

Friday, December 29th, 2006:

The Penn State Cancer Institute is leading the way to serve those seeking cancer genetic counseling. An institute survey analysis shows that physicians' being mindful of the patients' expectations and anxiety while they receive counseling may provide an opportunity to improve the quality of the program and increase patient satisfaction.

The findings were published as "A Survey of Patients' Experiences with the Cancer Genetic Counseling Process: Recommendations for Cancer Genetics Programs" in the December *Journal of Genetic Counseling*. The research was completed by Dana T. Kausmeyer, M.D.; Eugene J. Lengerich, V.M.D., M.S.; Brenda C. Kluhsman, M.S.S., Ph.D.; Dorothy Morrone, R.N.; Gregory R. Harper, M.D., Ph.D.; and Maria J. Baker, Ph.D.

"This paper is important in helping to identify potential areas of improvement for cancer genetics programs across the country," Baker said. "I decided to conduct the survey several years ago because I wanted to get some feedback about our program, not only what patients liked, but also what areas could potentially be improved."

More than 300 patients were contacted, with 156 completed surveys returned. The recommendations were culled from the answers to eighty open-ended and closed-ended questions.

Findings include the following:

- Patients can be anxious while awaiting test results and may benefit from additional support during this time, including a number of online services like chat rooms and message boards.

- Fear of genetic discrimination from insurance companies and employers may prevent patients from following through with their appointment. An introductory packet should include information on genetic discrimination protection.
- The surrounding environment in which patients are seen, including the reception area, can be a source of anxiety for patients. Thus the setting in which patients will be seen should be taken into account when developing a cancer genetics program.
- The majority of patients surveyed have the expectation that it is the genetic counselor's responsibility to contact them with information about new discoveries, an overwhelming burden for cancer genetics professionals.
- Patients were interested in cancer-related information throughout the process and were interested in participating in available research studies. It is hoped that enhancing the cancer genetics Web site will address these needs.

While these findings can be helpful to any cancer program, the Penn State Cancer Institute has instituted several changes based on the recommendations.

“For example, patients are now copied on all correspondence, not just the summary letter written directly to the patient at the end of the cancer genetic counseling process,” Baker said. “Most importantly, we have significantly enhanced our program Web site to meet some of the needs expressed by patients in the survey.”

Links and information have been added to that site, which can be found at <http://www.hmc.psu.edu/cancer>, in the “For Our Patients” section under *Our Clinical Services*, based on the survey input. The site includes a page on new advances or discoveries in cancer genetics; links to support resources, books, and helpful Web sites; and educational information

on insurance and employee discrimination concerns. The site also includes cancer risk assessment tools and information on clinical research studies and patient registries.

The Penn State Cancer Genetics Program was developed in 1998 to help individuals concerned about a personal or family history of cancer. The program has evolved as a result of discoveries emanating from the human genome project.

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