PUERTO RICO CENTRAL CANCER REGISTRY

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NPCR 2024 SUCCESS STORY

Puerto Rico Central Cancer Registry Data Improve Access to Hospice Care

AUTHORS: Karen J. Ortiz-Ortiz, Axel J. Gierbolini-Bermúdez, Marjorie Vázquez-Roldán, Carlos R. Torres-Cintrón, Tonatiuh Suárez-Ramos, Yisel Pagán-Santana, María Ramos-Fernández

SUMMARY

Established in 1951, the Puerto Rico Central Cancer Registry (PRCCR) is one of the oldest cancer registries in America. It became part of CDC's National Program of Cancer Registries (NPCR) in 1997.

In 2010, the PRCCR began collecting information on claims from principal health insurance companies and the government health plan and created the Health Insurance Linkage Database (PRCCR-HILD). The PRCCR-HILD has strengthened the data used for cancer care research.

In Puerto Rico, Medicaid operates through a managed care system in which health insurance companies oversee health care delivery. While some health insurance companies cover hospice services, this is not mandatory, potentially lowering the quality of care at the end of life. So, we used PRCCR-HILD to evaluate the effect of integrating hospice services into Medicaid coverage.

CHALLENGE

Hospice services address the palliative needs of patients with limited life expectancy. Hospice care improves a patient's quality of life by reducing emergency department visits, hospital admissions, intensive care unit stays, and life-extending procedures. Hospice care is an optional benefit that U.S. jurisdictions may provide as part of Medicaid coverage. As of 2024, only American Samoa, U.S. Virgin Islands, and Puerto Rico do not include this benefit. In Puerto Rico, some health insurance companies that manage Medicaid can make exceptions to cover hospice services, but patients or their families must apply for this service. This process can take time and lower the quality of a patient's life at the end of life. This is an important concern, as nearly 27% of cancer patients who died between 2018 and 2021 had Medicaid insurance only.

SOLUTION

We developed a preliminary secondary data analysis to evaluate the effect of hospice enrollment on end-of-life expenditures, emergency department visits, and hospitalizations for Medicaid patients with cancer. Using data from the PRCCR-HILD, we examined patients who died of cancer between 2016 and 2021 and were enrolled in Medicaid. Hospice enrollment was categorized in periods as follows: 1 to 7 days before death, 8 to 14 days before death, 15 to 30 days before death, 31 to 90 days before death, and 91 to 180 days before death. Of a cohort of 3,422, only 19.9% of cases received hospice service before their death. Health care costs during the last 30 and 180 days of life were respectively $3,257 (95% confidence interval [CI]: $1,851 to $4,663) and $16,146 (95% CI: $8,596 to $23,696) higher for Medicaid cancer patients not enrolled in hospice compared to those enrolled in hospice. Those who did not receive hospice services had a greater number of emergency department visits and hospital admissions and were more likely to die in acute care facilities, all of which were statistically significant. The results of this study highlighted the benefits—including cost savings and improved quality care at the end of life—for patients who received hospice care compared to those who did not.

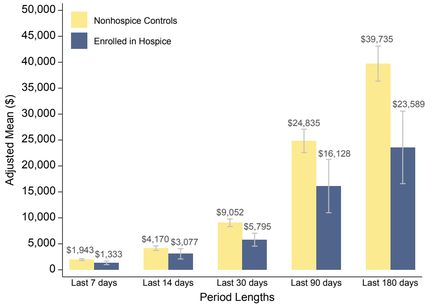
RESULTS

In partnership with the American Cancer Society of Puerto Rico, these results were discussed with Puerto Rican legislators, the Puerto Rico Health Insurance Administration, and the Department of Health. In turn, the Puerto Rico Health Insurance Administration expanded benefits to include hospice services as part of its basic coverage, effective in July 2024.

CONCLUDING REMARKS

This study highlights the benefits of integrating hospice services into Medicaid coverage. It encourages PRCCR to continue examining disparities cancer patients may face in advanced care planning processes. It also showed the benefits of strengthening collaborations and using registry data to inform decision makers about how hospice care can improve cancer patients' quality of life at the end of life.

Figure 1 Healthcare Expenditure at the End-of-Life Hospice Enrollment Status with Nonhospice Controls^



Note:

^Doubly robust methods were used, combining coarsened exact matching and regression adjustment, using generalized linear models with a gamma distribution and a log link function to analyze the effects of hospice enrollment on expenditures. Expenditure was adjusted to December 2021 U.S. dollars using the consumer price index.

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