Researchers: Myeloid malignancies underreported in US

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Researchers at Moffitt Cancer Center in Tampa, Fla., and colleagues from the UF Shands Cancer Center in Gainesville, Fla., have found that cases of myeloid malignancies are being underreported since a change in registry protocols and laboratory practices starting in 2001.

Their study is published in a recent issue of *Cancer Epidemiology, Biomarkers and Prevention*, a publication of the American Association for Cancer Research.

"Since the 1970s, cancer registries have monitored myeloid leukemia incidence in the United States," said study lead author Benjamin M. Craig, Ph.D., an assistant member in Moffitt's Department of Health Outcomes and Behavior. "According to data from nine Surveillance Epidemiology and End Results (SEER) sites, myeloid leukemia incidence decreased from 1975 to 1989, increased from 1990 to 2000, and decreased after 2000. We hypothesize that the drop in myeloid leukemia incidence since 2001 is the result of both changes in registry protocols and practice patterns that favor the use of commercial laboratories and do not reflect changing disease patterns among the population."

"The big surprise from our findings wasn't that myeloid leukemias were missed; it was the magnitude of uncaptured cases," said Christopher R. Cogle, M.D., an associate professor of hematology and oncology in the University of Florida College of Medicine's department of medicine.

According to the authors, in 2001 SEER issued a guideline saying that "a myeloid malignancy diagnosed after a previous myeloid malignancy would not be recorded as a subsequent primary."

For the authors, this guideline shift may have reduced the registration of myeloid malignancy cases and changed the composition of registered cases, especially if some subtypes are more likely to co-occur with other subtypes.

"We conducted a retrospective, claims-based review of the SEER Medicare National Cancer Institute-sponsored database from 1999 to 2008," explained Craig.

Using the SEER-Medicare database, the researchers evaluated four claims-based programs with algorithms designed for sensitivity and specificity to get a more accurate assessment of the incidence of myeloid malignancies.

"Our primary results show that SEER registered only half of the acute myelogous leukemia (AML) cases and a third of chronic myelogous leukemia (CML) cases, and even these figures may be underestimated because the results were based on a claims-based algorithm that requires a bone marrow biopsy," said Craig. "CML is often diagnosed in the outpatient setting, which potentially circumvents registration. Additionally, registrars might have difficulty distinguishing between CML 'blast phase' and AML."

When examining databases, the researchers found that often CML cases were being coded as AML for reimbursement while CML cases that progressed to the blast phase were miscoded as AML, and that AML cases were thought to be CML cases until new cytogentic and molecular testing became available. They found that this approach agreed with the 2001 SEER guidelines that prohibit AML registration after CML

registration.

The implications of their findings went beyond Medicare to suggest that specific changes are needed in the registry system, concluded the authors.

"When we analyzed the uncaptured myeloid leukemia cases, we found that many of these cases were linked to individuals already registered in SEER for another cancer," said Craig. "This problem may be resolved by requiring myeloid leukemia registration regardless of other cancer diagnoses, which is partially addressed in the updated 2010 coding rules."

The researchers agreed that a more difficult remedy to accomplish is the reliance on inpatient surveillance for myeloid leukemia incidence while the outpatient bias against registration exists, a bias causing the SEER-registered CML cases to favor moderately advanced CML cases and exclude higher and lower grade cases where patients are asymptomatic.

"The imprecise coding of myeloid leukemia as 'unspecified leukemia' or 'anemia,' and to implement myeloid leukemia treatment without confirmation by bone marrow biopsy, suggests that claims-based algorithms may miss myeloid leukemia cases," said Craig.

"U.S. cancer registries have the difficult challenge of capturing blood cancers and solid tumors. Our results beg for more resources to be committed to them," Cogle said. "Improved case capture will generate better data for policy makers, scientists, physicians and patients."

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