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Conference Explores Hype And Hope In Communicating Science News

BREAKTHROUGH! Occasionally, a news story acquires a life of its own.

Impact can be felt in a flash—as was the case earlier this month, when the switchboards at NCI and the nation's cancer centers lit up in response to a story about the promise of angiogenesis.

The story, which appeared in on the front page of the Sunday, May 3, issue of The New York Times, contained all appropriate caveats. Only an uncommonly knowledgeable reader could notice that the story's enthusiasm seemed excessive, considering that the drugs in question were yet to be tested in humans.

The history of cancer research in the US is replete with incidents of hype and hope soaring above the underlying science. An argument can be made that sometimes hype has served the public interest. If not for promises that the cancer cure was just around the corner, the National Cancer Act would have been a more difficult sell in 1971.

A recent conference organized by the NCI-Designated Cancer Centers Public Affairs Network made an attempt to examine hype-and-hope in the context of science and history. The conference—titled Breakthrough! How News Influences Health Perception and Behavior—brought together science writers, editors of scientific journals, scientists, patient activists, and public information directors of NCI-designated cancer centers to consider the nuances of genuine breakthroughs and their imaginary counterparts.

The conference considered the following case studies:

—*The National Cancer Act*: excessive promises vs. steady progress.
—Mammography screening guidelines: communicating uncertainty.
—BRCA1: genetic testing, public knowledge and fears.
—Cloning: the story of Dolly and the story of Richard Seed.
—Clinical trials: accurate interpretation of results.
—Alternative medicine: science or belief?

Under ordinary circumstances, public information officers are charged with aiding reporters and the public in distinguishing hype from science. In this special issue of **The Cancer Letter,** they are wearing a different hat, that of reporters covering the three-day conference that took place at Cold Spring Harbor Laboratory, Feb. 27-March 1.

The conference was co-chaired by Eric Rosenthal of Fox Chase Cancer Center and Jan Witkowski of Cold Spring Harbor Laboratory. The organizing committee also included Susan Cooper of Trudeau

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Institute, Dianne Shaw of the University of North Carolina-Lineberger Comprehensive Cancer Center, and Laurie Young of the University of Arizona Cancer Center.

Additional copies of this special issue are available through the public affairs offices of the NCI-designated cancer centers. Also, the text is available at no charge on **The Cancer Letter** web site: http://www.cancerletter.com/news.

The National Cancer Act: Early Promises Were Overstated

By Mary Jane Schier

Like it or not, smokescreens have been a part of the armamentarium in America's 27-year war on cancer.

On occasion, scientists have made promises they knew they couldn't keep, advocates have amplified those promises in their quest for funding increases, and reporters have made small victories seem like great breakthroughs worthy of top billing in the following day's newspapers.

Since no one appears to be proud of this history of breakthroughs that weren't, the conference session on the National Cancer Act produced a clear message: Cancer research is a continuum that requires balanced reporting and truthful interpretation by scientists, the media, institutional representatives, and special interest groups.

Vincent DeVita, director of the Yale Cancer Center and NCI director from 1980 to 1988, recalled misperceptions and excessive promises made in the early years of the country's assault on cancer.

Much of the news coverage of the 1970's erroneously promised that cancer could be cured within a few years if only enough money would be allocated to cancer research.

The war on cancer was compared to the targeted program that landed an American man on the moon in 1969, said Frank Rauscher III, chairman of the Molecular Genetics Program at the Wistar Institute. His father, the late Frank Rauscher Jr., was the second NCI director after the Cancer Act was implemented.

"The press and some scientists 'sold' the National Cancer Act with promises they made, which could not be fulfilled," Rauscher said.

Through a series of historic pictures from his family album, Rauscher remembered how then-President Richard Nixon declared the war on cancer and how other political leaders jumped on the cancer bandwagon. At the time, Nixon asked for frequent updates from the National Cancer Advisory Board and NCI officials, so he could point to the progress being made, especially when he ran for re-election in 1972.

Cristine Russell, a reporter for The Washington Post, said one of the biggest mistakes made in reporting the war on cancer was—and often still is—implying that cancer is one disease, which can be cured with a big breakthrough.

Russell was on a fellowship at the Washington Journalism Center in 1971 when she was introduced to the complex subject of cancer research.

Three months of reporting on the politics of cancer turned into her first article for The Washington Post, published about a month before Nixon signed the Cancer Act on Dec. 23, 1971. One segment of her story cautioned against false hopes based on the fact that the government was allocating additional funds to cancer research.

"Now, looking back more than 25 years, we know the language about the war on cancer was wrong and misleading," Russell said. "Calling the campaign a war implied that we would end it soon... yet the war on cancer is still going on today."

Over the years, many newspaper articles about cancer "were fragmented and scary," in particular, the numerous warnings about alleged cancer-causing

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compounds, Russell said. Such stories and other media reports suggesting that "virtually everything causes cancer led to what we labeled the 'carcinogen-of-the-week' syndrome... and prompted considerable public mistrust," she said.

Reporters rarely have the time to delve into the complex details when writing about cancer research. Russell said helping readers and viewers appreciate the context of reports about cancer should be every reporter's goal, no matter what the deadline.

A reporter prepared to explain the intricacies of cancer research and treatment knows that sometimes, "deciding not to write a story is as important as writing one," Russell said.

Waiting a day, a week, or longer, allows reporters to put complicated science stories in better perspective, she said. But even when writing near deadline, reporters should convey consensus about the subject, as well as conflicting views.

"We must teach the public how to deal with the uncertainties in science," Russell said.

Zach Hall, former director of the National Institute of Neurological Disorders and Stroke, echoed the need for balanced reports by scientists and journalists, as well as truthful claims from advocacy groups.

During Hall's tenure at NINDS, a controversy arose over funding for Parkinson's disease research. Some scientists and public interest groups made distortions about the amount of money needed for Parkinson's research, Hall said.

"We were not on the verge of a cure for Parkinson's disease, yet the advocates implied that if Congress would give us enough money, we could find a cure," said Hall, who left NINDS in 1997 to become associate dean for research and the Lange Professor of Physiology at University of California, San Francisco, School of Medicine.

Hall said misleading claims included the estimate of the number of Americans with Parkinson's disease. "There are about 500,000 people with Parkinson's disease in this country, but the advocates claimed at least 1 million," he said.

Ellen Stovall, executive directror of the National Coalition for Cancer Survivorship, said scientists and journalists have a responsibility to help the public "understand the whole spectrum of science from the laboratory bench to the patient's bedside, yet this spectrum is often ignored."

In 1994, Stovall served on a panel that reviewed the National Cancer Program. One of the panel's conclusions was that, "we are not applying what we already know works to people in this country," she said.

From her experience as a cancer survivor and advocate, Stovall said she learned that, "The American people want the truth about cancer."

Several conference speakers and participants agreed that communicating complex information about cancer presents a particular challenge for daily television, cable, and radio reporters facing fast deadlines and limited air time, often as few as 90 seconds, to tell a story.

Television reporters especially insist on having cancer patients in their reports, even when the news involves preclinical research.

This presents an ethical dilemma for the public affairs staff at research institutions, who are asked to find the patients for the reporters to interview. While some cancer centers have policies opposing this practice, others work with researchers to help find appropriate patients.

Mary Jane Schier is the university editor and senior science writer at the University of Texas M.D. Anderson Cancer Center.

When Scientists Can't Agree, What's The Press To Do?

By Susan Edmonds

At what point does science provide sufficient evidence to make a public health recommendation?

In the case of mammography screening for women between ages 40 and 49, the data were not clear. Answers depended upon the level of evidence of efficacy for screening that one was willing to accept, according to speakers at the "Breakthrough!" conference session on the mammography debate.

For journalists and the public, the questions were: How do you view the conclusions drawn by statisticians, clinicians, radiologists, breast cancer advocacy groups, and other health organizations? Are these messages credible? If the "experts" can't agree, what should women in the 40-49 age group do?

Even the terms used in the mammography debate, such as "false positive" and "false negative" are confusing and often interpreted differently by scientists, said session moderator Richard Horton, editor of The Lancet.

"In the Lancet, we shun the word 'conclusion' and use the word 'interpretation,' because it seems that no point of view is ever going to be conclusive,

no debate is ever going to be concluded," Horton said. "But some scientists and others would have it a different way. They will tell you the debate is over. They forget that sometimes doubt and skepticism can strengthen our arguments, not weaken them."

Developing a statement on mammography screening was challenging because of the uncertainty in the data, said Barbara Rimer, who until last fall was chairman of the National Cancer Advisory Board and is now director of the NCI Division of Cancer Control and Population Sciences.

Statisticians and epidemiologists require evidence from randomized trials for any public health recommendation, Rimer said. Ideally, developing guidelines about cancer screening would be a rational process largely based on evidence, which would be graded, starting with the highest level of evidence, the randomized, controlled trial.

However, systems of rational assessment do not factor in public perceptions, advocates' preferences, and consumer involvement in decision-making, Rimer said. "As a society and as individuals, we don't make global decisions about medical priorities," Rimer said. "We take our medical tests and make our medical decisions one by one."

Twice NCI used "rational assessment" systems to develop statements on mammography screening for women in their 40s. In 1993, a panel of experts developed what became known as the "Fletcher report," and in 1997, an NIH Consensus Development Conference issued a consensus report. Both panels decided not to make global recommendations for screening women in their 40s. And in both instances, the reports were criticized for not factoring in public perceptions.

Even worse, the press and the public found it difficult to believe that the processes were not politically tainted in some way, said Rimer, who served on the Fletcher panel in 1993. "As hard as it was for people to believe at the time, we conducted that process in isolation from the political process that was swirling around us," she said. "It was stunning to me that as soon as the report was released, the popular conclusion was that we had capitulated to President Clinton and HHS Secretary Donna Shalala as part of health care reform."

Process Of Decision Making Vs. Politics

One reason for the political story line was the unclear process NCI used to reach its 1993 decision, said Kirsten Boyd Goldberg, editor and publisher of **The Cancer Letter**. As a result, "politicians and special interest groups were able to rush in to the communication void and wrest control of the story," Goldberg said.

Reporters preparing stories on the 1993 Fletcher report received press releases and letters attacking the report from radiologists and health groups that favored screening.

These organizations argued that evidence from trials, though not statistically significant, still "inferred" a benefit for younger women, Goldberg said. "This 'inferential' benefit was, in effect, what NCI and ACS had based the 1987 guideline on for women in their 40s." Thus, reporters questioned why NCI was backing away from the earlier guideline, in the face of little change in the evidence.

Not clearly communicated at the time was a decision by NCI to demand statistically significant evidence from randomized clinical trials—rather than the earlier inferential evidence—not only for mammography, but for all cancer screening methods, Goldberg said.

This policy change officially took place on NCI's Physician's Data Query database, which stopped referring to screening guidelines, instead issuing "summary of evidence statements" about cancer screening methods.

"Had NCI officials been forthright in communicating that they were changing the rules of the game, and why they were changing the rules, rather than hiding it in the depths of PDQ—which is obscure even to some oncologists—the process of developing a statement on screening mammography might not have been so confusing and contentious," Goldberg said.

News articles might have focused on the process and problems inherent in issuing public health guidelines based on constantly-changing data from screening studies. Instead, articles emphasized questions such as, "Will women be confused? Was NCI taking away hope?" Goldberg said.

In response to special interests or their own medical values, members of Congress attacked the 1993 NCI decision to abandon the screening recommendation for younger women. A similar dynamic took place during the mammography debate of 1997.

In 1997, new data from studies in Sweden caused NCI to decide to re-examine the 1993 statement. The NIH Consensus Conference, however, became a "communications disaster," Goldberg said.

First, the conference was highly charged emotionally, because the stakes seemed so high to the scientists, physicians, and advocates who attended. Second, the three-day conference left little time for the panel to review the evidence and prepare a thorough report. Third, it seemed that NCI already had an idea of recommendation it preferred. When the consensus report was released, NCI Director Richard Klausner said that in his opinion, the studies had reached statistical significance, there was enough evidence to recommend screening to younger women, and the NCAB would advise NCI on what to recommend to the public, Goldberg said.

Susan Braun, president and CEO of the Susan B. Komen Foundation, said too much was expected of the consensus conference. "Asking the panel, overnight, to take a lot of unresolved information and put it into a report by the next morning, was untenable," she said. "The results of that played out in the press, in Congress, and in public."

Rimer said the NIH consensus model has become outmoded. "Science has become too complex to ask any group of individuals to try to debate overnight and turn out a credible report the next day," she said. "We have to develop a model that allows that process to happen over weeks."

Rimer led the NCAB review in 1997 to formulate a statement about mammography screening for NCI. "As we were debating, the political pressure increased, and many of us started receiving calls and apparent threats from legislators," Rimer said. "At one point, I wrote to Sen. [Arlen] Specter (R-PA) and offered to resign if this continued."

In statements widely quoted in the press, Specter, chairman of the Labor, HHS & Education Appropriations Subcommitee, made thinly veiled threats to block or reduce NCI funding if the NCAB did not produce a recommendation for screening.

"The part of it we have to guard against as citizens is threatening to take away the allocation of a science agency because [Congress] doesn't like a decision," Rimer said.

Political pressure had the opposite effect, she said. "We were all so mad that they were threatening us that it gave us a bonding and an ability to withstand the pressure in a different way than they ever expected. Our reaction was, we'll be damned if we'll let Congress make our decisions for us."

As soon as the report was issued, the NCAB was portrayed by some journalists as a non-scientific group that had caved in to political pressure, Rimer said. "Association was seen as causation," she said.

Simplify, Without Becoming Simplistic

Not well reported was the fact that when the NCAB statement came out, most groups involved in the controversy were starting to agree that the data showed about a 17 percent decrease in breast cancer mortality as a result of mammography, Rimer said.

"The interesting point turned on whether this decrease justified a recommendation for screening," she said. "On a strictly medical basis, the NIH panel had come down on the side of informed decision-making. But consumers and other non-screening experts on the NCAB came down in favor of screening."

"In an area of medical uncertainty, the fact of the matter is, either position could be justified," she said.

Results of content analysis of 233 stories in the print media on the 1997 mammography controversy found that the coverage left out some important, but complicated, concepts, Rimer said. These included the limitations of mammography, false negatives, false positives, difficulty of breast cancer detection in dense breasts, and the recommendation that women over 50 should get screened. Only 22 percent of the stories provided absolute numbers, rather than relative numbers, which tend to oversell screening, she said.

"You in the media have a challenge, as medicine becomes more complex, to simplify without becoming simplistic," Rimer said. "You can help people to understand that science evolves, data change, and that significance often is in the eye of the beholder."

Braun said organizations like the Komen Foundation play a role as translators of scientific information to the public. The organization advocated screening for women in their 40s, she said.

The recommendation to women to make a decision after consulting a health professional "is something of a middle-class concept," Braun said. "There are many people who don't have a doctor, who don't have access to the information, and if they did, it wouldn't be on the top of their priority list to sit down and analyze it."

The foundation's offices reported "mild confusion" during the 1997 controversy, Braun said. "Those who were looking for reasons to no longer be screened, got them," she said. "Those who were

looking for reasons to set up guidelines favoring screening for women in their 40s got them. And those who were without information or a doctor decided not to decide."

Journalists could do a better job of covering the different cultures or belief systems within science and medicine, and of separating evidence from opinion, said Cristine Russell, of The Washington Post. "The other challenge is the 'true believer' problem. It's really hard as a journalist to say, in parentheses, this is a true believer, and this is someone who is more skeptical because they come from a different part of science."

Susan Edmonds is media relations manager at the Fred Hutchinson Cancer Research Center.

Genetic Testing: Few Answers For Public Questions, Fears

By Darrell Ward

When medical researchers discovered the BRCA1 and BRCA2 mutations that predispose women to breast and ovarian cancer, the findings were greeted with the excitement and fanfare such advances deserve.

Tests for the mutations quickly followed, as did questions about social, ethical, and psychological implications of those tests and their clinical usefulness.

If a woman tests positive for a BRCA1 or BRCA2 mutation, "what does she then do with that information? Even more important perhaps, what does her physician make of that information?" asked Ellis Rubinstein, editor of Science, and moderator for the session "Genetic Testing: BRCA1 as Case Study," which explored these issues.

Steven Narod, a member of the team that discovered BRCA1 and BRCA2, provided the case for testing for BRCA mutations. Carriers of BRCA1 mutations are estimated to have an 85 percent risk of breast cancer and a 45 percent risk of ovarian cancer by age 75. Carriers of BRCA2 mutations may have an 80 percent risk of breast cancer and a 27 percent risk of ovarian cancer by age 75.

Hereditary breast cancer is thought to account for three to five percent of all breast cancers, and up to 11 percent of all invasive ovarian cancer, Narod said.

Whether BRCA testing can reduce morbidity and mortality in carriers remains unknown, largely because most options for preventing breast and ovarian cancer have limited or unproved effectiveness. Strategies available for reducing the risk of breast cancer are prophylactic mastectomy, mammography screening, and chemoprevention, but no method is perfect.

"There is no conclusive evidence that prophylactic mastectomy works," said Narod. Furthermore, the psychological, sexual, and cosmetic consequences are severe.

Mammography may provide a 17 percent reduction in mortality in women under 50, Narod said. "But when faced with an 85 percent risk of breast cancer, a 17 percent reduction is not a solution to the problem," he said.

Chemoprevention using tamoxifen is one possibility that has been shown to reduce the incidence of breast cancer in high-risk women.

The options available for preventing ovarian cancer are prophylactic oophorectomy, ultrasound or CA125 screening, and chemoprevention using birth control pills, Narod said.

Prophylactic oophorectomy has not been tested in randomized trials, and screening for ovarian cancer has yet to be proven effective. "Most of the data for CA125 show that it is not effective, and the jury is still out on whether ovarian ultrasound reduces mortality for these carriers," he said.

Taking birth control pills for six or more years can reduce the risk of ovarian cancer in the general population by 60 or 70 percent, Narod said. "Our early data show a similar effect in carriers of BRCA1 mutations," he said.

Barbara Biesecker, director of the genetics counseling branch of the National Human Genome Research Institute, said there are few answers for women who test positive for BRCA mutations and ask, "what now?"

"We're in this awkward interim period where we can make predictions about people who are at increased risk before we can offer them [recommendations] to reduce their morbidity and mortality," Biesecker said.

In addition, counselors do not have enough information to answer questions regarding the risk of losing a job or health insurance as a result of testing. So far, these fears are based on stories people have heard, Biesecker said.

The same fears cause people not to participate in certain research protocols. Even when they do participate, it may be difficult to provide equitable services to everyone in an extended family. Some

family members may be located in rural areas far from a research center.

Laboratory resources present similar problems. BRCA testing is not available at every laboratory, and in some cases the results can be rendered uninterpretable.

Areas that require study include whether test results motivate individuals to obtain screening or an appropriate intervention, and how testing affects family relationships, particularly when one sister tests positive and another tests negative, Biesecker said. A better understanding is needed of why a positive result is life-altering information for some people, while others "barely shrug their shoulders, make a decision, and walk out of the clinic," she said.

Biesecker urged the science writers to help "get *the providers interested* in learning more about genetics."

"It takes providers a long time to get up to speed in genetics," said Biesecker. "They are going to need it not just for BRCA1 and BRCA2, but for all the genetic testing that is coming down the pike."

Biesecker questioned the assumption being made by many physicians, primarily oncologists, that predictive testing is beneficial to all patients. "Somehow, we have this idea in our information age that for some people to choose not to get this information is burying their head in the sand," she said. "In fact, people might be comfortable with their circumstance and not want to find out that they have an 80 to 90 percent lifetime risk of developing breast cancer."

Leslie Alexandre, senior vice president for corporate affairs, OncorMed Inc., questioned to what degree genetic testing might be responsible for discrimination against cancer patients. "There is no question that the fear of losing health insurance or being discriminated against in employment is one of the greatest barriers to people being tested," she said.

People with cancer experience tremendous discrimination already, she said. "If insurance companies want to discriminate, all they have to do is ask on their forms whether your mother, father, or any first-degree relatives have had cancer."

Andrew Holtz, a freelance producer and a former CNN medical correspondent, noted that every time he does a story that mentions the concern about insurance and employment discrimination, he is raising those fears.

"[Journalists] are not in a position to withhold that information," Holtz said. "It's out there and the more we discuss it, the more concerned we're going to be, and then it falls into the lap of the policy makers to do something about it."

BRCA1 is a prototype of what's going to happen in the future, Holtz said. "The decisions that are made about the information—the insurance and employment questions, the gene-testing decision trees—are basically the same, no matter what the gene, no matter what the disease."

Darrell Ward is a senior medical writer at The Ohio State University.

How Dolly Made Front Page And A Physicist Got Air Time

By Lauren Ward

Along with addressing the fundamental human dream of immortality, the story of cloning revealed the competitive pressures that shape news coverage and defined a great divide that separates the culture of journalism from the culture of science.

At the session on the coverage of cloning, science reporters Gina Kolata of The New York Times and Joe Palca of National Public Radio described the criteria that shaped their coverage of the cloning story. Presenting the scientists' perspective, Carol Greider, a molecular biologist from Johns Hopkins University who serves on the National Bioethics Advisory Commission, and Jan Witkowski, director of the Banbury Center at Cold Spring Harbor Laboratory, said cloning was the next logical step in genetics research, and that the sheep experiment was yet to be replicated.

Given these caveats, was the story responsibly reported to the public?

The Making of Dolly

Kolata broke the story of the cloning of Dolly the sheep after receiving a summary of an upcoming issue of the journal Nature. Such summaries are routinely distributed to reporters in advance of publication.

According to the summary, the journal planned to publish a paper by British scientists Ian Wilmut and Keith Campbell. The summary did not use the word "cloning," Kolata said.

"You really had to read between the lines," she said. "It didn't say any of the buzz words we all started using later."

After receiving the full journal article under an

embargo, Kolata spoke with Wilmut, promising to the scientist and to Nature editors that the Times would not break the embargo. Nonetheless, Kolata prepared her story in the event that someone else broke the embargo.

Kolata filed her story six days before the Feb. 27, 1997, Nature publication date. "We at the Times decided that this paper was so shocking and so incredible that we had to be prepared just in case somebody else broke the embargo," she said.

Indeed, the London Daily Observer, a tabloid, broke the embargo over the weekend. The story was out, which meant the Times could proceed with the Kolata story.

Thus, the cloning story appeared in the second edition of the Sunday, Feb. 23, issue of The New York Times. Dolly was a runner-up to a story on the capital gains tax.

"By the third edition, they had decided cloning was more important than capital gains," Kolata said, and the story made the upper left-hand column.

What followed was a frenzy of news stories over the next few months.

Cloning Humans?

NPR reporter Joe Palca said that initially he failed to recognize the value of the Dolly story.

On Feb. 23, 1997, an NPR weekend editor alerted Palca to the Dolly story appearing in the London Observer, but failed to mention its appearance on the front page of The New York Times and its impending publication in Nature, Palca said. Those two factors could have spurred Palca into taking the story seriously, he said.

Nearly a year later, on Jan. 6, NPR reported that an unemployed physicist named Richard Seed declared his intent to clone humans.

Palca first became aware of Seed's claims several weeks earlier, after Seed addressed a scientific meeting. The claims failed to electrify Palca, he said. "I thought there's no way that some rational person would stand up and say 'I'm going to clone a human being' and it's going to be worth paying attention to," Palca said.

However, Palca's editor was interested in the story. Digging through the archives, Palca found that Seed had caused a "mini-media frenzy" in the early 1980s when he announced his plan to open fertility clinics around the country.

"One definition of what is news is something that your editor's interested in," Palca said.

Finally, Palca visited Seed and his collaborators, including an infertility specialist, in Chicago. Nothing was in place to begin human cloning. However, Palca said, "I asked (the fertility specialist), what if Richard Seed puts the money together to open a practice in a place that doesn't have any prohibitions?" The infertility specialist replied that he could offer cloning to good patient candidates, according to Palca.

"At that point, I decided that this was a story," Palca said.

In his remarks, Palca acknowledged that Seed lacked a clinic, patients and other aspects that would lend the story credibility. However, Palca said, "Seed put a face on the idea of human cloning. I'm not troubled that he may not have the expertise.

"He may have the vision," Palca said.

In the case of Richard Seed, NPR decided to serve as its own publicist.

In an unusual move, NPR issued a press release about the story, Palca said. "NPR felt—maybe it's an inferiority complex from being an evanescent medium—that they wanted to alert media that we had this big scoop," said Palca.

The press release made Palca uncomfortable, he said. However, the strategy was successful. Hours after the press release came out, CNN called to interview Palca on the Seed controversy.

The New York Times waited until the day after NPR ran the story on Seed before publishing one of its own.

"We didn't write about it that day because it didn't come up to the standards of what we would do," said Kolata. She added, however, that a strong case could have been made for doing the story.

The Kolata and Palca stories point to a fast-paced, competition in reporting science.

"We need to do these things instantly," Kolata said. "We are not in the days when journalists have the luxury of deciding on their own what to do, because once the competitive pressure gets going we all have to write those stories whether we like them or not."

As they make news judgments, media outlets cannot afford to ignore public perceptions, Kolata said.

"If we don't write about something, people will not say that's because it doesn't meet their standards," Kolata said. "They will say that's because The New York Times is asleep."

The Public Reaction

The stories about Dolly the sheep and Richard Seed provoked unprecedented discussions in bioethics, scientific, political, and lay circles.

Pointing to provocative headlines in The New York Times and Newsday, Witkowski said the media have been responsible, at least in part, for creating a climate of "genetic determinism."

"That we are simply what our genes are is nonsense," Witkowski said. "Maybe the whole of the media have a responsibility to educate their headline writers that these headlines are not appropriate."

Greider said it would have been preferable to "use this particular story to educate the public about genetics rather than fueling fears of science fiction writers."

Many people who readily condemn the idea of cloning do not understand the implications of the story, Kolata said.

"The question should be, here are some applications of cloning," Kolata said. "Taking these applications, what do we think of them, do we like them or not like them, and if so, why and how do they compare with things that we already think are O.K. or that we tolerate because they are already out there."

"The most egregious apocalyptics [came] from the community of bioethicists," said Robert Cook-Degan, staff director of the National Cancer Policy Board at the National Academy of Sciences and moderator of the panel.

Clashing Cultures

While Kolata and Palca said they were awed by cloning as a fundamentally new research advance, Greider and Witkowski were less mesmerized.

"The overwhelming perceptions among basic scientists were 'What's the big deal?'" said Greider, who noted that Dolly is the only such clone to date. "Scientists are skeptical until they have evidence that it's reproducible," she said.

"I still don't know why this became such a media event," agreed Witkowski.

Journal editors Marcia Angell and Ellis Rubinstein challenged the notion that the cloning story was routine. "I hope that curiosity has not left the halls of Cold Spring Harbor," said Rubenstein, editor of Science, responding to Witkowski's remark. "The scientific community was stunned by the [cloning] research." In fact, Rubinstein said, Science named cloning the "breakthrough" of the year.

The implications of cloning research reach beyond the lab, said Angell, executive editor of The New England Journal of Medicine.

"The human story is colossal," she said. "It speaks to some of the most profound human urges we have: to immortality."

Lauren Ward is an associate director of the news bureau, University of Pittsburgh Medical Center.

Stories On Clinical Trials Can Have *Unintended* Results

By Joe Michaels

Few people would challenge the view that clinical trials are the cornerstone of medical research. However, only 2.6 percent of all cancer patients in the US enroll in clinical trials.

Why so few? Could this be because scientists have not learned to use the media effectively? Or is this because clinical trials are too complicated a concept for much of the public to grasp, especially while confronting a life-threatening disease?

"Increasingly, reporting health news is a matter of reporting the results of the latest epidemiological studies," said Marcia Angell, executive editor of The New England Journal of Medicine at the session that addressed the barriers to recruitment to clinical trials.

The relevance of many findings eludes reporters and clinicians, Angell said. Consider a recent study that found that in 40,000 patients tPA increased survival following a heart attack from 93 percent, while the widely-used Streptokinase increased survival to 94 percent.

What relevance does this finding have to emergency medicine? None whatsoever, said Angell. "I hope no doctor asks a patient having a heart attack which drug they would rather have," she said. "P-values are no substitute for common sense."

Though there are many types of clinical trials—single arm, prospective randomized, double blind-crossover, nested case control, cohort study, historical control, and meta analysis—and none of them is perfect, said Robert Young, president of Fox Chase Cancer Center.

Young said a clinical trial can be vulnerable because it is based on a wrong hypothesis, fails to enroll enough patients to reach statistical significance, or has insufficient power or confounding factors, and there is a chance of false positive. "Scientists are people, too," Young said.

"They are subject to error, bias, fame, fraud, and greed."

Finally, there are inherent problems in interpreting results, especially in large studies. "You get to the point when a statistical benefit exceeds the biological benefit just on the basis of adding more and more patients to a trial," Young said. "You have to be careful about p-values. They are important, but not the end-all and be-all of the differences in the benefits."

Kathy Crosson of the NCI Patient Education Branch, Office of Cancer Communications, pointed to a communication gap between scientists and the public, as well as physicians and the public.

According to opinion research conducted by NCI, Americans have a high level of interest in medical and scientific discoveries and health.

Americans think research is equal to or slightly more important than other national issues, and they give cancer the highest priority for funding among diseases, Crosson said.

However, the public does not know how research priorities are determined, Crosson said. There are misconceptions about placebos.

What makes patients decide to join a clinical research study? "Patients who enroll often make the decision to participate quickly," Crosson said. "Often their physician's recommendation is the most important factor, with family support as the second biggest influencer."

In addition, language matters. Commonly-used terms are often misunderstood and, while no one term is preferable to "clinical trial," less scientific language is better, NCI studies found. Crosson advised avoiding the term, "state-of-the-art," because the public finds it sounds "too military." Instead, use positive words and messages such as, "progress," "benefits," and "hope," she said.

At times a story that begins as coverage of results of a clinical trial becomes unrecognizable by the time it appears in the newspapers, said Otis Brawley, director of the NCI Office of Special Populations Research. Illustrating the potential damage from misleading headlines and incomplete reporting, Brawley presented a case study of coverage of a head-to-head trial of two drugs for benign prostatic hyperplasia.

In August 1996, a study published in the New England Journal of Medicine reported that the drug Hytrin (terazosin) was more effective than the drug Proscar (finasteride) in BPH. The journal article and an accompanying editorial emphasized that the findings were relevant to men with small prostates.

Unfortunately, the Associated Press chose to avoid getting bogged down in details. Instead, the wire service ran a short news story that included a punchy quote from a urologist who co-authored the NEJM paper.

The urologist described Proscar as "useless" and not better than "an expensive placebo." The story failed to mention that the findings were relevant only to men with small prostates and had no relevance beyond BPH, Brawley said.

As copyeditors nationwide focused on the quote, the story acquired punchy headlines including "Proscar Is No More Than An Expensive Placebo" and "Prostate Research: 1 Drug Useless."

"The small-prostate aspect of the study was buried or cropped entirely by the media that ran the AP story," Brawley said. Some newspapers cut the story so severely that the disease for which Proscar was allegedly useless was simply left out, Brawley said.

Still, the story had an impact, albeit one that was unintended. The headlines caused apprehension among participants of the Prostate Cancer Prevention Trial, which was studying the ability of Proscar to prevent prostate cancer.

After the story appeared, about 10 percent of the nearly 19,000 men enrolled in PCPT dropped out of the study. Though some were ultimately convinced to return to the trial, "significant harm was done to a $60 million, very important prostate cancer prevention study and to public health," Brawley said.

Headlines are problematic, agreed Richard Saltus, science writer for the Boston Globe. "There are pressures at every stage of the news gathering and reporting process," he said.

For instance, editors often push science writers to give a story more impact by making the results sound more dramatic, he said.

"Clinical trials are challenging to report," Saltus said. Concepts as meta-analysis, multivariate analysis, and subgroup analysis are difficult to explain in an article. However, while "science reporters and editors are educable," their mission as journalists is "not to put best face on clinical research or try to encourage people to sign up," he said.

Saltus said he regrets not being able to do more "disease-of-the-week" stories, because a story on a rare disease may raise awareness and help people whose illness has not been diagnosed.

Richard Horton, editor of The Lancet, said he would like to see the news media report more in-depth on medical research. "We need to be more investigative," Horton said. "There are usually several stories behind the story. We need to ask, 'Why was study funded? Why was the result published in this journal?'"

Joe Michaels is director, marketing and public relations, Barbara Ann Karmanos Cancer Institute.

Alternative Medicine Tests The Boundaries Of Science

By Avice Meehan

Evidence versus belief. Validity versus value. Placebo versus the "real thing." Help versus harm. These paradoxes—and others—divided a panel convened to discuss the appeal (or danger) of alternative medicine.

"We need to find that common ground where unorthodox solutions can be considered and brought into the mainstream," said Zachary Hall, former director of the National Institute of Neurological Disorders and Stroke, who is now the associate dean for research and professor of physiology at the University of California at San Francisco.

"The placebo effect is very real and undoubtedly has a biological basis," Hall said. "One also wants to be careful about destroying the belief system of a patient that may be helpful—as long as it is not harmful."

Common ground was, however, in short supply, with Marcia Angell, executive editor of The New England Journal of Medicine in one camp and Wayne Jonas, director of the NIH Office of Alternative Medicine in the other. The challenge for journalists, noted Paul Goldberg of The Cancer Letter and science writer Victor Cohn, is figuring out how to navigate between fact and hype.

Claiming the high ground for allopathic medicine, Angell drew a sharp distinction between medicine subject to empirical proof and "remedies that are scientifically untested and biologically implausible, to boot."

Angell said the current popularity of alternative medicine is a return to the past when efficacious remedies, such as the herbs foxglove and poppy, were used without a full understanding of their medical properties, and wholly useless remedies such as leeching or purging held sway.

"We now have powerful methodological tools to efficiently test safety, efficacy and dose effects, within a method intended to correct for bias," Angell said. "The results have been spectacular. What we see now—the new emphasis on alternative therapy—is a retrogression, a reversion to the anecdote and speculation method of testing. Ironically, this is occurring at a time when scientific medicine is making its greatest advances."

Angell said alternative medicine is more of a religious movement than the medicine of the future. As such, it is dominated by charismatic or prophetic figures. These prophets, she observed, appropriate language from other scientific disciplines, including quantum physics, and combine it with mysticism and a "large, arcane vocabulary" to promote "biologically implausible" medical approaches that range from "therapeutic touch" to homeopathy.

"Alternative medicine is a system of belief," Angell said. "Alternative medicine is not an alternative to medicine, but an alternative to religion in a secular age. And it's not a very pretty religion." Rather, alternative medicine, said Angell, is "fundamentally narcissistic."

"Questions about the physical world must be answered with the scientific method," Angell said. "All proper remedies should be subject to the same methods.

"There is medicine that works and there is medicine that may or may not work."

The Argument For Alternative Medicine

OAM director Jonas agreed that "we must use good science" in validating the claims of alternative or complementary therapies. However, he outlined a fundamentally different paradigm for that research.

"Does alternative medicine work? This really is a bad question in terms of science," Jonas said. "We would not today ask, 'Does surgery work?' One has to get into the details, where the devil is."

Jonas outlined a series of premises that must be taken into consideration. They included:

—We have an incomplete knowledge of the world.

—Research methods evolve.

—Research rarely provides unequivocal information.

—Good research minimizes chance, bias and confounding.

—Many of these treatments do more good than harm.

"People are set up and susceptible to abuse in

these areas because there is so little known," Jonas said. He characterized the interest in alternative or complementary medicine as a "publicly driven movement."

Jonas argued that it is important to match research goals and methods, and proposed an "evidence pyramid" that juxtaposed validity (derived from empirical analysis) and value (derived from analysis of effect). Patients are looking for different information than physicians, he said.

Jonas also observed that the discussion of the efficacy of alternative medicine represents "an interchange of cultures in which knowledge and belief go back and forth."

"Randomized clinical trials are clearly the way to go and a number of groups want this type of information," he said.

OAM is about to begin a clinical trial to examine whether St. John's wort, or hypericum, is effective in treating depression. The trial, which will be done in conjunction with the National Institute of Mental Health, will use purified St. John's wort as opposed to the highly variable preparations currently available for purchase.

Jonas noted that one definitional challenge within alternative medicine is that it is a "garbage bag" of items thrown together. It includes everything from the "frontier" (psychic healing and homeopathy) to "emerging" therapies (herbal medicines) and the "complimentary or alternative related" (biofeedback).

The Office of Alternative Medicine funds 10 centers around the country and is working with other institutes within NIH. Jonas said OAM receives more than 1,300 inquiries a month and the vast majority of these (78 percent) are inquiries related to cancer.

Covering Alternative Medicine

Paul Goldberg, editor of **The Cancer Letter**, said that while Jonas often speaks of the need for rigorous testing of alternative intervention, his view of allocation of resources in science is at times puzzling. As an example, Goldberg read a passage from Jonas's paper in Nature Medicine of August 1997:

"Is it possible... that specific non-molecular information can be stored and transmitted through water or wires as claimed in homeopathy? Even though this concept is implausible, the potential implications it holds for understanding basic biological and cellular communication are enormous."

"This statement leads me into the wilderness," Goldberg said. "I don't know the difference between saying this and saying, `Is it possible that Dolly-the-cloned-sheep can fly? Even though this concept is implausible, the potential implications its holds for national security are enormous.'"

"Alternative medicine is becoming an avalanche, an avalanche that can hurt some people," said Victor Cohn, former science editor at The Washington Post and now affiliated with the Harvard School of Public Health. "People can be scammed in their final months. What should journalists do? Look for facts and reliable evidence. The way someone answers questions can tell you a great deal."

Cohn, author of "News and Numbers," a handbook for journalists, said that, "proof of anything requires more than miracles." The challenge for writers attempting to make sense of the claims of the proponents of alternative medicine is "that we cannot prove a negative."

"We cannot prove that little green aliens from Mars are not inhabiting this room at this moment," Cohn said.

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