Patient reports of relatives' cancer history often not accurate

May 11 2011

Doctors often rely on a patient's knowledge of family medical history to estimate his or her risk of cancer. However, patient reports of family cancer history are not highly accurate, according to a study appearing May 11th online in the *Journal of the National Cancer Institute.*

Primary care physicians routinely ask about family history and may base their recommendations—for screening or referrals to specialists, for instance—on the results. But it is not clear how many people in the general population have accurate information on their relatives' cancer history.

To explore this issue, Phuong L. Mai, M.D., of the National Cancer Institute and colleagues examined the accuracy of patient reports of family cancer history in the Connecticut Family Health Study. The study included a survey in which a representative sample of Connecticut residents were asked about cancer diagnoses in first- and second-degree relatives. A total of 1019 respondents provided information on cancer history for 20,578 relatives. The researchers then tried to confirm cancer history for four of the most common adult malignancies - breast, colorectal, prostate, and lung cancer - for 2,605 randomly-selected relatives.

Confirmation was obtained through state cancer registries, Medicare, death certificates, other health records and databases, and interviews directly with the relatives or their proxies.

The accuracy of reported cancer diagnoses in relatives was low to moderate and varied by type of cancer: 61.1 percent for breast cancer; 27.3 percent for colorectal cancer; 32 percent for prostate cancer; and 60.2 percent or lung cancer. In contrast, reports on relatives with no cancer were highly accurate. Reports for first-degree relatives (parents, siblings, and children) were more accurate than for second-degree relatives (grandparents, aunts, uncles, nieces, and nephews).

The authors conclude that efforts are needed to improve the accuracy of family cancer history reporting. "Given that the population from which we sampled is similar to primary care populations, the results of this study suggest that family cancer history collected in the primary care setting might be useful as an initial screening tool, and, if positive, confirmation of the reported cancers is needed for the purpose of making cancer screening recommendations or referral to a specialty clinic."

In a related editorial, Rachel A. Freedman, M.D., and Judy E. Garber, M.D., of the Dana Farber Cancer Institute in Boston say that the study highlights the limitations of relying on patient reports of family cancer histories for risk assessment. They add that the current debate on electronic medical records and patient privacy should include this issue. And they note that on-line family history tools, such as the Surgeon General's pedigree tool, genealogy websites, and Facebook pages may contribute to more accurate reporting.

"However," they write, "if we want to be able to appropriately integrate family history into personalized clinical care, studying systematic ways to enhance family history ascertainment should be a research priority."

Provided by Journal of the National Cancer Institute