoses including arthritis, congestive heart failure, diabetes, hypertension, hepatitis, myocardial infarction, and stroke. Non-Hispanic white patients were more likely to report a diagnosis of fracture (after age 50 years), osteoporosis and thyroid disease (hyper- or hypothyroidism). African American patients were also more likely than whites to report three or more comorbid conditions, in addition to cancer (52.2% for African Americans versus 40.8% for whites, $P < 0.001$). More than 20% of all survivors reported depression.

The most common comorbidities reported among pilot participants were hypertension, hypercholesterolemia, and arthritis. Overall, the prevalence of comorbid conditions was similar by cancer site (Supplementary Fig. S1), with a few notable exceptions. Patients with breast cancer were more likely to report a history of arthritis, depression, and osteoporosis compared with patients diagnosed with prostate, lung, or colorectal cancer. Patients with prostate cancer were more likely to report a history of hepatitis (any type) compared with other cancer sites. Expectedly, patients with lung cancer were more likely to report a medical history of both emphysema and chronic obstructive pulmonary disease compared with patients with breast, prostate, and colorectal cancer.

African American cancer survivors were more likely to report poorer overall QOL postcancer diagnosis compared with non-Hispanic whites measured by responses to the FACT (Fig. 2A). As previously noted, the measure assesses patient-reported QOL in physical, social, functional, and emotional well-being domains, with African American survivors having significantly lower mean scores in all measured domains with the exception of emotional health (Fig. 2B). In an attempt to explain differences in QOL scores, we conducted an ANOVA to determine which factors might explain these differences. Racial differences in education, marital status, income, employment, and the presence of comorbid conditions appear to explain these differences as adjustment for these variables reversed the observed differences in QOL score (Table 4). FACT scores were also significantly higher in men with prostate cancer compared with the other cancers (Supplementary Fig. S2; $P = 0.027$) and inversely related to the number of reported comorbid conditions in any patient (Supplementary Fig. S3; $P < 0.001$).

## Discussion

We were successful in recruiting 1,000 cancer survivors into this hospital-based cohort study with an overall response rate of nearly 70%. This was likely facilitated by offering a mix of data collection methods and a convenient, noninvasive method to collect biospecimens. Approximately 30% of our patients were able to complete the web-based survey unassisted; however, there were distinct racial differences in mode of data collection with African American patients more likely to require some interviewer assistance in completing the survey. This is likely explained by differences in computer literacy and access by race (25). We were able to show that differences in education and income, as well as age and marital status, were associated with mode of survey completion in both racial groups. African Americans in our cohort were more likely to report lower socioeconomic status. KCI is located in the heart of downtown Detroit and is one of the primary

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**Table 3.** Clinical characteristics and first course treatment by cancer site for participants in the Detroit ROCS pilot

| | All *N* (%) | Non-Hispanic white *N* (%) | African American *N* (%) | *p* value* |
|---|---|---|---|---|
| **Breast cancer** | 439 | 174 | 265 | |
| AJCC Stage | | | | 0.550 |
| I | 173 (39.4%) | 69 (39.7%) | 104 (39.2%) | |
| II | 171 (39.0%) | 69 (39.7%) | 102 (38.5%) | |
| III | 69 (15.7%) | 29 (16.7%) | 40 (15.1%) | |
| IV | 26 (5.9%) | 7 (4.0%) | 19 (7.2%) | |
| Subtype | | | | 0.007 |
| $ER^+$ or $PR^+$, $HER2^+$ | 60 (13.7%) | 26 (14.9%) | 34 (12.8%) | |
| $ER^+$ or $PR^+$, $HER2^-$ | 261 (59.5%) | 116 (66.7%) | 145 (54.7%) | |
| $ER^-/PR^-$, $HER2^+$ | 26 (5.9%) | 4 (2.3%) | 22 (8.3%) | |
| Triple negative | 74 (16.9%) | 22 (12.6%) | 52 (19.6%) | |
| Unknown | 18 (4.1%) | 6 (3.4%) | 12 (4.5%) | |
| First course treatment summary | | | | 0.159 |
| Lumpectomy alone | 40 (9.1%) | 11 (6.3%) | 29 (10.9%) | |
| Lumpectomy with radiation | 262 (59.7%) | 102 (58.6%) | 160 (60.4%) | |
| Mastectomy (with or without adjuvant therapy) | 116 (26.4%) | 54 (31.0%) | 62 (23.4%) | |
| Radiation, chemotherapy, or hormone | 21 (4.8%) | 7 (4.0%) | 14 (5.3%) | |
| **Colorectal cancer** | 101 | 51 | 50 | |
| AJCC Stage | | | | 0.912 |
| I | 17 (16.8%) | 8 (15.7%) | 9 (18.0%) | |
| II | 12 (11.9%) | 6 (11.8%) | 6 (12.0%) | |
| III | 41 (40.6%) | 22 (43.1%) | 19 (38.0%) | |
| IV | 31 (30.7%) | 15 (29.4%) | 16 (32.0%) | |
| Location | | | | 0.195 |
| Distal | 59 (58.4%) | 33 (64.7%) | 26 (52.0%) | |
| Proximal | 42 (41.6%) | 18 (35.3%) | 24 (48.0%) | |
| First course treatment summary | | | | 0.748 |
| Local resection | 5 (5.0%) | 3 (5.9%) | 2 (4.0%) | |
| Segmental resection alone | 20 (19.8%) | 12 (23.5%) | 8 (16.0%) | |
| Segmental resection with adjuvant therapy | 65 (64.4%) | 31 (60.8%) | 34 (68.0%) | |
| Chemotherapy and/or radiotherapy | 11 (10.9%) | 5 (9.8%) | 6 (12.0%) | |
| **Lung cancer** | 197 | 101 | 96 | |
| AJCC Stage | | | | 0.018 |
| I | 46 (23.4%) | 19 (18.8%) | 27 (28.1%) | |
| II | 16 (8.1%) | 7 (6.9%) | 9 (9.4%) | |
| III | 50 (25.4%) | 22 (21.8%) | 28 (29.2%) | |
| IV | 85 (43.1%) | 53 (52.5%) | 32 (33.3%) | |
| Histology | | | | 0.460 |
| Non–small cell | 173 (87.8%) | 87 (86.1%) | 86 (89.6%) | |
| Small cell | 24 (12.2%) | 14 (13.9%) | 10 (10.4%) | |
| First course treatment summary | | | | 0.056 |
| Surgery alone | 35 (17.8%) | 18 (17.8%) | 17 (17.7%) | |
| Surgery with adjuvant treatment | 23 (11.7%) | 9 (8.9%) | 14 (14.6%) | |
| Radiotherapy alone | 15 (7.6%) | 5 (5.0%) | 10 (10.4%) | |
| Chemotherapy alone | 47 (23.9%) | 32 (31.7%) | 15 (15.6%) | |
| Chemo and radiation | 75 (38.1%) | 35 (34.7%) | 40 (41.7%) | |
| Other | 2 (1.0%) | 2 (2.0%) | 0 (0.0%) | |
| **Prostate cancer** | 263 | 88 | 175 | |
| AJCC Stage | | | | 0.017 |
| I | 51 (19.4%) | 16 (18.2%) | 35 (20.0%) | |
| II | 139 (52.9%) | 39 (44.3%) | 100 (57.1%) | |
| III | 35 (13.3%) | 13 (14.8%) | 22 (12.6%) | |
| IV | 38 (14.4%) | 20 (22.7%) | 18 (10.3%) | |
| Gleason Score | | | | 0.026 |
| 6 | 67 (25.5%) | 20 (22.7%) | 47 (26.9%) | |
| 3+4 | 68 (25.9%) | 18 (20.5%) | 50 (28.6%) | |
| 4+3 | 56 (21.3%) | 17 (19.3%) | 39 (22.3%) | |
| 8 or higher | 65 (24.7%) | 31 (35.2%) | 34 (19.4%) | |
| Unknown | 7 (2.7%) | 2 (2.3%) | 5 (2.9%) | |
| First course treatment summary | | | | 0.019 |
| None/surveillance | 43 (16.3%) | 16 (18.2%) | 27 (15.4%) | |
| Radical prostatectomy alone | 79 (30.0%) | 37 (42.0%) | 42 (24.0%) | |
| Radical prostatectomy plus salvage radiation | 16 (6.1%) | 4 (4.5%) | 12 (6.9%) | |
| Radiotherapy alone | 64 (24.3%) | 13 (14.8%) | 51 (29.1%) | |
| Radiotherapy plus hormone therapy | 46 (17.5%) | 12 (13.6%) | 34 (19.4%) | |
| Hormone therapy alone | 15 (5.7%) | 6 (6.8%) | 9 (5.1%) | |

*Excludes unknown/other category; Cochran–Armitage $\chi^2$ reported for ordinal variables (AJCC Stage and Gleason grade) and $\chi^2$ for categorical.

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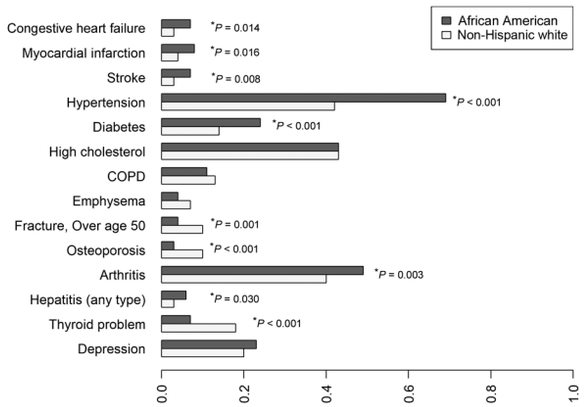


**Figure 1.**
The prevalence of select comorbid conditions by race.

hospitals that African American patients living in the city travel to for their cancer care. At the same time, because KCI is a tertiary referral hospital, white patients living outside the city often travel to the cancer center after referral from community hospitals in the surrounding area, particularly if their cancer is more aggressive and likely requiring treatments often unavailable in community oncology clinics. This is supported by our observation of very few differences by race in either the clinical characteristics of their disease at time of diagnosis or their elected first course of treatment despite the fact that there are notable racial differences in stage at presentation and outcomes for these cancers in the United States (2). Unfortunately, our African American survivors were more likely to report both health behaviors, such as smoking, and more comorbid conditions that negatively impact both short- and long-term outcomes (26–28). African American cancer survivors were also more likely to report poorer overall QOL compared with their white counterparts. Our results suggest that racial difference in overall QOL were explained by racial differences in socioeconomic factors, marital status, and the presence of comorbid conditions.

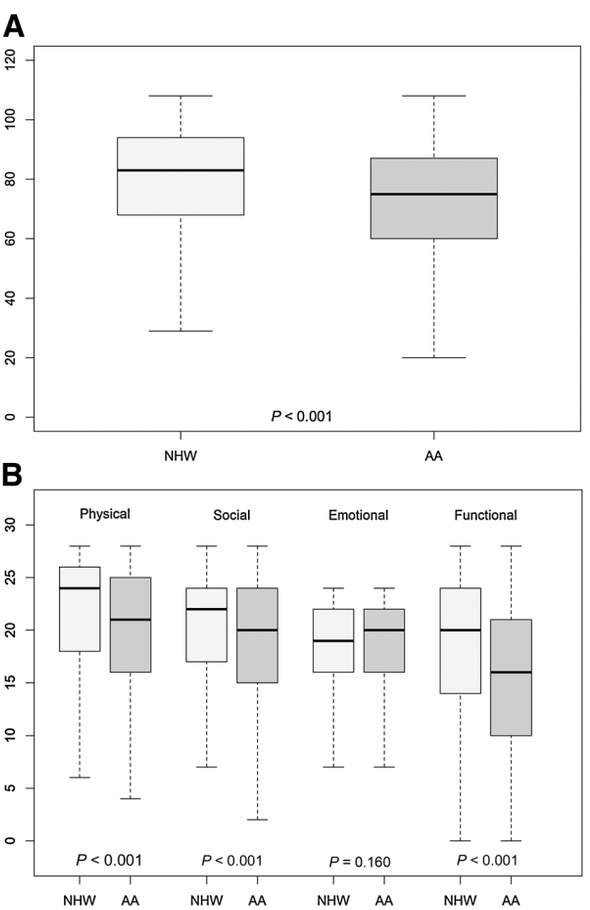


**Figure 2.**
QOL as measured by FACT scores by race. **A,** Overall FACT Score. **B,** FACT Subscales. AA, African American; NHW, non-Hispanic white.

This study has numerous strengths. The web-based survey instrument as designed is an efficient and cost-effective method to collect data with minimal burden to participants as evidenced by our high response rates. The web-based survey was most effective in reaching younger groups with higher socioeconomic status suggesting that multiple approaches to survey completion are required. More than twice as many patients required an interviewer-administered survey as completed the survey online. However, for a study as large as this one, 30% online completion represents a significant reduction in study costs. Similarly, collecting DNA from consenting participants via a mailed saliva specimen kit is a relatively inexpensive, cost-effective method and hugely successful with 90% of participants consenting to provide a specimen. However, in some cases the DNA yield on returned kits was insufficient (106 samples; 14%) which required a second mailed kit. Of those mailed a second kit, we received approximately 50% and continue to track these patients for biospecimens. We are currently planning a combination of mailed saliva kits and blood draws on a subset of participants for the larger Detroit ROCS cohort study that will enable investigation of additional blood-based, prognostic markers. Our longstanding partnership with the Detroit SEER registry, as well as the physicians and facilities contained within its catchment area not only enabled identification of eligible cases, but eased collection of tumor blocks from consenting participants. As approximately 60% of participants are African American, the study is well-powered to identify factors that differentially impact survivorship outcomes by race.

There are some noteworthy limitations. First, our data collection methods included the potential for differences in recall of information between patients who complete the survey unassisted compared to those who received an interviewer-administered survey. To address this possibility, we evaluated the distribution of responses by race and method of data collection and found no significant difference in the distribution of self-reported BMI or family history of cancer (Supplementary Table S1). Interestingly, patients who participated in the interviewer-administered survey were more likely to report being a current smoker; however, this was more likely attributed to differences in smoking associated with a respondent's education between those completing the survey on their own versus with interviewer assistance. Furthermore, our eligibility criteria for the pilot allowed for dates of cancer diagnosis up to two years prior to the beginning of enrollment, which could result in some survivor bias. This potential bias is likely to impact data for patients diagnosed with lung

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**Table 4.** Mean overall FACT scores by self-reported race, adjusted for important covariates

| | | Adjusted least squares means | | | | | |
|---|---|---|---|---|---|---|---|
| | Unadjusted | Education | Marital status | Employment | Income | Comorbidity score | Fully adjusted[a] |
| Race | | | | | | | |
| Non-Hispanic white | 79.4 | 78.5 | 74.3 | 75.3 | 77.8 | 80.6 | 74.4 |
| African American | 73.4 | 74.2 | 73.2 | 74.1 | 79.9 | 75.5 | 78.1 |
| Racial difference | 6.0 | 4.3 | 1.1 | 1.2 | −2.1 | 5.1 | −3.7 |
| *P* | <.001 | <.001 | 0.379 | 0.240 | 0.116 | <.001 | 0.004 |

[a]Adjusted for all covariates listed in the table (education, marital status, employment, income, and comorbidity score) and treatment status (posttreatment vs. still undergoing treatment).

cancer because of the higher stage at diagnosis and shorter survival on average compared with other included cancer sites. Another limitation is that some of the questions on the survey that gather information on lifestyle behaviors have not been validated with the exception of the International Physical Activity Questionnaire-Short Form. In addition, it is possible that other unmeasured multilevel social, behavioral, system, and neighborhood factors could also account for some of the differences found by race. Balancing participant response burden with collection of as much data as possible is required for this registry-based study. Many of these important multilevel sociocultural factors will be examined in future studies in more detail.

This pilot cohort was originally designed to provide evidence of the feasibility of this methodology in conducting a larger scale epidemiologic investigation of predictors of both short- and long-term outcomes for African American cancer patients. This study provided the framework for expansion to include more than 5,000 African American cancer survivors diagnosed with these same four cancers as well as a sample of their primary caregivers. Detroit ROCS is a unique, population-based investigation aimed at identifying factors important to cancer survivorship in African Americans, ranging from molecular studies to those investigations that focus the economic consequences of a cancer diagnosis and the role of the built environment. The Detroit ROCS cohort is uniquely set up to better understand the impact of health behaviors and access to treatment in disadvantaged populations. Data gleaned from this cohort will lead to identification of the important determinants of QOL, disease recurrence, and mortality with a goal of ultimately reducing cancer racial disparities in the broader African American population.

## Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

## Authors' Contributions

**Conception and design:** J.L. Beebe-Dimmer, T.L. Albrecht, T. Hastert, F.W.K. Harper, M.S. Simon, K.L. Schwartz, A.G. Schwartz

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**Analysis and interpretation of data (e.g., statistical analysis, biostatistics, computational analysis):** J.L. Beebe-Dimmer, J.J. Ruterbusch, F.W.K. Harper, K.L. Schwartz, A.G. Schwartz

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