be played back later, from the viewpoint of each participant, he said.

There probably are about 100 “serious” MOOs (as opposed to purely social ones) said Remy Evard, manager of advanced computing and networks at Argonne. “Most are private, behind a company firewall or limited to a small number of people.” Only about five research-oriented MOOs exist to Evard’s knowledge, including BioMOO, which caters to environmental researchers, so far there is no MOO for cancer researchers. “The cancer community as a whole doesn’t use this technology yet,” said Evard.

Getting a MOO started requires a lot of administration, noted Stevens. Cancer researchers probably wouldn’t want to maintain it, “but they could talk to us about getting access to part of the world we already run,” he said.

A certain social milieu is needed to establish a MOO, said Evard. “There are probably two reasons you would go, one, if there was a known expert you could talk to, or to hear a talk, or otherwise gain access to knowledge. The other is if your collaborator was there.”

As a resource for researchers, the internet is a rapidly moving target. Keep an eye on this space.

— David Holzman

Useful Internet Addresses

Cancer-Related Sites
   This site includes a list of 47 inherited disease genes by positional cloning under the “research projects” category.
4. For a listing of cancer discussion lists http://www.medinfo.org

Collaboratory Projects
1. Department of Energy Mathematical, Information, and Computational Science Division
   http://www.er.doe.gov/production/octr/mics
   There may be a call for proposals this month.
2. The Spectro-Microscopy Collaboratory at the Advanced Light Source
   http://www-itg.lbl.gov/BL7Collab.html
   This site includes information on a telepathology prototype that may interest pathologists.

Good Search Engines — Programs that allow Internet searches by names or keywords.
Alta Vista http://www.altavista.digital.com
Lycos, Inc. http://www.lycos.com
Open Text http://www.opentext.com/

Why Patients Enroll In Clinical Trials: Physicians Play A Key Role

Physicians play a critical role in their patients’ decisions to participate in clinical trials of high-dose chemotherapy with bone marrow or stem cell transplant for advanced breast cancer, according to an exploratory study by the National Cancer Institute. The importance of a physician’s recommendation was stressed repeatedly during small group discussions and interviews with 29 breast cancer patients, almost all of whom had participated in one of the NCI’s transplant trials.

“It was one of the most prominent themes to emerge from the interviews,” said Ellen Eisner, coordinator of the qualitative research study for NCI’s Office of Cancer Communications. The finding contrasts with the results of an earlier study using focus groups and interviews with community oncologists, who said they felt that patients often lost confidence in them when they suggested a clinical trial (see News, Oct. 18, 1995). The oncologists said their patients wanted definitive advice on a single, proven treatment.

“The problem is that when you introduce the concept of a randomized trial to a patient or a family . . . their impression is that you don’t know what to do
and therefore they want to find somebody that does know what to do," said one physician.

While it is not clear why patients and physicians have different perspectives on the confidence issue, the current findings do emphasize the oncologist's influence, noted NCI's Jeffrey Abrams, M.D., who helped oversee both studies. "It is clear that physicians need to be more aware of the critical role they play in patients' decision making," he said.

Both physician focus groups and patient interviews are part of NCI's effort to increase accrual to three high-priority transplant trials. Low accrual rates in two of the trials have delayed results by several years. Although the results of qualitative research cannot be generalized, Eisner said, they do give insights into incentives and barriers to participation in trials that are difficult to get through quantitative research.

Major Barriers

Two major barriers from the patients' perspective are problems with medical insurance coverage and the necessity to be away from home for an extended period. Physicians, too, said these were major obstacles to patients.

Physicians and patients also agreed on the sense of urgency that accompanies a diagnosis of advanced breast cancer. Patients want to start treatment as soon as possible, physicians said — one factor that may send them to treatments outside a trial. But even patients who did participate in trials reported feeling that they had to make a decision quickly. "I felt if I wanted to live, I wasn't going to putz around," said one participant.

There was little agreement, however, on the issue of randomization, long thought to be a barrier to participation in the transplant trials. Physicians said that the availability of transplants outside randomized trials is a major barrier, because many patients have made up their minds that a transplant is their best hope. This view is bolstered by a new report from the U.S. General Accounting Office that documents the growing use and insurance coverage of transplants (see sidebar, next page).
Physicians in some cases may also believe that a transplant is their patient’s best hope. Some patients said their physicians introduced the option of transplantation first as a promising treatment and only later within the context of a randomized clinical trial. But randomization evoked little concern among women in this study who had elected to participate in a trial. Very few of those interviewed admitted they would have left the trial if they had not been randomized to the transplant arm. Many participants had “assumed a spiritual attitude in terms of randomization, believing that God or fate would determine what was best for them,” according to the report on patient interviews.

Physicians, however, said that some patients “feel they are being manipulated if there is a possibility they will not be randomized to the experimental treatment arm.” Physicians also said that “it is hard to convince a patient to go on these trials when the study arms are so different (i.e., standard versus aggressive treatment).”

Abrams said that the two arms will not be so different in a new trial that NCI will launch this summer. In response to suggestions similar to those expressed in the focus groups and interviews, patients on both arms of the new trial will receive high-dose chemotherapy. However, one group will receive three drugs given sequentially with growth factor support while the other will receive high-dose chemotherapy with a transplant. Women in whom cancer has spread to four to nine axillary lymph nodes will be eligible for this trial, in contrast to the three current trials, which accept only patients with 10 or more positive nodes.

Is the informed consent procedure a barrier to participation? Yes, according to physicians, who said their patients were often frightened away from trials after reading about the risks involved. Patients admitted that the consent form was overwhelming and frightening. But many of those who decided to participate said they had been informed about the trial specifics by their physicians before seeing the form and had already made up their minds to participate.

“We think this suggests that providing patients with an adequate explanation of the trial prior to their seeing the consent form may make a difference,” said Abrams. “It underscores the time and effort required of a physician who participates in clinical research.”

Overall, the interviews confirmed “the high value and trust that patients place in their physicians’ recommendations,” the report concludes. “We’ll be looking for appropriate ways and times to communicate these results to oncologists,” Eisner said.

— Caroline McNeil

New GAO Report Says Insurance Coverage Growing for Bone Marrow Transplants

Many insurers are now covering high-dose chemotherapy with bone marrow or stem cell transplant for breast cancer, according to a new report from the U.S. General Accounting Office, even though the results of phase III trials of the procedure are not yet available. Twelve major insurers contacted by the GAO said that they based their decision to cover this treatment on preliminary clinical research but also on non-medical factors such as fear of litigation and adverse public relations.

Use of bone marrow transplants for breast cancer grew from about 500 cases in 1989 to 4,000 in 1994, according to figures obtained by the GAO from the Autologous Blood and Marrow Transplant Registry-North America. The growing use of the treatment has significant implications for health care costs, said the GAO. The procedure typically costs from $80,000 to more than $150,000, compared with approximately $15,000 to $40,000 for conventional therapy.

Lawsuits over insurance coverage for the procedure have received significant media attention in recent years. At least seven states have mandated that insurance companies, under certain conditions, provide coverage for transplants and seven more states have similar legislation pending. Moreover, the National Association of Insurance Commissioners is considering a model act for states that would set minimum standards of coverage for health insurers.

In the meantime, the GAO report has raised questions about the growing popularity of the procedure, noting that “the public is not well-served by the proliferation of an unproven treatment that is costly and possibly harmful.”

Scientists at the National Cancer Institute (NCI) said the report underscores the urgent need to complete studies of the controversial treatment. “The preliminary evidence on bone marrow transplants is based on small, mostly nonrandomized trials, which do not define the role of transplants in the treatment of breast cancer,” said Jeffrey Abrams, M.D., senior investigator at the NCI. “The GAO report clearly supports the need for large, carefully controlled, randomized trials.”

— Kara Davis

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