Policy Action Through Storytelling

A Webinar of the Clinician Champions in Comprehensive Antibiotic Stewardship (CCCAS) Collaborative

August 9th at 3pm EST / 12noon PST

CCCAS Collaborative Members recognize the importance of comprehensive antibiotic stewardship strategies to maintain the effectiveness of these critical medicines for treating human infections. This includes both clinical and food procurement strategies.
Antibiotic Resistance

• Overuse and misuse of antibiotics
  • Human medicine
  • Agriculture (80% of total antibiotic use)
• Lack of new antibiotic medications

“The greatest possibility of evil in self-medication is the use of too small doses so that instead of clearing up infection the microbes are educated to resist penicillin and a host of penicillin-fast organisms is bred out which can be passed to other individuals and from them to others until they reach someone who gets a septicaemia or pneumonia which penicillin cannot save.”

Alexander Fleming, New York Times 1945
Routes of human exposure to resistant bacteria

*Antibiotics*

Via FOOD
Slaughter, Handling, Consumption (undercooked meat, cross-contamination)

Via WORKERS
Handling of Feed, Manure; transfer to family, community

Via ENVIRONMENT
Contamination of ground & surface water, spray fields by resistant bacteria AND undigested antibiotics from manure

*HUMANS (General Populace)*

David Wallinga, Institute for Agriculture and Trade Policy
Antibiotic use in Agriculture
The root of the issue

Over consumption of meat

High production demands

Support for Industrialized ag production

Efficiencies at the cost of public health such as overuse and mismanagement of resources
(such as: food, water, and antibiotics)

Why is there less action on this aspect of antibiotic use?

• Lack of awareness
• Challenges of motivating food choice changes
• Power of meat industry
What is missing?

• Strong participation by health care facilities
• Consistent clinician voice
  • institutional policy
  • procurement
  • public policy
Clinician Champions in Comprehensive Antibiotic Stewardship (CCCAS) Collaborative

CCCAS Collaborative Members recognize the importance of comprehensive antibiotic stewardship strategies to maintain the effectiveness of these critical medicines for treating human infections. This includes both clinical and food procurement strategies.

Use your Clinician voice to Take Action!

- Advocate for Public Policy changes
- Propel Institutional Food Purchasing and Policy Development
- Educate Peers and the Public
- Identify Research Gaps

Apply to be a Member!
https://noharm-uscanada.org/CCCAS
Speakers

Julia E. Szymczak, PhD
University of Pennsylvania (PENN)
Assistant Professor of Epidemiology, Perelman School of Medicine
Senior Scholar, Center for Clinical Epidemiology and Biostatistics

Evan Lerner
University of Pennsylvania (PENN)
Director of Media Relations for the School of Engineering and Applied Sciences
Telling Compelling Stories to Change Policy Around Antibiotics

Julia E. Szymczak, PhD
Assistant Professor
Department of Epidemiology and Biostatistics
Perelman School of Medicine
Disclosures

• We have no financial relationships to disclose in relation to this presentation
Objectives

• To review the social dynamics surrounding antibiotic use (Julie)
• To review how a qualitative researcher approaches eliciting stories as data (Julie)
• To provide a case study of how stories can change policy in health care (Julie)
• To demonstrate what a story is and what makes a story effective in communicating information and engaging audiences (Evan)
Antibiotic Use as a Social Problem
“If I see a patient a week after surgery, and there’s still a little redness, and Mom’s nervous I am inclined to just put the kid on the antibiotic. It just makes everyone comfortable, and then a week later, the redness is gone. Did I treat an infection or was there just some redness? Some inflammatory post-operative discharge? I don’t know. I’m more careful about how I give antibiotics than I used to be in the past. You don’t want to be part of the societal issue of creating superbugs, but it is surprisingly difficult to look Mom in the face when she is convinced it’s infected and you’re trying to say ‘look, it’s not infected,’ when you don’t even know for sure yourself and a week later it could pus out and Mom’s like ‘see? Should have put her on antibiotics. I can’t believe you did this to my kid!’ That is what you imagine the scenario being if you don’t do something. It’s so much easier to say ‘look, we’ll put her on a little antibiotic.’”

-Interview, Pediatric General Surgeon, 22 years out of training

Conceptual Framework for Antimicrobial Use

Social Dynamics of Antimicrobial Prescribing*

• Relationships between clinicians
  – “Prescribing etiquette” – norms

• Relationships between clinicians and patients
  – Patient pressure, but possible prescriber overestimation of patient demand

• Risk, fear and emotion
  – Decision making shaped by fear of worst case scenario

• (Mis)perception of the problem
  – NIMBY – Not In My BackYard

• Contextual and environmental factors
  – Time pressures, fatigue, competing priorities

*Szymczak & Newland, Forthcoming in SHEA Textbook “Practical Implementation of an Antimicrobial Stewardship Program”
Why We Need to Tell Stories About Antibiotics

• Tragedy of the commons
  – The goals of the individual conflict with the goals of the community
  – Individual incentives lead to overuse of shared resource

• Behavior and outcome are loosely coupled
  – Risk is difficult to “see”
  – Downstream consequences
Qualitative Methodology: Eliciting Stories as Data

• Observations about behavior and social life as it is experienced by people rather than in categories predetermined by the researcher

• Exploratory, open-ended research questions with a commitment to inductive reasoning
  – A focus on emergent issues, topics that are difficult to operationalize quantitatively and understanding the impact of social context
Qualitative Methodology: Eliciting Stories as Data

- A focus on human subjectivity and the meanings that participants attach to events
  - Who are these people?
  - How do they make sense of the situation they find themselves embedded in?
  - How do they perceive the world around them?
  - What motivates them?
  - What worries them?
Qualitative Methodology: Eliciting Stories as Data

• Simply ask for a story – people often have an urge to tell them
  – Prompts
  • Can you tell me a story?
  • Can you share an experience?
  • What do you think was a turning point in your understanding of X?
  • Can you recall a day when X?
  • What is the most frustrated/happy/hopeless/nervous you’ve been when X?
JS:
Can you recall a time in your practice of medicine when you’ve come face to face with caring for a patient with a drug resistant organism?

Pediatric Infectious Diseases Specialist:
One of my first patients in fellowship was a little girl. I’ll never forget this, and it was almost 20 years ago. She was 6 years old. She had cystic fibrosis and end-stage lung disease and she came to my hospital for a lung transplant. She was colonized with a bacteria called Burkholderia cepacia that was multi-drug resistant. And they did the transplant and they immunosuppressed her so she wouldn’t reject the transplant and the organism went everywhere. It was in her blood. It puffed out her wound. It was bilateral mastoiditis. She was very, very, very sick. And it was all ours and there were no antibiotics to treat it. We tried an antibiotic from Europe, called temocillin, on compassionate use. But her organisms grew right up to the disc. And we tried it anyway, and she never cleared her bloodstream and she died of Burkholderia cepacia sepsis, and it was horrible. We were packing her dehisced wound, her sternotomy wound with acetic acid-soaked gauze, liked they used to do during the Civil War on the battlefield, just to decrease the bioburden. It was horrible. And things like that aren’t unusual anymore – to have an organism you cannot treat. When I try to be a steward for antibiotics and I get resistance from colleagues in other disciplines, I want to tell them this story because I just don’t think they see this connection. Imagine how you would feel if you had to tell a parent, look, “we know what your child has, we know what this bacteria looks like, how it acts, what it is doing to your kid. But we can’t do anything about it.” How would you feel?
How Stories Can Change Policy
Between a Rock and a Hard Place: Why Physicians and Advanced Practice Providers Work While Sick

- Mixed-methods study conducted in 2014 at one hospital

- Why do attending physicians and advanced practice providers come to work while sick?

- Survey with fixed-response questions and open-ended prompts eliciting stories about working while sick

(1) Szymczak et al. JAMA Pediatrics 2015 169(9):815-821
• Results: Closed Ended Questions
  – 94% of respondents believed that working while sick puts patients at risk
  – Despite this, 83.1% worked sick at least once in the past year with 9.3% reporting they had worked sick more than 5 times in the past year
  – Respondents reported working with significant symptoms, including fever, diarrhea and acute onset of significant respiratory symptoms
Results: Open Ended Questions

- Respondents work while sick because they
  - Don’t want to let colleagues down
  - Don’t want to let patients down
  - Fear ostracism from colleagues
  - Have staffing concerns and difficulty finding coverage
  - Feel there is strong cultural norm to come to work unless remarkably ill
  - Feel ambiguity about what constitutes too sick to work
“One day in the ICU several of us asked a co-fellow to go home because she was extremely ill with vomiting and diarrhea - she was so ill we had to place an IV to give her fluids and we felt she was a danger to herself and to patients. We volunteered to cover her work so that patients would be cared for. The chief of our division overheard this conversation and stated 'When I was fellow, there was no such thing as a sick day.' As a fellow, hearing that from division chief leads you to believe that there simply is no option to stay home.”

(Fellow, Critical Care/ICU)

“I was trained that if you are calling out you’d better be dead. It is a mantra that has always stuck with me.”

(Nurse Practitioner, Critical Care/ICU)
Presented message at leadership meetings across institution
  – Presentation of open-ended data led to engaged discussion and was attention-grabbing, especially for leaders who have many other competing concerns

Commitment from leaders to change hospital policy and implement systems developed to make it easier for staff to call out sick
  – As of 2016, policies in place, we are in process of measuring impact

We used stories to advocate for change

Illuminating Challenges Through Stories: Engaging Leaders and Changing the Conversation
What Happens Next?
Communicating Science using Stories

Evan Lerner
Director of Media Relations
University of Pennsylvania
School of Engineering and Applied Science
What’s a Story?

(Dillingham, 2001, with transformation, Ohler, 2003)
What’s a Story?

Something changes in the middle so that the end is different from the beginning.

(Dillingham, 2001, with transformation, Ohler, 2003)
“Chemistry is the study of change.”

-Walter White

AMC's Breaking Bad
Stories are About Change

“This is a story about a man who transforms himself from Mr. Chips into Scarface.”

-Vince Gilligan
“Narrative Structure”

“He walked us through creating a super PAC and every episode was a continuation of that story.”

Mass Communication and Society “Stephen Colbert's Civics Lesson”

Bruce W. Hardy, Jeffrey A. Gottfried, Kenneth M. Winneg & Kathleen Hall Jamieson
Beginning

Setting the Stage

• Who are the “characters?”
• What is going to bring them into conflict? What’s the problem?

• What are the stakes? Which side are “we” on?
• Who cares?

Why should I listen to this story?
Middle

The Conflict

• Change is the result of conflict.
• Only one outcome will occur. The winner of the conflict determines which one it is.
• Did we win? Why or why not?

The climax: What changed?
End

Closure: What’s Next?

• Revisit the stakes: what happened to the characters?
• Are they happy with the outcome?
• What else could have happened?

What do we need to do differently next time to achieve a different outcome or avoid the conflict entirely?
Beginning

Setting the Stage

One of my first patients in fellowship was a little girl. She was 6 years old. She had cystic fibrosis and end-stage lung disease and she came to my hospital for a lung transplant. She was colonized with a bacteria called Burkholderia cepacia that was multi-drug resistant. They immuno-suppressed her so she wouldn’t reject the transplant.

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• What are the stakes? Which side are “we” on?
• **Who cares?**
Beginning

Setting the Stage

Why should I listen to this story?

A child’s life hangs in the balance.
The Conflict

It was in her blood. It puffed out her wound. She was very, very, very sick. There were no antibiotics to treat it. She never cleared her bloodstream and she died of Burkholderia cepacia sepsis, and it was horrible. We were packing her dehisced wound, her sternotomy wound with acetic acid-soaked gauze, liked they used to do during the Civil War on the battlefield, just to decrease the bioburden. It was horrible.

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Middle

The Conflict

The climax: What changed?

The child died.
Closure: What’s Next?
Things like that aren’t unusual anymore – to have an organism you cannot treat. When I try to be a steward for antibiotics and I get resistance from colleagues in other disciplines, I want to tell them this story because I just don’t think they see this connection. Imagine how you would feel if you had to tell a parent, look, “we know what your child has, we know what this bacteria looks like, how it acts, what it is doing to your kid. But we can’t do anything about it.” How would you feel?

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What do we need to do differently next time to achieve a different outcome or avoid the conflict entirely?
Stories in Action

• It’s a framework — thinking in terms of a story helps you put yourself in your audience’s shoes.

• Ask yourself: What happens next?
Making Antibiotic Resistance Real Through Storytelling

A Guide for Clinicians to Drive Action on Antibiotic Resistance Using Their Personal Experience

As clinicians, you see firsthand the effects of antibiotic resistance on your patients and public health. Not only are you in a position to prevent detrimental outcomes, but polls show that doctors are among the most trusted professions. Your experiences and insight can illustrate the problem in a compelling way that leads to action.

Last year Dr. Scott Weissman, a member of the Clinician Comprehensive Antibiotic Stewardship (CCCAS) Collaborative, testified to Congress about his battle with a nearly untreatable infection that presented in one of his patients. His testimony is an example of how stories can change minds and policy. Health Care Without Harm and the CCCAS Collaborative offer the following guidance to help clinicians tell their stories to motivate transformative policy change.

Early in my career as a Pediatric Disease specialist, I was asked to consult on a patient who had been born with a condition called bladder extrophy, where her bladder was not fully enclosed at birth. She had had dozens of surgeries in her life to provide her with normal functioning and quality of life. She had suffered urinary tract infections more frequently than other children her age, and had received more than her fair share of antibiotics to treat them, but was being referred to me because the bacteria were increasingly difficult to treat.

For the next three years, we struggled to get these infections under control, but had only brief periods of symptom-free health before infection would return, showing up as stomach pain, flank pain, headache. We tried antibiotics by mouth, antibiotics by IV, antibiotics into the muscle, even antibiotics directly into the bladder. We tried probiotics, crenberry

**Know Your Audience.** Who is listening? Are they well-informed? Although you may have a deep understanding of the issue, it doesn’t mean your audience does. Aim to balance the details you want to give them with what they need to hear.

Prompt: What does your audience care about: the health of their family, their community, reducing costs, etc.?

**Make the Issue Personal.** Starting the testimony with a story about a patient creates a space where the audience can connect with the issue on a personal level.

Prompt: Think of a time when you had a patient or loved one struggle with antibiotic resistance. How did that change your perspective?

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**Key Facts on Antibiotic Resistance**

Incorporate the following (or other relevant) key facts into your story to provide scientific context:

- CDC estimates that in the United States, more than two million people are sickened every year with antibiotic-resistant infections, with at least 23,000 dying as a result.

- Antibiotics are among the most commonly prescribed drugs used in human medicine. However, up to 50% of all the antibiotics prescribed for people are not needed or are not optimally effective as prescribed.

- Antibiotics are responsible for nearly one out of five emergency department visits for adverse drug events.

- [Antibiotic misuse results in] at least $1 billion in excess medical costs per year.

- Approximately 80% of the overall tonnage of antimicrobial agents sold in the United States in 2012 was for animal use, and approximately 60% of those agents are considered important for human medicine.

- Methicillin-resistant Staphylococcus aureus (MRSA) is prevalent in meat and poultry in the United States; samples from 5 U.S. cities demonstrated S. aureus contamination in 77% of turkey samples, 42% of pork samples, 41% of chicken samples, and 37% of beef samples. Ninety-six percent of S. aureus isolates were resistant to at least 1 antibiotic agent, and many were additionally resistant to other antimicrobial classes.

- Infants and children are affected by transmission of susceptible and resistant food zoonotic pathogens through the food supply, direct contact with animals, and environmental pathways.

- In 2013, a total of 19,056 infections, 4,200 hospitalizations, and 80 deaths were reported to the Foodborne Diseases Active Surveillance Network, a CDC surveillance system covering 15% of the U.S. population.

- About 90% of the antibiotics used in agriculture are given as growth-promoting and prophylactic agents, rather than to treat infection.

- The recommended levels of antibiotics for feeds were just 5-10 ppm in the 1950s but have been increased by 10- to 20-fold since then.

- The scale of agricultural use of antibiotics is enormous: in terms of annual quantities, their use in animals is 100 to 1,000 times that in the human population.

- The U.S. Interagency Task Force for Combatting Antibiotic-Resistant Bacteria outlines five core goals for implementing the National Strategy on Combating Antibiotic-Resistant Bacteria and addressing the policy recommendations of the President’s Council of Advisors on Science and Technology (PCAST) report on Combating Antibiotic Resistance.

- Current trends to address antibiotic use in animal agriculture is limited to pursuing additional research and data collection rather than action to reduce use.

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Making Antibiotic Resistance Real Through Storytelling | 4
Putting Your Story into Action

Your story can be used in many forms to engage multiple audiences in driving change. As a clinician your voice has a powerful effect among multiple spheres of influence. Share your story in everyday education, in conversation with peers, in testimony to legislators, in communicating with your health facility leadership to motivate action towards comprehensive stewardship.

WITH YOUR LEGISLATORS. Use your story to convey urgency with legislators to address the use of antibiotics in animal agriculture through swift policy action and well-funded implementation of the responsible use of these life-saving medicines. As a clinician, you have a unique and respected voice that can speak to the public health implication unlike any other. Use this voice to advocate for healthy food policy through sign-on letters, in-person testimonials, and legislative visits.

WITH YOUR PEERS. Incorporate your story into discussions at interdisciplinary meetings or more formally via presentations at grand rounds or professional conferences. It is likely your personal experience will resonate with them and ignite the recollection of their own experience. Encourage them to develop a story from their own experience to do the same.

IN YOUR HOSPITAL. Tell your story as a key component in conversations with your facility administration to encourage the development of a **Antibiotics Purchasing Resolution** within your facility. Conveying how this issue impacts your ability to provide effective clinical care is a powerful way to motivate organizational change that has ripples beyond the hospital walls and into the food production system where the majority of antibiotics are used.

IN YOUR COMMUNITY. Telling your personal story and how antibiotic resistance has personally impacted your experience is an effective way to connect with your patients, family, and community at an individual level. Providing opportunities for action whether through individual purchases, or when cost-prohibitive, through policy advocacy is a way to empower those you interact with.

Additional Resources

The following resources offer additional guidance and support for the storytelling process.

- [www.narrativepractice.org](http://www.narrativepractice.org) - The Center for Narrative Practice believes that narrative, stories, and storytelling should be recognized as a part of all disciplines and fields, and that storytelling is a learned skill that can aid the world in becoming a more humane, accepting, and moral place.

- [www.centerforcommunicatingscience.org](http://www.centerforcommunicatingscience.org) - The Alan Alda Center for Communicating Science works to enhance understanding of science by helping train the next generation of scientists and health professionals to communicate more effectively with the public, public officials, the media, and others outside their own discipline.

- [www.narrativemedicine.org](http://www.narrativemedicine.org) - The Columbia University Program in Narrative Medicine fortifies clinical practice with the narrative competence to recognize, absorb, metabolize, interpret, and be moved by the stories of illness.

- [www.hatchforgood.org](http://www.hatchforgood.org) - Hatch offers a suite of tools and a growing community that can help leverage the power of narrative to increase reach, resources and impact for social impact organizations.

Get Involved

Interested in joining a clinician network active in promoting comprehensive antibiotic stewardship through policy, education, and procurement? Learn more and sign up for the Clinician Champions in Comprehensive Stewardship (CCCAS) collaborative at [https://harm.org/CCCAS](https://harm.org/CCCAS).
Get Smart About Antibiotics Week

2016 Get Smart Week is November 14-20.

Get Smart About Antibiotics Week is an annual one-week observance to raise awareness of the threat of antibiotic resistance and the importance of appropriate antibiotic prescribing and use.

OVERVIEW
Learn about Get Smart Week and other antibiotic resistance observances...

PARTNERS
Get Smart Week has many partners, including federal agencies, health departments, professional societies, corporations, advocacy groups...

ACTIVITIES AND EVENTS
Participate in the annual Get Smart Week Twitter chat, find resources for planning and evaluating events...

PROMOTIONAL MATERIALS
View and use graphics, press materials, print products, and web and e-tools to promote Get Smart Week...

EDUCATIONAL RESOURCES
A variety of resources about antibiotic resistance are available for healthcare professionals, the general public, and policy makers...

http://www.cdc.gov/getsmtar/healthcare/getsmtarWeek.html
Gearing up for Get Smart Week 2016, Health Care Without Harm and the Clinician Comprehensive Antibiotic Stewardship (CCCAS) Collaborative are collecting stories from clinicians about their experience with antibiotic resistance to motivate transformative policy change.

In a recent webinar featuring medical sociologist, Julia E. Szymczak, we demonstrated the power of clinician storytelling and offered practical guidance to help leverage healthcare professionals' experiences and insight to illustrate the problem in a compelling way that leads to action.

Now we'd like to hear from you. Tell us your story about antibiotic resistance.

Please copy and paste your story in the form below. If you prefer to send your story as an attachment, you may email your submission to HealthyFood@HCWH.org.

***By submitting you acknowledge that we will share this story publicly for 2016 Get Smart Week activities. All use will be properly attributed to you.***

Questions

Julia E. Szymczak, PhD  
Evan Lerner

Become a Clinician Champion!  
CCCCAS  https://noharm-uscanada.org/ccccas