Science writers’ reactions to a medical “breakthrough” story

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Abstract

In numerous incidences, the news coverage of medical research has incited unjustified optimism or fear. The medical literature provides an archive of the scientific community’s condemnation of these misleading reports, but little is known about how they are judged by newsmakers. This study explored science writers’ reactions to a controversial \textit{New York Times} story that inflated the hopes of thousands of cancer patients. More than 60 science writers in the US, Canada, and Great Britain participated in a 12-day email discussion triggered by the \textit{Times} article. We analyzed 255 of these email postings and coded (1) positive and negative critiques of the \textit{Times} story, (2) references to the article’s repercussions including the creation of false hope, (3) attributions of responsibility for the resulting public misunderstanding, and (4) suggestions to improve the public’s comprehension of medical research news. The participating science writers generally responded negatively to the controversial article: 83% of the critiques were unfavorable. In addition, the science writers in the sample were cognizant and concerned about the impact of their work on the public, and accepted the largest share of the responsibility for the false hope created by the news coverage of medical research. Finally, the suggestions offered by respondents to improve the public’s understanding of medical research news were similar to those proposed by the scientific community. Thus, some commonality exists between how scientists and science writers believe the news coverage of medical research could be improved. © 2002 Elsevier Science Ltd. All rights reserved.

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Physicians are often saddled with the time-consuming and unpleasant task of debunking the news media’s coverage of medical research. After sensationalized reports about the latest “health scare” or “medical miracle,” doctors’ offices are routinely inundated with inquiries from patients. A now infamous case of this phenomenon was triggered by a 1998 \textit{New York Times} article about two anti-angiogenesis drugs discovered by Harvard cancer researcher, Dr. Judah Folkman (Kolata, 1998). The story written by Gina Kolata, a staff science reporter at the \textit{Times}, ran on the front-page under the headline “Hope in the Lab: A Special Report—A Cautious Awe Greets Drugs that Eradicate Tumors in Mice.” While the drugs featured in the story were highly experimental and not yet ready for human trials, the article contained enthusiastic endorsements from prominent scientists, including one Nobel laureate who described the treatment as so promising that it might “cure cancer in two years.” The following day, the story was picked up by newspapers across the country and ran as the lead story on all three network television newscasts. Thousands of patients contacted cancer clinics and government agencies asking for access to the new therapy, only to be told that the drugs would not be available for human trials for at least a year and by prescription for several years, if ever (Brownlee, Shute, & Tangley, 1998; Ferraro & Hutchinson, 1998; Fisher, 1998; Nichols, 1998; Somerson, 1998).
The controversy surrounding the *Times* article intensified when researchers quoted in the story disputed the accuracy of the statements attributed to them ("Corrections," 1998; Watson, 1998). Then, Kolata’s motives for writing the piece were questioned when the news broke that the day after the story was published she had circulated a book proposal about Folkman’s work with a $2 million price tag (Cimons, Getlin, & Maugh, 1998).

Physicians, scientists, and medical ethicists publicly condemned the *Times* story for raising patients’ hopes about a treatment that might never prove to be viable. In subsequent press reports, members of the scientific community characterized the article as “cruel” (Hawkes, 1998; Lasalandra, 1998). The journals *Nature* and *Science* issued strongly-worded editorials rebuking the decision of the *Times* to feature experimental drugs on the front-page (Marshall, 1998; "Problems with Media Gatekeepers," 1998).

Kolata’s story was also critically evaluated by her peers. Numerous postmortem analyses of the article and resulting media frenzy appeared in the popular press, including cover stories in *Newsweek*, *Time*, and *U.S. News and World Report* (Begley, Kalb, & Gideonse, 1998; Brownlee et al., 1998; Gorman, 1998). In addition, the controversy triggered a 12-day dialogue on an email discussion list maintained by the National Association of Science Writers (NASW). More than 60 science writers in three countries participated in this lengthy, often intense debate.

Science reporters are frequently portrayed in the medical literature as ruthless sensationalists who operate without regard for the public’s welfare (Anderson, 1999; Bedford, 1998; Borthwick-Duffy, Widaman, & Grossman, 1998; Freed, Katz, & Clark, 1996; Gonzalez, 1982; Goodman, 1993, 1992; Lebow, 1999; Meyer, 1992; Poe, 1999; Smith, 1996; Swafford, 1997; Wilson, 2000). However, some medical journalists dispute this perversive caricature of their profession. British medical reporters interviewed by Entwistle (1995) reported being extremely concerned about inciting undue optimism or pessimism among their readers, so much so that several claimed to never use incendiary language such as “breakthrough.” However, these reporters acknowledged that if they wrote too cautiously their stories would not get published and that they did not hesitate to print overstated quotations from scientists. Similarly, Winsten (1985) found that US science writers acknowledged that competitive pressures routinely pushed them to stretch the “boundary of truth” to the limit. At the same time, these journalists were critical of peers whom they perceived as overstepping this boundary and misleading editors and the public about the importance of developments in science.

The NASW online discussion documents science writers’ immediate reactions to a story which inflated the hopes of thousands of cancer patients. We analyzed this dialogue to investigate four research questions:

1. How was Kolata’s article critiqued by her peers?
2. Was the public misunderstanding generated by the article discussed more or less than other repercussions?
3. Who do science writers hold responsible for the widespread public confusion that results from medical research news?
4. What strategies do science writers propose for improving the public’s comprehension of medical research stories?

**Method**

“Nasw-talk,” the core email discussion group of NASW, is intended for discourse about “almost any subject of relevance to science writers and science writing” (National Association of Science Writers, 1998). Subscriptions to “nasw-talk” are open to anyone, not just NASW members. A person who joined “nasw-talk” would receive a copy of any message posted to the list, and could email a reply which would in turn be distributed to all other subscribers. An archive of past “nasw-talk” postings is also available to the general public, and can be searched by date, thread, subject, or author. Before initiating this study, we obtained permission from the NASW officer who maintained the “nasw-talk” list.

We analyzed 255 “nasw-talk” messages which referenced the *Times* article. The dialogue about the controversial article began on the day after the piece was published (May 4, 1998) and continued for 12 days (May 15, 1998). A total of 327 messages (175 pages of text) were posted in the discussion thread about the article. However, 70 postings (21%) were not included in our analysis because they contained no commentary relevant to the research questions described above. Also, 2 (1%) postings were excluded because the professional credentials of the authors could not be established.

Sixty-three science writers in the US, Canada, and Great Britain participated in the dialogue that was coded. Lexis-Nexis and Internet searches were conducted to verify the professional credentials of participants. The sample captured a diverse and accomplished group of science writers employed by a variety of news organizations and universities. The work of the journalists in the sample has been featured in major news outlets such as the *New York Times*, *Washington Post*, *USA Today*, *The Guardian*, *Newsweek*, *Time*, *US News and World Report*, and National Public Radio. In addition, the sample included individuals who have won the Pulitzer Prize and the Peabody Award.
To begin summarizing the data, two analysts independently identified the themes related to the stated research questions. After developing coding categories separately, they integrated the coding systems, and refined code definitions through several iterations of preliminary analysis. Across the four research questions, 21 coding categories were used:

Critiques of the Times article

The discussion about the merits and failings of the *Times* article encompassed seven topics: (1) significance of the story, (2) balance and accuracy of the story, (3) story placement, (4) reporter’s motives for writing the story, (5) credibility and credentials of sources, (6) verification of quotations, and (7) adequacy of context. In addition to coding the topics of critiques, the affect of commentary was also noted to distinguish positive and negative criticisms.

Repercussions of the Times article

Five repercussions of the *Times* article were included in the discussion: (1) snowballing media coverage, (2) public misunderstanding, (3) increased opportunities for science writers (e.g. book deals), (4) rising stock prices, and (5) increased opportunities for scientists (e.g. research funding). While “public misunderstanding” was the category of primary interest, all five repercussions were coded in order to assess their relative prominence in the dialogue.

Attributions of responsibility for public misunderstanding

Statements assigning responsibility for public misunderstanding were categorized by the group held responsible: (1) science writers, (2) editors, (3) the public, and (4) the scientific community.

Suggestions to improve public understanding of medical research news

Suggestions for reducing the public confusion generated by medical news stories revolved around five themes: (1) avoiding stories about therapies without proven human applications, (2) explaining statistics and scientific terminology, (3) explaining the barriers to developing viable treatments for humans in stories about experimental therapies, (4) covering general trends in an area of research instead of just specific studies, and (5) explaining the incremental nature of science to the public.

Each coding category was assigned only once to a posting regardless of how many examples of the code were present. The number of coding categories contained in a single posting ranged from 1 to 9 with a median of 2.

To assess the reliability of the coding categories, 20% of the postings were randomly selected and coded by two analysts. The coders agreed on the classification and affect of the critiques 97% of the time and on the categorization of repercussions, attributions of responsibility, and suggestions 98%, 93%, and 100% of the time, respectively.

We tracked the number of authors who contributed to the coding categories to assure that the opinions of high-volume posters were not disproportionately represented. The Results section includes quotations that are illustrative of the coding categories. The authors of the quoted postings consented to their use in this paper.

Results

Author to postings ratios

The number of postings per author ranged from 1 to 32 with a median of 2. The author to postings ratios of the 21 coding categories ranged from 1:1.0 to 1:2.2 with a mean of 1:1.4. Thus, the opinions of high-volume posters were not disproportionately represented in this analysis.

Critiques of the Times article

Of the 208 critiques directed at the *Times* article, 83% were negative (Table 1). In total, 45 authors posted negative critiques of the article, and 22 authors posted positive critiques. Only 15 of the 45 authors who posted negative evaluations of the article also posted positive commentary.

During the 12-day discussion, the significance of the story was frequently debated. Thirty-four postings by 23 authors discounted the importance of the story, arguing that it presented no new findings or information that would immediately impact the public:

> Curing cancer in mice is interesting but it’s not new. As the head of the cancer center here told me, “Curing cancer in a test tube is easy. Curing it in mice is easy. We can do that. Curing it in humans is the problem.”...Even the issue of anti-angiogenesis is not groundbreaking. And by the time you’ve watered it down that much, is there anything left?

*Author #9, newspaper science reporter*

However, others (11 postings by three authors) defended the story’s importance, arguing that the therapy featured in the story could potentially represent a significant scientific advance:
One of the things that gives this particular research a little extra credibility is that this specific approach to tumor control has been slowly working its way up the research ladder for some 20 years. It isn’t something that just came out of the woodwork. I remember Folkman appearing at an ACS science confab (do they still have those?) when the arterial attractor was originally discovered.

Author #19, newspaper science reporter and book author

The balance and accuracy of the Times article represented another common target of criticism. Nine postings by eight authors positively critiqued this aspect of the story. The article included several caveats including one in the second paragraph which cautioned readers that “the history of cancer treatments is full of high expectations followed by dashed hopes when drugs with remarkable effects in animals are tested in people” (Kolata, 1998, p. A1). Some authors defended the adequacy of the qualifiers included in the story:

I thought Gina Kolata did a great job with the anti-angiogenesis drug story. She started the piece with lots of caveats and didn’t get to the exciting findings until she had cautioned against unreasonable optimism.

Author #3, science correspondent for a nationally syndicated radio news program

However, 34 postings by 19 authors negatively evaluated the story’s balance or accuracy. Some of these argued that the story lacked important qualifying information:

The majority of the quotes are astonishingly hoorah, hoorah, we’ve conquered cancer….I think the article might have given some real specifics on why we should be cautious about thinking this is the cure. For one thing, I don’t see anything in the article that tells me that researchers have licked the obstacles of delivering the dose right to the tumor. Lab mice have tumors conveniently planted right on their backs. People don’t.

Author #25, freelance science journalist and book author

Other postings in this group questioned the accuracy of the information and quotations presented in the story. For instance, one author challenged the validity of the article’s declaration that “the drugs are the only ones ever tested that can seemingly eradicate all tumors in mice, even gigantic ones, equivalent to a two-pound growth in a person” (Kolata, 1998, p. A1):

Gina [the Times reporter] said very specifically that the angiogenesis drugs in question *eradicate* tumors and are effective against *all* kinds of cancer – and this is simply not so. I thought the article was very irresponsible, not just in placement but in the way it was written too. It was simply inaccurate. For starters, even later on in the article, Gina gives enough detail for you to infer that the angiogenesis inhibitors don’t really *eradicate* cancers but simply suppress them to microscopic levels. That relieves the symptoms but once the drugs are stopped they start growing again. Saying these drugs eradicate tumors is like saying the AIDS drug cocktails eradicate HIV; at its most feverish, the hype on protease inhibitors never went that far. But she said eradicate, no caveats at all.

Author #20, staff writer for science trade journal and book author

The appropriateness of the story placement was also discussed at length. Twenty-eight postings by 22 authors condemned the decision of the Times editorial staff to run the story on the front page. The rationale for this criticism was that the story’s positioning cued readers to believe that the research findings were exceptionally

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### Table 1

<table>
<thead>
<tr>
<th>Target of critique</th>
<th>–Affect</th>
<th>+ Affect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Significance of story</td>
<td>34 (23)</td>
<td>16</td>
<td>45 (26)</td>
</tr>
<tr>
<td>Balance and accuracy of story</td>
<td>34 (19)</td>
<td>16</td>
<td>43 (26)</td>
</tr>
<tr>
<td>Story placement</td>
<td>28 (22)</td>
<td>13</td>
<td>32 (24)</td>
</tr>
<tr>
<td>Credibility and credentials of sources</td>
<td>23 (17)</td>
<td>11</td>
<td>26 (18)</td>
</tr>
<tr>
<td>Reporter’s motives for writing the story</td>
<td>19 (11)</td>
<td>9</td>
<td>25 (15)</td>
</tr>
<tr>
<td>Verification of quotations</td>
<td>20 (10)</td>
<td>10</td>
<td>21 (10)</td>
</tr>
<tr>
<td>Adequacy of context</td>
<td>15 (12)</td>
<td>7</td>
<td>16 (13)</td>
</tr>
<tr>
<td>Total</td>
<td>173 (45)</td>
<td>83</td>
<td>208 (52)</td>
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</table>
significant, as they were too important to be featured alongside other research reports in the science section of the newspaper:

The problem is how the story was played on the front page and that was a malfunction of the paper’s editorial judgment. The editors grossly over-played her [Kolata’s] story by placing it in the off-lead position of the Sunday front page—as close as a traditional broadsheet can get to a tabloid screamer treatment. If the story had run on the science page, its play and positioning would have been more tempered and more in line with the highly experimental nature of the treatment and the cautious tone of the story.

Author #29, newspaper science reporter and book author

Only four postings by four authors supported the front-page placement of the story. These authors argued that the research findings featured in the article deserved the high-profile exposure.

As mentioned in the introduction of this paper, the article contained several dramatic quotations from scientists endorsing the experimental drugs. It should be re-emphasized that the quoted individuals disputed the accuracy of the statements attributed to them. However before the scientists lodged their complaints, 23 postings by 17 authors questioned the validity of the quoted statements or the credentials of the researchers who supposedly made them:

“Curing cancer in two years” is outlandish no matter who said it, but especially so from a scientist who many of us know as, er, flamboyant, to put it gently. Now maybe it’s his problem if he shoots his mouth off, but doesn’t it become the reporter’s problem if it skews the story?

Author #8, science writer for a national newsmagazine

In response to postings questioning whether one of the quoted scientists was qualified to comment on this issue, three postings by three authors defended the credentials of the source in question.

Also, as discussed in the introduction, Gina Kolata’s motives for writing the story became the target of criticism when she circulated a book proposal about Folkman’s work. Nineteen postings by 11 authors questioned whether Kolata had “hyped” the story to create a market for her book:

To me, it was the clear implication that she had the proposal done, then ran a story timed to no event in particular…then immediately sent out a book proposal seeking big bucks. The issue I see is that the story may have been written (and hyped) because of the book proposal.

Author #28, staff writer for a science magazine and book author

However, six postings by four authors supported the legitimacy of Kolata’s actions:

…if she thinks this is a huge story, then she is entitled as a journalist to write books, magazine articles, screenplays, whatever about it. Plenty of honest journalists have made honest dollars by turning their workday reporting into books. It’s a core option in our trade.

Author #45, science writer for national newsmagazine

When information emerged that Kolata had quoted a scientist from a conversation that they had at a dinner party and not verified the quotation afterwards (Watson, 1998), 20 postings by 10 authors criticized this protocol:

It just sends alarm bells ringing in my head when I hear that a person was quoted on something they happened to say at a party, particularly in a man–woman conversation, since it’s so easy to get someone to say completely outrageous and ridiculous things in those circumstances.

Author #48, freelance science journalist

Only one posting defended Kolata’s use of quotations obtained in a social setting.

Finally, 15 postings by 12 authors condemned the absence of a news peg (triggering event) or other contextual elements from the Times article. Several of these postings argued that without a news peg the story did not belong on the front page:

…I found no news peg, i.e., no recently published journal article or presentation at a meeting. Was there an initiating event by the researchers or their organization, such as a press release or conference to announce new results?…If there was no news peg, then I would have rather seen it written as a feature.

Author #52, freelance science journalist

Only one posting praised the context included in the story.

It is interesting to note that on the first day following the publication of the Times story, the number of positive and negative critiques posted were almost equal; 56% were negative and 44% were positive (Fig. 1). On the second day, news of Kolata’s book proposal became public, and the gulf between negative and positive commentary increased dramatically; 26% of the negative critiques posted in the next 24 h questioned Kolata’s motives for writing the story. The volume of negative critiques peaked on Day 4 after scientists quoted in Times article questioned the accuracy of statements.
attributed to them; on this day negative criticisms averaged one per posting. After Day 5 very few positive critiques of the story were posted during the remaining 7 days of the discussion. Dialogue about the story waned during the weekend, but was rekindled the following week before terminating on Day 13.

Repercussions of the Times article

The dialogue contained 247 references to the repercussions of the Times article (Table 2). The snowballing media coverage and the widespread public misunderstanding were the most frequently discussed consequences; each of these topics was mentioned in around 80 postings by 35 or more authors. References to book deals and other opportunities for science writers generated by the article were included in 48 postings by 24 authors. The story’s impact on the stock price of Entremed, the biotech company slated to manufacture the drugs highlighted in the article, was discussed in 38 postings by 22 authors. Finally, only two postings by two authors alluded to increased research funding and other opportunities for scientists which could result from the story. Posters referenced both personal experiences and subsequent news reports as evidence of the repercussions that they mentioned.

Attributions of responsibility for public misunderstanding

Ninety-eight postings by 34 authors contained statements that assigned responsibility for public misunderstanding of medical research news (Table 3). The most frequent targets of these attribution statements were science writers themselves; 44% of the attributions (43 postings by 21 authors) were directed at their own profession. Several journalists reported that they had been taught not to consider the impact of their work on the public, but experience and conscience had forced them to question this aspect of their training:

When I was a lad (my God, he’s going to break out in song!)…as a journalist, I was taught and firmly believed that our obligation was to write the best we could and damn the results. Not our problem. The goal was to get information out there and let people operating in a democracy make up their own minds. I’m now convinced that’s sometimes wrong, that we do have some responsibility for what we write and don’t write. We do have to give some thought to the readers of our copy and see if we are doing harm. I don’t mean worry about giving offense, that’s part of the job and if someone is offended, normally tough doodle. But that doesn’t excuse giving false hope to dying people, or those who love them….I refer to another song, by Tom Lehrer, about Werhner von Braun, the amoral German rocket scientist who didn’t care what happened to the rockets he designed as long as someone let him design rockets: “The rocket goes up, who cares where it comes down. It’s not my department,” says Wehrner von Braun. To which, Bob Hope once remarked, “but sometimes it hits London.” Nothing we do is that catastrophic, but we do bear some responsibility for what we write. I think sometimes it is our department. I was taught wrong.

Table 2
Mentioned repercussions of the Times article

<table>
<thead>
<tr>
<th>Repercussion</th>
<th>n (Authors)</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>Snowballing media coverage</td>
<td>82 (38)</td>
<td>33</td>
</tr>
<tr>
<td>Public misunderstanding</td>
<td>77 (35)</td>
<td>31</td>
</tr>
<tr>
<td>Increased opportunities for science writers</td>
<td>48 (24)</td>
<td>19</td>
</tr>
<tr>
<td>Rising stock prices</td>
<td>38 (22)</td>
<td>15</td>
</tr>
<tr>
<td>Increased opportunities for scientists</td>
<td>2 (2)</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>247 (60)</td>
<td>99</td>
</tr>
</tbody>
</table>

Table 3
Groups held responsible for public misunderstanding of medical research news

<table>
<thead>
<tr>
<th>Group</th>
<th>n (Authors)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Science writers</td>
<td>43 (21)</td>
<td>44</td>
</tr>
<tr>
<td>Editors/industry pressures</td>
<td>40 (23)</td>
<td>41</td>
</tr>
<tr>
<td>Public</td>
<td>10 (10)</td>
<td>10</td>
</tr>
<tr>
<td>Scientific community</td>
<td>5 (4)</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>98 (34)</td>
<td>100</td>
</tr>
</tbody>
</table>

Fig. 1. Number of critiques and total postings by day.
Another 41% of the responsibility attributions (40 postings by 23 authors) were directed at editors and the competitive pressures of the news industry. These postings generally asserted that the management of news organizations prioritized profit ahead of public interest:

If there’s anything that makes me madder about medical writing than the research-is-a-series-of-breaking-news-stories philosophy of some newspaper scribes, it is the wow-that-will-boost-newsstand-sales-let’s-run-it-above-the-fold philosophy of some editors!...In my opinion, it does no good, and in fact does positive harm, to tantalize the public, and especially those poor individuals facing death (their own or a loved one’s) with supposed cures that they will not live to see.

Only 10% of the attributions (10 postings by 10 authors) held the public accountable for the confusion generated by news reports about medical research. Many of these postings attributed blame to the cursory manner in which individuals process news. Some authors espoused a rather hopeless view of the problem, arguing that even a “perfect” story would still be misunderstood by some individuals:

The fact is you can write the most perfectly pitched story in all creation, and readers will ignore your caveats, misunderstand your reservations, fail to read the 3 paragraphs about the lamentable record of mouse cures, and so on. You can’t force your readers to read every single word and then give them a quiz to make sure they’ve got it, just as you intended. In short, you have to write the story the way you think fit, and after that it’s out of your hands. Readers will make of it what they will. You don’t have the degree of control that some people seem to think you have.

It is interesting that the authors who supported this argument failed to acknowledge that well written, balanced stories would likely be misunderstood by far fewer readers that those which lack caveats and overstate the significance of research findings.

Finally, 5% of the attribution statements (five postings by four authors) targeted the scientific community. The general tone of these comments was that the egos and ambitions of some scientists prompt them to make overwrought statements to the press.

I wanted to stay out of this discussion because I’ve “been there and done that” with regard to cancer treatments. The disease is unique, as you all know, in stirring up false hopes. Therefore, I always stayed away from the promises held by rat research. A valued colleague...once looked at a press release describing a drug that “cured” leukemia in mice. “I’ll probably miss a really good story one of these days,” he said, “but I’m ignoring mouse research from now on.”

Table 4

<table>
<thead>
<tr>
<th>Strategy</th>
<th>n (Authors)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoid stories about therapies without proven human applications</td>
<td>8 (6)</td>
<td>33</td>
</tr>
<tr>
<td>Explain statistics and scientific terminology</td>
<td>6 (4)</td>
<td>25</td>
</tr>
<tr>
<td>Explain the barriers to developing viable treatments for humans in stories about experimental therapies</td>
<td>4 (3)</td>
<td>17</td>
</tr>
<tr>
<td>Cover general trends in an area of research instead of just specific studies</td>
<td>3 (3)</td>
<td>13</td>
</tr>
<tr>
<td>Explain the incremental nature of science</td>
<td>3 (3)</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>24 (14)</td>
<td>101</td>
</tr>
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</table>
The remainder of recommendations involved strategies to improve the content of news stories about medical research. Six postings by four authors suggested that science writers should take special pains to clarify the statistics and scientific terminology that they include in stories:

Another thing that we need to be careful about is reporting what cancer researchers mean by responding and extending survival. Patients and lay people tend, not unreasonably, to think that those words denote getting better, returning to health, suffering less, or some such improvement in quality of life. In many cases, though, the researchers mean that some physiological measure irrelevant to any of the above has changed or that the person expired three or four months later than expected, suffering all the while from both the disease and the terrible toxicity of the treatments….I do think that we have a responsibility to explain that even when treatments work, they may only drag out the misery, and the cure may be worse than the disease.

Author #5, freelance science journalist and book author

Qualifying stories about experimental therapies with an explanation of the barriers to producing viable therapies for humans was proposed in four postings by three authors. These posting argued that explaining the obstacles to new treatment development would help insulate the public from developing unrealistic expectations:

There will always be a number of new “discoveries.” How to handle those discoveries seems to be the question. Sure, we discovered a cure for cancer in mice. Shouldn’t the story (breaking or otherwise) have been why doesn’t it work on humans, yet? When will it be available for use in humans? What other problems need to be overcome before it can safely be used?

Author #27, university science writer

Three postings by three authors recommended that science writers should cover general trends in an area of research instead of just specific studies. The rationale for this strategy is that it would put research into context and help the public understand the true significance of new research:

…it seems to me this is a perfect example of what we were talking about a few weeks ago—treating science stories as isolated, largely contextless news events ….Had it been possible to present the story as just one more step in an on-going process, there would have been no problem. But somehow we never quite seem to manage that. So people think a modest advance is a breakthrough.

Author #55, freelance science journalist

Finally, another three postings by three authors suggested that science writers should educate the public about the incremental nature of science. The authors of these postings argued that providing the public with basic knowledge about the scientific process would enable them to more critically evaluate research findings.

Constructively, what it probably means is that we should do a lot more take-outs on how science works, particularly the segments of it so frequently misunderstood. For example, this piece would have been much better if there had been a sidebar on all the failed breakthroughs. The sidebar could even be interesting. But we (more to the point, our editors) have the impression that readers aren’t interested in process. They are. It’s just more difficult to write.

Author #19, newspaper science reporter and book author

Discussion

In general, the science writers who took part in the NASW email discussion responded negatively to the Times article, and their evaluations became increasingly unfavorable as questions about the story’s accuracy and the reporter’s motives for writing it were raised. The public misunderstanding generated by the Times story was one of the repercussions most frequently mentioned. Furthermore, participants attributed the lion’s share of the responsibility for the premature and false hope created by the news coverage of medical research to their own profession. These findings are consistent with the results of earlier qualitative studies which found science writers to be cognizant and concerned about the impact of their work on the public (Entwistle, 1995; Winsten, 1985).

In addition, the science writers who participated in the dialogue offered several thoughtful suggestions for how they might improve public understanding of medical research news. It is interesting to note that most of the recommendations offered by participants have also been proposed by members of the scientific community (Houn et al., 1995; Wiltse, 1992; Winsten, 1985). Thus, some commonality exists between how scientists and science writers believe the news coverage of medical research could be improved.

The ethics of studying email postings warrant comment. Everyday thousands of pages of dialogue are posted in Internet discussion forums such as email lists...
and chat rooms. These outlets offer a rich source of data involving no cost or participant burden. Even though Internet postings may be copyrighted, this prohibition is generally waived under a “fair use” exemption when the material is used for research. However, what is legally permissible does not negate the ethical issues involved in using the words of others. Before analyzing materials archived on the Internet, researchers should carefully consider issues of subject consent and protection. The protocol that we followed was first securing the consent of the NASW officer who maintained the “nasw-talk” list. Then, after our analysis was complete, we obtained the permission of the posters quoted in this paper. It is uncertain whether this protocol was legally or ethically mandated. However, the Internet is new research territory, and we advise caution and conservatism in the areas of subject consent and protection.

It should be emphasized that the science writers included in this study were not randomly selected and may not be representative of their profession. The journalists who contributed to NASW email discussions, or at least those who participated in the dialogue surrounding the Times article, may be more thoughtful and concerned about the impact of their profession on society than their peers. In any case, our findings indicate that there is a constituency of science reporters, some of whom are associated with major media outlets, concerned about misinforming the public. Whether this espoused concern actually translates into higher quality coverage is unknown, and additional research should be conducted to explore this question.

While the study sample limits the generalizability of findings, the “nasw-talk” list captured a candid discussion among science writers about an unfolding news event. Even though “nasw-talk” posters are aware that their messages are not private (National Association of Science Writers, 1997), they most likely do not interact with the anticipation that their responses will be studied. Thus, the responses analyzed here were most likely free of testing biases. Another merit of the “nasw-talk” postings was that they recorded science writer’s immediate reactions to a developing news story. At most institutions, including ours at the time of this study, securing approval to conduct research with human subjects generally takes at least 10 days. Thus, we would not have been able to match the timeliness of the “nasw-talk” data using traditional research methods (e.g., interviews, surveys). As this study demonstrates, Internet discussion forums offer investigators exciting new research possibilities.

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