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Knowledge of genetic cancer risks often dies with patients

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If you were dying from cancer, would you consider genetic testing? A recent study conducted by researchers from Virginia Commonwealth University Massey Cancer Center showed that most terminally ill cancer patients who were eligible for genetic testing never received it despite that it could potentially save a relative's life.

The research, "Exploring Hereditary Cancer Among Dying Cancer Patients—A Cross-Sectional Study of Hereditary Risk and Perceived Awareness of DNA Testing and Banking," was recently published in the *Journal of Genetic Counseling*, and is the first to document the prevalence of hereditary cancer risk and the need for genetic services and patient education among terminally ill cancer patients.

The study was conducted by VCU Massey researchers John M. Quillin, Ph.D., assistant professor in the Department of Human and Molecular Genetics in the VCU School of Medicine; Thomas J. Smith, M.D., professor in the Division of Hematology/Oncology in the VCU School of Medicine; Joann N. Bodurtha, M.D., professor in the Departments of Human and Molecular Genetics, Pediatrics, Obstetrics-Gynecology, and Epidemiology and Community Health in the in the VCU School of Medicine; and Laura Siminoff, Ph.D., professor and chair of the Department of Social and Behavioral Sciences in the VCU School of Medicine.

Investigators interviewed 43 dying cancer patients, nine of whom had a strong genetic risk. Significant findings included:

- Twenty-one percent of dying cancer patients qualify for genetic assessment
- None of the patients had genetic testing, even though their clinical conditions warranted it
- Patients have a limited understanding of genetic services
- Hereditary cancer is not being fully identified or tested at the time of diagnosis

"About 10 percent of patients are literally taking their DNA clues to cancer with them to the grave," said Smith, oncology and palliative care specialist at VCU Massey Cancer Center and co-lead researcher. In general, about 5 to 10 percent of cancers have a strong hereditary component.

Current genetic tests for at-risk relatives often fail to identify certain genetic markers for cancer, and clinicians are increasingly recognizing the value of beginning genetic assessment with a person who has cancer. Because the implications of genetics extend beyond the patients to their family members, this research proposes a new way of thinking about patient care that includes the larger reach of hereditary risk.

"Our findings suggest opportunities for identifying hereditary cancer are being lost, even as the window for identifying familial risk is closing," says Quillin, genetic counselor at VCU Massey Cancer Center and co-lead researcher. "By recognizing signs of hereditary cancer among dying patients, physicians can nurture patients' legacies while they nurture their lives."

Just as VCU Massey Cancer Center practices a multidisciplinary approach to treating and fighting cancer, interdepartmental collaboration was critical in this study. Researchers are now further exploring knowledge, attitudes and behaviors of palliative care oncologists with respect to genetic testing.

"Genetic testing should be completed early, shortly after diagnosis. Patients should ask their doctors if there is a genetic part to their disease, and test for it sooner rather than later," Smith says.

Provided by Virginia Commonwealth University