2022 NPCR PUERTO RICO SUCCESS STORY

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Use of Claims Data to Obtain the Cost of Cancer Care

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

Over time, the Puerto Rico Central Cancer Registry (PRCCR) has improved its infrastructure to manage cancer data and perform novel types of research efficiently. In 2010, the PRCCR began to collect health insurance claims information from principal health insurance companies and the government health plan and created the Health Insurance Linkage Database (PRCCR-HILD). This study was supported by a federal grant to PRCCR at the UPR Comprehensive Cancer Center and by a National Cancer Institute U54 Grant.

To date this database has grown to more than 299.6 million records from 2009 to 2019, and 196.8 million pharmacy claims records from 2010 to 2019. The IT team has developed in-house software to access this information by PRCCR staff as end users for data completeness and quality purposes. In addition, the Claims database is used for health inequities research purposes. Using the PRCCR-HILD, the PRCCR developed the PRCCR Controls Database (PRCCR-CTRL), which is expected to be a valuable tool for cost analysis studies and population-based epidemiological studies in a Hispanic population. This success story describes the use of the developed tool to determine the lifetime and phase-specific cost of squamous cell carcinoma of the anus (SCCA) cases aged ≥21 diagnosed during 2009-2016 in Puerto Rico (PR).

CHALLENGE

Reliable cancer-related medical care cost estimates provide critical insight into the cancer economic burden. Also, they are used as input to cost-effectiveness analyses and decision analyses and help guide resource allocation decision-making. One of the most widely used methods to estimate the direct medical costs of cancer care is the net cost. It is calculated as the difference between the mean costs for cancer patients and the mean costs for individuals without cancer who are otherwise comparable. The control group would come from random enrollees who are not cancer patients. The control group serves as the counterfactual to estimate net healthcare costs related to cancer care versus usual healthcare. Currently, the PRCCR receives and processes insurance claims for healthcare services of patients with cancer as part of the PRCCR-HILD. However, there are studies, like those evaluating costs, that need individuals without cancer, as a 'control' group, to compare risk factors between patients with and without cancer. Recognizing the limitations, the PRCCR has been working on the PRCCR Controls Database (PRCCR-CTRL) to determine the lifetime and phase-specific cost of SCCA in PR.

SOLUTION

One of the most valuable sources of data for the PRCCR is the PRCCR-HILD, which has information on approximately 90% of PR's cancer cases since 2009, including all ages, which can potentially be used for different study designs. The purpose of PRCCR-CTRL is to enhance PRCCR-HILD capabilities by including a database of individuals without cancer for comparison purposes. PRCCR-CTRL was designed to develop procedures in SQL and other programming elements necessary to create the database of controls that allow evaluating and comparing some aspects of groups of people such as demographic characteristics, municipality of residence, comorbidities, dates of service, type of plan, use of some medications, and whether they have received some services, among others. To demonstrate the application of this tool, we matched SCCA cases and non-cancer control (1:1) by age and sex for each phase of care (initial, continuation and terminal). SCCA-related costs were calculated by subtracting costs between SCCA patients and the control group.

RESULTS

As part of the development of PRCCR-CTRL, approximately 1.2M records were identified. After consolidation, approximately 1M unique people were identified as potential controls. In terms of SCCA application research, healthcare expenditures were measured by reimbursements to health insurance carriers during 2009-2016 for services provided to subjects in the case and control group. Monthly cost data were estimated from 2009-2016 claims data and standardized to 2019 US dollars. The control group was used to estimate the costs unrelated to SCCA. Differences in average monthly treatment phase costs between anal cancer patients and the control group were defined as anal cancer-related costs. Phase-specific monthly cost estimates were combined with survival data from PRCCR to calculate lifetime costs for patients with SCCA from diagnosis until death.

For each patient, the corresponding phase-specific monthly cost was multiplied by the number of months patients were in each treatment phase. The results were as follows: the average monthly costs per patient were higher in the initial phase ($4,755), followed by the terminal phase ($3,499). The main cost driver in all phases was outpatient costs. Inpatient costs increased substantially at the terminal phase of care. The average lifetime cost per patient with SCCA was $137,343 (95% CI: $130,873-$145,241) (2019 US dollars) (Table 1 & Figure 1). The average cost of SCCA per year was $9,193 (95% CI: $8,744-$9,895). The lifetime economic burden for 2018 in PR was nearly $8.7 million. Although SCCA continues to be relatively rare among the general population, our study shows that the lifetime economic burden is substantial and could continue to increase due to the increase in SCCA incidence in PR. These findings could support the evaluation of the impact of strategies to reduce the burden of SCCA through HPV vaccination and anal cancer screening for populations at higher risk.

SUSTAINING SUCCESS

This study demonstrates the feasibility of using the PRCCR to perform cost analysis. Likewise, the methodology used will serve to conduct similar studies to determine the economic burden of other types of cancer. Prospectively, PRCCR-CTRL database will enhance our infrastructure to expand the PRCCR research areas and disseminate research findings to interested parties on the island. The goal is to use the knowledge generated by these studies to continually improve the health outcomes among cancer patients in PR.
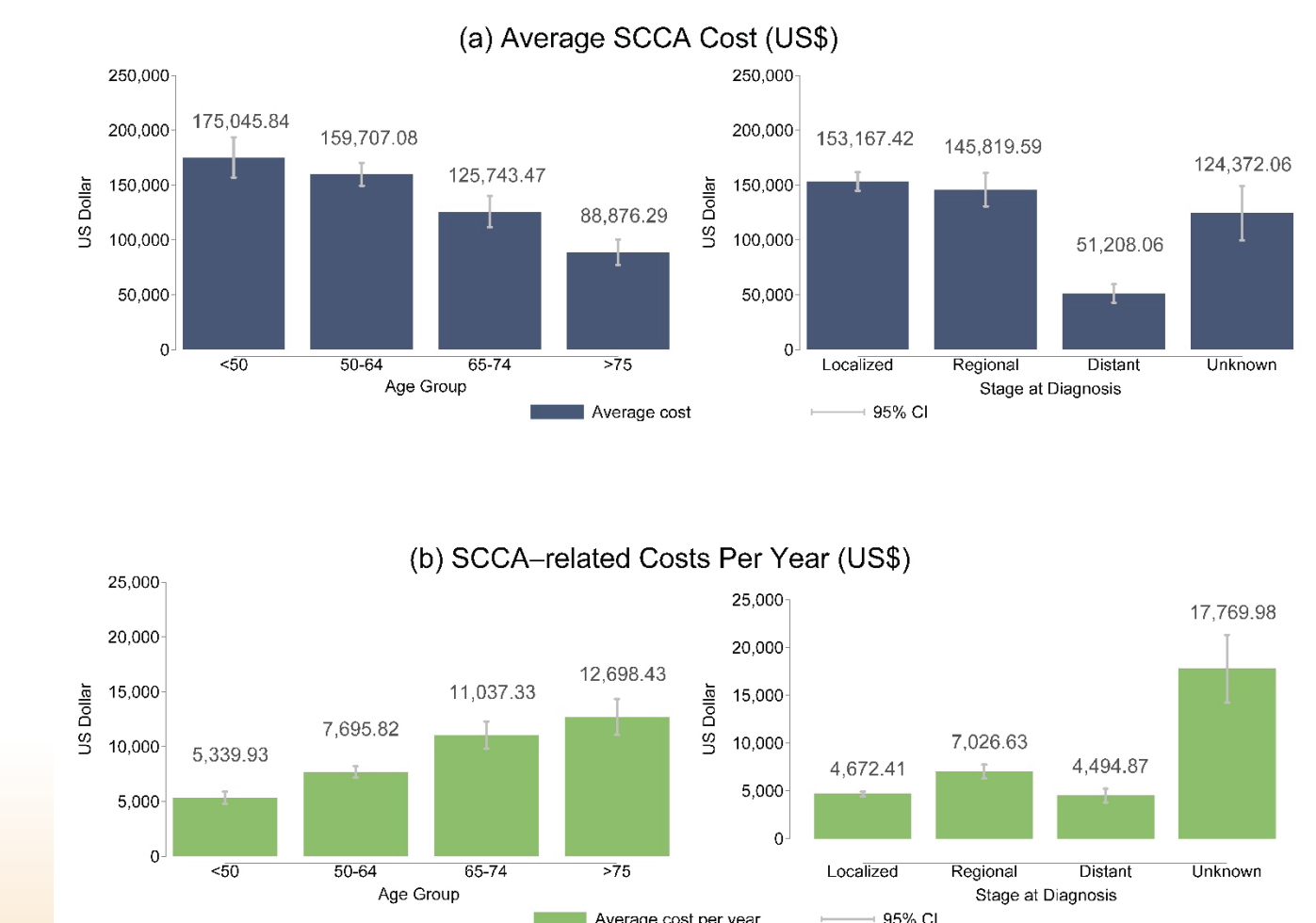
REGISTRY CONTACT INFORMATION

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TABLE 1: TOTAL LIFETIME SCCA-RELATED HEALTH CARE COSTS AND SURVIVAL (US $2019)* IN PR

Average SCCA cost (95% IC)	Average years of survival (95% IC)	SCCA per year cost (95% IC)
137,343 (130,873 - 145,241)	17.98 (15.57 - 18.34)	9,192.88 (8,744.19 - 9,895.06)

*Future costs were discounted at a 3% discount rate.

FIGURE 1: LIFETIME SCCA-RELATED HEALTH CARE COSTS IN PR, BY (A) AGE AND (B) STAGE AT DIAGNOSIS (US $2019)*

(a) Average SCCA Cost (US$)

(b) SCCA–related Costs Per Year (US$)

*Future costs were discounted at a 3% discount rate.