Patients Wrestle With Anxiety And Fear in Treatment Choices Affecting Sexuality

Clinicians have long observed that anxiety, worry, and fear cause some people to over- or underuse health care. These emotions can be especially intense with cancers that threaten sexual function or self-image. As a result, studies are now under way to learn more about how patients think and feel about breast, cervical, and prostate cancers in hopes of eliminating unnecessary treatments, reducing costs, and improving outcomes.

The task is not simple. The medical community has not reached consensus on at least one important management issue for each of these cancers. How effective is prophylactic mastectomy? Should low-grade Pap test abnormalities be handled aggressively or conservatively? Is surgery the best approach to localized prostate tumors, or is watchful waiting equally effective?

No Agreement

"If you ask five different experts what’s appropriate, they’ll tell you five different things," said Joy Melnikow, M.D., of the University of California, Davis, in discussing management of abnormal Pap smears. "Since there’s no agreement among experts about what’s appropriate utilization, it gets very tricky to define whether psychological factors lead to over- or under-utilization, except at the real extremes."

Nevertheless, clinicians and patients still must wrestle with psychological factors that affect their decisions. One of the most difficult is faced by women at high risk for breast cancer — should they have prophylactic mastectomy? And if they do, can they be sure they will not get cancer, given the uncertainty over the surgery’s effectiveness? (See News, Oct. 16.)

Prophylactic mastectomy is relatively uncommon, and there are no reliable data to confirm or deny suspicions that psychological factors result in over-utilization of the procedure. Two studies, however, suggest that worry is a strong motivator. In one study, women with or without a family history of breast cancer were asked to choose either regular monitoring or mastectomy when presented with vignettes about women at increased risk of breast cancer, said investigator Michael Stefanek, Ph.D., at the University of Maryland in Baltimore. The study found that women who reported more worry about breast cancer were more likely than the others to recommend mastectomy, as were those women whose estimation of cancer risk was much higher than the actual risk.

In another study, Stefanek and colleagues evaluated 164 women with a family history of breast cancer who were asked to choose either regular monitoring or mastectomy when presented with vignettes about women at increased risk of breast cancer, said investigator Michael Stefanek, Ph.D., at the University of Maryland in Baltimore. The study found that women who reported more worry about breast cancer were more likely than the others to recommend mastectomy, as were those women whose estimation of cancer risk was much higher than the actual risk.

Stigma

With cervical cancer, research has shown that anxiety causes some women with abnormal Pap smears not to comply with treatment. Now it appears there may be problems with overtreatment as well. Clinicians report anecdotes of overtreatment related both to anxiety and to the stigma of possibly having a cancer linked to a sexually transmitted disease. (More than 90% of cervical cancers are associated with human papillomavirus infection.) But data are scarce.

The overtreatment issue involves precancerous Pap smear abnormalities known as ASCUS (atypical squamous cells of undetermined significance) and...
LSIL (low-grade squamous intraepithelial lesions). Experts disagree on whether to treat these conditions aggressively or with watchful waiting. The National Cancer Institute's ASCUS LSIL Triage Study (ALTS) aims to resolve the issue. But even without ALTS, clinicians say it is apparent that anxiety, rather than informed consideration, drives some women to demand treatment that probably is not needed.

"Often we're dealing with a young, lower-socioeconomic-status woman who maybe isn't as educated, doesn't have the same support system as other women," said Patricia Braly, M.D., of Louisiana State University in New Orleans. Also, stigma is clearly involved with HPV infection, she said, "and I think that's the basis for a lot of the anxiety and demand to be treated."

Braly said better patient education is needed, but physicians often don't have the time or patience to explain various management alternatives, and simply treating a patient is quicker. "If you want to be crass about it," she said, "you can charge for that [treatment], where you don't charge for educating the patient."

Unnecessary Treatment

In some cases, physicians may be responsible for overtreatment by persuading patients of the need to treat low-grade cervical lesions that could be effectively managed by monitoring, said Diane Harper, M.D., at Dartmouth-Hitchcock Medical Center in Lebanon, N.H. Cervical cancer has a long latency, and a woman in her late teens with a low-grade Pap smear may not get invasive cancer until her thirties, or ever. But if her doctor suggests an aggressive approach, she will undergo numerous colposcopies, biopsies, and perhaps treatments during this time, Harper said, "on something that may truly have regressed on its own."

In the absence of consensus on managing low-grade Pap abnormalities, clinicians say it is especially important to include patient preferences in treatment decisions. At UC Davis, Melnikow is asking women with abnormal Pap smears which of six possible management approaches they prefer. ALTS will include a patient treatment preference questionnaire. And at the Medical College of Georgia in Augusta, researchers have already asked more than 500 women what they would prefer if they

VA Physicians May Take Part in More NCI Clinical Trials

Clinical investigators in medical centers run by the U.S. Department of Veterans Affairs will find it easier to participate in all National Cancer Institute clinical trials under the terms of an agreement signed by the two agencies last month. The agreement is part of NCI's broader effort to bolster the clinical trials system by involving major health providers, managed care organizations, and other groups in clinical research.

The 3-year joint demonstration, which goes into effect Jan. 1, paves the way for more NCI trials to be carried out in VA facilities and by VA physicians. In selected cases, VA will also pay the medical care costs of eligible veterans who enroll in NCI trials in non-VA facilities.

More than 50 VA medical centers are already affiliated with NCI's cooperative clinical trial groups. Under the new agreement, all VA facilities providing oncology services may apply for participation in the cooperative groups. Applications will be reviewed according to the usual peer-review process.

For VA centers that are part of academic medical centers, the agreement calls for more extensive participation in NCI's early clinical trials program for testing new drugs. It also provides for closer ties between the two agencies in planning clinical trials and proposes joint research efforts to address cost-effectiveness issues.

The new initiative encompasses all phases of NCI treatment, prevention, and diagnostic trials. In addition to cooperative group studies, the agreement applies to all trials reviewed and approved by NCI staff; studies conducted in clinical or comprehensive cancer centers under an NCI-approved protocol review and surveillance mechanism; and protocols performed under the direct support of an NCI peer-reviewed research grant.

"Developing an expanded pool of VA cancer researchers will strengthen our clinical research program across the board," said Robert Wittes, M.D., director of NCI's Division of Cancer Treatment, Diagnosis, and Centers.

— Caroline McNeil
had either an ASCUS or LSIL Pap smear. (If ASCUS, a majority of women chose a repeat Pap smear, but if LSIL, most wanted colposcopy, according to Daron Ferris, M.D. "It was a clear line drawn in the sand," he said.)

With prostate cancer, psychological factors may be causing many men to avoid treatment. But the issue is murky because experts do not agree on whether prostate cancer screening is appropriate or, if cancer is diagnosed, which treatment approach is best.

Health experts say that men's greater denial than women toward any disease may be especially pronounced for this malignancy. "With prostate cancer, there is this great fear of losing control of some of the intimate functions in one's life — potency and urinary control," said Mark S. Litwin, M.D., at UCLA. "And those cut very deep for many men."

Media attention recently to celebrities with prostate cancer — Gen. Norman Schwarzkopf and financier Michael Milken, for example — has helped persuade some men to seek screening and treatment, Litwin said. But many with signs of prostate cancer still avoid medical care. Investigators studying one prostate cancer screening program found that 10 months after getting abnormal results, most of the men still had not taken any action, said Edward DeAntoni, Ph.D., at the University of Colorado Health Sciences Center in Denver. When asked why, subjects generally reported "procrastination."

Arnon Krongrad, M.D., calls it "diagnostic drop-out." In a study at the Miami Veterans Affairs Medical Center, he found that 43% of men with abnormal screening results did not pursue prostate biopsy.

As in other cases where consensus is lacking, researchers are asking prostate cancer patients which management approach they prefer. Investigators with the Prostate Intervention Versus Observation Trial, comparing radical prostatectomy with watchful waiting for localized disease, are studying men who are eligible to participate but do not. Preliminary findings indicate that the majority decline because they do not want to be randomized, said Timothy Wilt, M.D., at the Minneapolis Veterans Affairs Medical Center, with treatment preferences fairly evenly divided between surgery and watchful waiting.

The researchers don't know why. But they are preparing a survey to uncover the factors, psychological or otherwise, that persuade men to make these treatment decisions.

And at UCLA, a handful of studies are under way to explore the ability of education and support to bring men into the management process and keep them from dropping out because of denial or some other psychological factor.

"It's a significant problem," Litwin stressed. "And if you lose one life because the guy was too embarrassed to come in, then I think that's a tragedy."

—Hugh McIntosh

Awards, Appointments, Announcements

The Association of Community Cancer Centers, Rockville, Md., recently presented its Award for Outstanding Contributions to Clinical Research — its highest honor — to Henry T. Lynch, M.D., director of the Cancer Center at the Creighton University School of Medicine, Omaha, Neb. Lynch was honored for his "pioneering work in establishing the hereditary basis for certain cancers and his leadership in developing the cardinal principles of cancer genetics."

The association also honored President Bill Clinton with its National Achievement Award for "his work to speed the drug approval process at the U.S. Food and Drug Administration."

Gorgas Medal

The Association of Military Surgeons of the United States, Bethesda, Md., named Robert N. Hoover, M.D., Ph.D., as recipient of the 1996 Gorgas Medal for his "outstanding research accomplishments in developing and directing a widely acclaimed program of epidemiologic investigation."

Hoover is director of the Epidemiology and Biostatistics Program of the National Cancer Institute's Division of Cancer Epidemiology and Genetics.

AARP Awards

The American Association of Retired Persons recently recognized five organizations for their work as AARP partners in breast cancer education.