In their article, Drs. Matthew Cooperberg, Sangtae Park, and Peter Carroll summarize four national registries that have studied risk migration, practice patterns, outcome predictions, and quality-of-life outcomes in prostate cancer. Each of these four large registries—the Prostate Cancer Outcomes Study (PCOS), the Department of Defense Center for Prostate Disease Research (CPDR), the Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE), and the Shared Equal Access Regional Cancer Hospital (SEARCH)—has a particular strength that complements the others. As more patients enroll in these registries, researchers will gain greater insight into the patterns of care and clinical and health-related quality of life for diverse cohorts of prostate cancer patients.

As each treatment is associated with distinct side effects and expected survival rates that are similar, health-related quality of life is an important factor to consider while making this decision. Moreover, prolonged emotional effects and possible problems with appetite, fatigue, cognitive function, and financial difficulties should be considered. With an ever-increasing number of treatment options, prostate cancer patients’ concerns about possible treatment-related toxicities often influence the ultimate treatment decision. For this reason, comprehensive pictures of patterns of care, survival, and quality of life among prostate cancer patients are especially important.
programs. Of the 205 patients currently enrolled, 70% are African-American, 61% are over the age of 65, 45% have less than 9th grade literacy levels, and 60% have annual incomes of less than $20,000. Diagnostic and staging information is collected from medical records at baseline, and treatment information is followed through periodic chart reviews. In addition, participants are interviewed with respect to health-related quality of life prior to the initiation of treatment and at 3- and 12-month follow-up, which allows for prospective assessments of health-related quality of life, treatments, and outcomes. Clinical presentation and patterns of care findings from this cohort are similar to those reported by the four large registries. Almost half of the patients in recent years presented with early-stage and low-risk disease. Nonetheless, only 12% chose watchful waiting and 60% underwent a radical prostatectomy or external-beam irradiation. However, early findings from the cohort indicate that among a population characterized by low socioeconomic status and good access to health care, poor health literacy skills are an important and often overlooked factor to consider when identifying individuals who present with high prostate-specific antigen levels.

Conclusions

With policymakers' current emphasis on cancer survivorship, long-term studies of prostate cancer patients are becoming increasingly important. Information obtained from the four large ongoing prostate cancer registries, supplemented by similar data elements from smaller cohorts of hard-to-reach individuals with prostate cancer, can provide important insights. The alphabet soup of privately and publicly funded prostate cancer registries represents a unique national jewel that can assist in improving our understanding of prostate cancer survivorship.

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