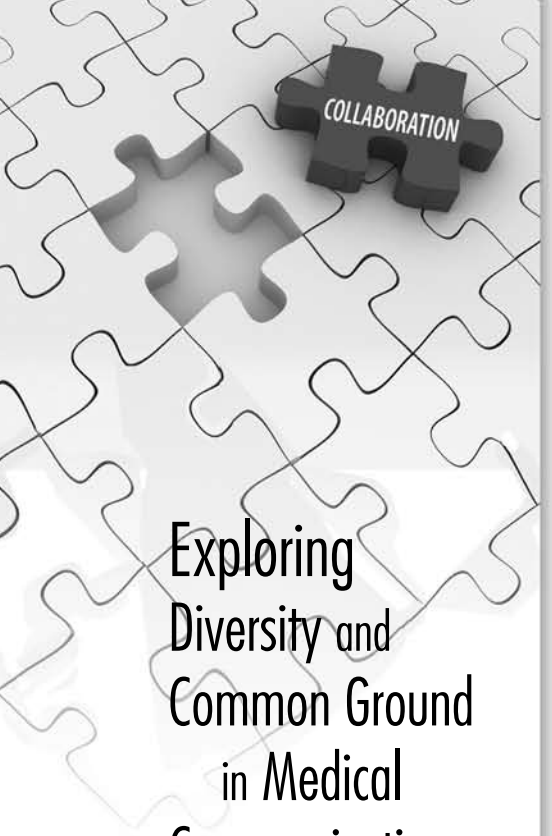

Exploring Diversity and Common Ground in Medical Communication

This article is the second in a series of articles based on interviews with leaders in allied organizations in an effort to explore the diversity of medical communication and the "hot topics" that AMWA and other groups are confronting. The AMWA Journal *welcomes input from readers about what fields and organizations should be covered.*

FROM BENCH TO BEDSIDE TO BREAKFAST NEWS—ELIMINATING ROADBLOCKS ON THE CONTINUUM OF MEDICAL COMMUNICATION

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On January 19, 2010, at 10:51 am, Ivan Oransky, MD, veteran journalist and executive editor of Reuters Health, issued an illuminating tweet:

> Study: "Significantly increased risk" of birth defects in some women http://bit.ly/6DDfOj
> Author: won't give absolute risks.
> Story: killed.

Dr Oransky's beef was with the authors of a report on a federally funded study published in *Occupational and Environmental Medicine*.[1] The investigators detected a significantly elevated risk of birth defects, compared with controls, among women in several occupations, including janitors/cleaners, scientists, and electronic equipment operators. But the study report did not give absolute numbers, and when Dr Oransky asked the authors to provide these important data, they refused.

Being an MD himself, Dr Oransky calculated the numbers he needed using the tables provided in the paper. "We do not express our results in these terms," replied the authors, when he asked them to confirm his calculations. "We do not feel it is prudent to publish … based on these results."

Explaining his decision not to report the findings, Dr Oransky said, "They did not provide enough information such that the story we could produce would allow our readers to judge whether it was worth paying attention to or not."

USEFUL INFORMATION

As a journalist, Dr Oransky's objective was to present the information to the public in a context that was meaningful to them: "… the best information I could get on which my readers could make a decision."

Did the researchers not share this goal?

One can only speculate, since Dr Oransky never heard back from them. Unless they happened to catch his earlier tweet, or read health journalism critic Gary Schwitzer's comments on the incident,[2] they might not even know that Reuters Health, one of the world's best-known providers of medical news, had killed the story.

This is a classic tale of medical communication breakdown. What should have been a free flow of information from the lab to the morning news feed hit a roadblock because communication failed between a researcher and reporter. What's ironic is that both people were medical communicators, and both presumably had the same goal: the dissemination of medical findings.

As AMWA celebrates its 70th anniversary, with a diverse membership numbering more than 5,600, it is appropriate to examine its mission—the promotion of excellence in medical communication—and its place on the communications continuum.

From the bench, to the bedside, to the breakfast news, medical communicators are the crucial link, with researchers on one end of the continuum and journalists on the other.

AMWA keeps no statistics on how many members are journalists, but many produce educational documents and media for patients and the public. Other members might identify more with the research end of Dr Oransky's story. Still, anywhere along the pipeline one can find plenty of blockages in the information flow, and each blockage is a breakdown in medical communication.

Scientists have identified communication and public education as significant challenges for science today. In a recent study from The Pew Research Center for the People & the Press, 85% of scientists said the public's low level of scientific knowledge is a major problem for science.[3] Yet in the same survey, scientists expressed mistrust of established methods of communicating that knowledge. Seventy-five percent criticized reporters for failing to distinguish between findings that are well founded and those that are not, and 48% said the media's oversimplification of scientific findings is a major problem.

"Rather than spurring greater efforts at communication, such mistrust and resignation have further motivated some scientists to avoid talking to reporters," Chris Mooney, author of *Unscientific America: How Scientific Illiteracy Threatens Our Future*, wrote recently in *The Washington Post*.[4]

COMMUNICATION BREAKDOWN

But it is not always mistrust that causes such communication breakdowns. Sometimes it is simply a lack of understanding. In their planning and preparation of manuscripts and presentations, medical writers may overlook the fact that their audience stretches beyond the scientific community. They may not recognize the importance of presenting results within a broader context, so that their meaning and implications are clear to the general public, not just to experts in the field.

"Scientific training continues to turn out researchers who speak in careful nuances and with many caveats, in a language aimed at their peers, not at the media or the public," Mooney wrote. "Many scientists can scarcely contemplate framing a simple media message for maximum impact; the very idea sounds unbecoming."

Medical journalists are generally well equipped to translate academic jargon for public consumption, but that doesn't absolve medical writers from the same goal of journalistic clarity. *The Lancet*'s historic retraction of the Wakefield vaccine/autism paper earlier this year is a case in point. The paper, published by the journal in 1998, suggested a link between the measles/mumps/rubella (MMR) vaccine and developmental disorders that emerged in 12 children following administration of the vaccine. The paper's publication launched a worldwide distrust of childhood vaccines that persists today, despite the decision by the UK General Medical Council to declare that elements of the paper had been falsified. The Council and *The Lancet* retracted the paper with the following statement:[5]

> "it has become clear that several elements of the 1998 paper by Wakefield et al. are incorrect, contrary to the findings of an earlier investigation. In particular, the claims in the original paper that children were "consecutively referred" and that investigations were "approved" by the local ethics committee have been proven to be false. Therefore we fully retract this paper from the published record."

In the flurry of blogging, tweets, and other commentaries that followed the retraction, *Forbes*' medical journalist and senior editor Matthew Herper pointed a finger at *The Lancet* for poor medical communication: "… *The Lancet* uses language that is likely to be impenetrable to anyone not versed in the scientific literature," he wrote.[6] "The retraction would serve the public health better if it stated its point a little more clearly and directly. This is not a matter of an obscure scientific error." The retraction should have been made clear enough to play a role in the public vaccine/autism debate, he argued.

Perhaps partly because of this lack of clarity, many people within the scientific community feel *The Lancet*'s retraction will never repair the damage done by its publication of Dr Wakefield's fraudulent paper. "*The Lancet*'s retraction shows just how hard it is to unring the bell," Dr Paul A. Offit, chief of infectious diseases at The Children's Hospital of Philadelphia, wrote in *The Philadelphia Inquirer*.[7] "How hard it is to reassure people once you've scared them," he continued. "Worst of all: The journal's too-little-too-late retraction will do nothing to restore the lives of children lost in this sad, tragic episode."

CLARITY AND ACCOUNTABILITY

Like Herper's criticism of *The Lancet*, Dr Oransky's tweet was a call for accountability and clarity from all medical communicators. As a member of the Board of Directors of the Association of Health Care Journalists (AHCJ), Dr Oransky devotes a lot of thought to assisting the flow of medical information to the public. To that end, he says, closer collaboration with AMWA might be useful.

With a membership of about 1,000, mostly journalists, the AHCJ includes in its goals the promotion of understanding between journalists and sources of news, as well as advocacy for the free flow of information to the public. Its Right to Know committee works to improve members' access to information, and it has developed guides to assist members on a range of issues, from covering medical studies to covering the hospital beat. At its annual meeting, the AHCJ draws on experts in both medicine and journalism, recognizing the range of needs of health care writers. Editorial independence is the cornerstone of membership eligibility, meaning that more than 50% of a member's work must be editorially independent journalism. "If you do a lot of advocacy work, or work for an

advocacy organization—it doesn't have to be industry in particular, it could be a group that is advocating for more research in a particular area—that would not be considered independent," explains Dr Oransky. "Our other focus is on pitching," adds the association's executive director, Len Bruzzese. "Our aim is to not have members who pitch press releases or stories to other journalists."

Collaboration between AMWA and AHCJ might foster better understanding along the medical communications continuum, and the National Association of Science Writers (NASW) is another important link in that chain. Like AHCJ, NASW recognizes potential areas of common ground with AMWA, says its president, Mariette DiChristina. NASW has a goal similar to that of AHCJ—the free flow of science news to the public—but besides journalists, NASW's membership of about 2,500 includes public information officers and people involved in publicity. A requirement of NASW membership is having been published in the lay press.

DiChristina, who is also the newly appointed editor-in-chief of *Scientific American*, says science journalists face increasing time pressures, underscoring the need for medical communicators to write clear, accurate press releases and journal articles. "Science is very complicated and journalists in general don't have the time they used to have. I don't think that's a flaw of either side, that's just the reality we all live with," she says.

Bruzzese, Dr Oransky, and DiChristina all teach journalism (Bruzzese at the Missouri School of Journalism, and Dr Oransky and DiChristina at New York University's Science Health and Environmental Reporting Program), and they recognize that journalists dedicated exclusively to medicine or science are a small and shrinking group. As dedicated health and medical journalists disappear, some experts predict that the communications gap between research and the mass media may expand. What role, if any, should the various players take in maintaining the flow of information to the public?

BRIDGING THE GAP

Blogs generated by physicians and researchers are sprouting, something Dr Oransky sees as holding interesting potential. Not all of this writing is strictly journalistic, he cautions. "If someone with an interest has funded the writing, at the end of the day that's not journalism." But "people who are not journalists are doing things that we can all agree are journalism," he says. "If we [AHCJ] can find people … and help them to develop their skills using our considerable resources … I would see that as a potential opportunity to work together."

While DiChristina also sees a place for scientists writing for the general public, she would not call their work journalism. "Scientists are good at giving the insider look. Journalists are good at reporting and analyzing. No scientist I know has reporter's training. You just always are going to need journalists to do that. But if you want an individual's perspective from their own research in the field, scientists are excellent at that. There are 2 different perspectives, and they both have value."

Like many journalists, DiChristina is careful to distinguish between the goals of science and the goals of journalism. "In general, my job is not to train researchers to speak to the public, it's to serve the public need. We're not there because we have some educational mission, we're there to satisfy a need to know."

Dr Oransky echoes this sentiment: "… there are some really important byproducts of what journalism does, but it's important to remember that at the end of the day journalism is not health education, it's about informing people." Additionally, he says, journalism should focus on accountability. "We need to be fact-checking and keeping the researchers honest—keeping people accountable—whether it's talking about conflicts of interest or study designs."

TACKLING HEALTH ILLITERACY

Despite these subtle distinctions, there is a growing recognition, within both the fields of medicine and journalism, that in order to inform the public about complex medical choices and treatments, communicators must be prepared to educate an audience that has a low level of health literacy. More than a decade ago, in their report "Worlds Apart: How the Distance between Science and Journalism Threatens America," Jim Hartz and Rick Chappell, PhD, a journalist and a space physicist, wrote about the inability of science to get its message across to the public.[8] "At the root of the problem—and the heart of the solution—are those who control the flow of crucial information about the value of basic scientific and technological research: the scientists themselves and the journalists who communicate their triumphs and failures to the American public," they wrote.

"Both scientists and journalists have been jolted from complacency by threats to their professional existence. Scientists, whose caste system of language and vocabulary isolates them from the public at large, fear failure in the politically charged funding arena. Journalists, whose increasing tendency to sensationalism has weakened their credibility, fear obsolescence in the fast-changing world of communications technology," they continued.

These words still ring true today, and sadly, the lack of communication between researchers and journalists still threatens the public's access to information.

In the wake of *The Lancet*'s retraction of the Wakefield paper, the journal's editor, Richard Horton, MD, noted that the depth of the damage it caused reaches way beyond the vaccine/autism debate, penetrating right to the foundation of medical communication. In an interview with National Public Radio's Bob Garfield, Dr Horton

acknowledged that today's medical debates are no longer confined to the academic arena.[9] "Everything is accessible to everybody, at any time," he noted. One would think that medical communicators, Dr Horton included, might consider this a triumph. Instead, he suggested that greater accessibility of information may backfire, with far-reaching consequences.

"We used to think that we could publish speculative research which advanced interesting new ideas which may be wrong, but which were important to provoke debate and discussion," said Dr Horton. "We don't think that now … We don't seem able to have a rational conversation in a public space about difficult, controversial issues, without people drawing a conclusion which could be very, very adverse."

That medical debate could somehow be sucked back behind closed doors and out of the public domain is highly unlikely. But Dr Horton's and Dr Oransky's frustrations reflect the significant obstacles that continue to hamper medical communication and the shared challenges that might be tackled with greater collaboration between researchers, writers, and journalists.

Kate Johnson began her journalism career in 1987 and has worked as a medical journalist for the past 18 years, mostly freelance, and as a medical writer and editor. She is a member of both AMWA and AHCJ.

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AMWA Offers Workshops to Help Medical Communicators Better Understand Medicine and Human Body Systems

AMWA's Concepts in Science and Medicine certificate is of value for medical communicators who are educated in nonscience fields. Each of the workshops provides an orientation to a scientific area and a foundation for further study. The certificate requires successful completion of 7 workshops plus the ethics-related workshop that is designated for this certificate. New workshops for the certificate are developed every year; recent offerings have included the following.

Basic Cell Biology
Basic Immunology
Basics of Human Anatomy and Physiology
Basics of Molecular Biology
Chemical Equilibria in Physiology
Communicating Results of Routine Clinical Laboratory Tests
Diseases of the Nervous System
Drug Interactions
Introduction to Basic Virology
Introduction to Cancer Biology
Introduction to the Cardiovascular System
Introduction to the Endocrine System
Introduction to the Musculoskeletal System
Introduction to the Nervous System
Introduction to Orthopedic Surgery
Introduction to the Renal System
Pharmacokinetics in Clinical Practice
Principles of Epidemiologic Research: Beyond the Basics
Sex and Beyond: Fertilization and Early Development

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