

How to Write Your Story and Be Heard- from Bruch to Twitter

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The story of arsenic life

- Let's journey to Mono Lake, California
 - Just east of Yosemite National Park in northern CA
- Lake has unique geochemical features
 - High concentrations of naturally-occurring arsenic
- Also home to some super-cool bacteria known as extremeophiles
 - Like the high temps and otherwise toxic chemicals in the environment

Why extremeophiles?

- Extreme environments in which these microbes live are thought to be similar to environments on other planets in which life might thrive
- Still looking for five key elements: carbon, oxygen, nitrogen, hydrogen, and phosphorous
 - Phosphorus chemically very similar to arsenic
- Some scientists hypothesized that the extremeophiles in Mono Lake could use arsenic in their DNA instead of phosphorous

The initial publication

- In December 2010, a paper was published in *Science* that showed the DNA in these bacteria had arsenic instead of phosphorous
 - Press conferences galore
 - VERY hyped finding
 - Sample headlines “Has NASA discovered extraterrestrial life?”
- The study even had its own Twitter hashtag: #arseniclife

The initial takedown

- Less than 24 hours after the paper appeared, so did a very thorough evisceration of the findings by a Canadian microbiologist, Rosie Redfield
 - Her concerns were echoed and amplified by other scientists and geeky types on Twitter
- Had the paper found what it said it did?
 - A growing number of scientists said NO

Takedown, Redux

- Authors of the paper *really* resented the online discussions
- Science, they said, was to be debated in published journal articles, not silly online venues like blogs, Twitter, and Facebook
- Six months after the original article was published, the authors addressed critics in a formal journal article, also in *Science*
 - Too little, too late. Online discussions had already discredited the research

The Final Nail...

- Earlier this year, Redfield and other biologists published their work that attempted to repeat the experiments in the original paper
 - They failed. Although the microbes in Mono Lake could tolerate high levels of arsenic, they did not incorporate it into their DNA.
- This kerfuffle was a wake-up call to many “old school” scientists about the power of the Internet and a few researchers voicing their concerns
 - They took down *Science*, which is a MAJOR feat

Not only do [online] tools accelerate science, said Rosie Redfield, a microbiologist at the University of British Columbia and one of the first scientist-bloggers to question the arsenic study's findings, they also change where the discussion happens and who can participate. Online tools have enabled scientists to have these conversations faster, and in the public sphere. "Anyone who wants to can see what's being said," Redfield said. "It's not a difference in what we're saying; it's that we're saying it publicly."

--from [Working at the Speed of Science](#)

Links to EDs

- The Internet has given people a voice
 - With that voice comes the power to change things
- It's no different in the world of eating disorders
 - Clinicians and researchers were the gatekeepers of information and ideas
 - People certainly disagreed, but they had no way of sharing their ideas
- Like Dr. Redfield said, online tools have changed where the exchange of ideas occurs and who can participate.

Current media coverage of EDs

- Most coverage is on celebrities
- Lots of discussion of body image
- Glorification of EDs
 - Survey of young people found that they were jealous of those with EDs
- “Mythbusting” serves to perpetuate MORE myths
 - It’s not about food, it’s about control
 - Parents need to back off

How the media REALLY affects EDs

- It affects how family and friends respond to the signs of an ED
 - “It’s just a phase”
- It affects who we think is at risk for EDs
 - Young, white females who diet and love fashion magazines
- It affects how doctors respond to an ED
 - “Don’t bother him/her about food. S/he will eat when s/he is ready.”

How to change the dialogue

- Not enough to just complain about existing media coverage of EDs
 - Need to provide an alternative
- Constantly arguing against a point (“Parents don’t cause EDs”) only cements that idea in the minds of those who disagree
- We need to create new media and a new dialogue and understanding of EDs

Tools that anyone can use

- Blogging
- Social media (Facebook, Twitter)
- Comments on articles
- Email
 - Tell editors and writers of good coverage
 - Suggest ideas to writers

How to approach a writer/editor

- Keep in mind what writers are looking for:
 - Something new/fresh
- Search the newspaper or magazine to see if the issue has been covered recently
 - No matter how good your idea is, if there was a story on anorexia last month, it's going to be a hard sell
- Writers need to know: why is this subject important? Why should I be writing about this NOW? What's new or surprising?

How I pitched an article on FBT

- Told the editor that parents were traditionally blamed for EDs and told to take a hands-off approach to their child's recovery
 - High rate of relapse and mortality, low rates of recovery
- New research showing the opposite was true
- People in DC area were using this approach and finding success with it
 - Most people still didn't know about FBT or that it was available locally

How to avoid BAD coverage

- You don't have to answer any questions or provide any information you don't want to
 - YOU are the gatekeeper here
 - Explain why you don't want to answer the question- it can provide a good opening to a more in-depth discussion on important issues (sharing lowest weight, highest # of daily purges, etc)
- Do NOT provide before/after photos
 - Happy/healthy pictures are fine

How to avoid BAD coverage

- Share information (studies, other news stories, quality statistics) with the reporter
 - Generally, they will read it and they will be grateful
- Don't be afraid to say "I don't know."
- Provide names of people (families, clinicians, experts) that they can talk to
- Be aware that reporters frequently don't have science/medical backgrounds

What you can't do

- You can't read the whole article before it is published
 - You CAN ask to see what quotes they are using
- You can't choose the headline
 - The writer generally can't even do that
 - You CAN tell the writer/editor that you might scream if you see another story titled “Dying to be thin...”
- You can't choose the accompanying artwork
 - Young girl with a tape measure around her waist
 - You CAN offer to help with art ideas

Make your own noise

- You don't need to depend on reporters and other media to get your message out
- Write your own articles
 - Edit Wikipedia articles on EDs that are outdated or inaccurate
 - Yahoo and other major news outlets have user-generated content
 - Post and share your blog

Become an expert

- Eating disorders are a huge subject area
- Find one or two areas you're really passionate about and focus on those
 - For me, it was how EDs are portrayed in the media and improving research on EDs
 - Others have focused on EDs in males, young children, older adults; access to treatment; etc.
 - It will help interested parties find you better via Google searches

ED Success Story

- New South Wales (NSW) in Australia has 2 publically funded ED hospital beds
 - Population of 7.2 million
 - Doesn't take a mathematician to tell you that is woefully inadequate
- Ella had been in and out of emergency rooms for months and on a nearly year-long waitlist for a publically funded bed
 - Her doctors told her she would be dead by the time a bed became available

ED Success Story

- Ella began a letter-writing campaign to health ministers and local MPs to make them aware of the situation
- Out of this campaign grew her non-profit organization Fed Up NSW Health
 - In a few days, Ella had launched a website, blog, and gotten more than 10 people to contribute personal stories
 - Website got well over 1000 hits in its first weekend

ED Success Story

- The next week, Ella sent out press releases to major news outlets in the Sydney area alerting them to the bed shortage and what it meant for ED sufferers
- Shortly after, Ella was contacted by a reporter from the Sydney Morning Herald, the largest newspaper in Australia
 - Long feature ran the next week that told the story of Ella and other ED sufferers waiting for beds

ED Success Story

- As a result of the publicity, Ella was moved up the waiting list and received a hospital bed the next week until a bed opened up at a private clinic
 - Luckily, Ella had private health insurance
 - She is now receiving inpatient care at a private clinic outside Melbourne (NOT near home)
- No, there aren't more beds available to ED sufferers but MPs and the public are MUCH more aware of the problem

Conclusion

- The media isn't THEM. It's US.
- Doesn't take a lot of computer savvy or college degrees to start changing things
 - It does take time and effort
- The media really affects how we understand and respond to EDs
 - Why this is important