

When Good Bacteria are Killed, C. Difficile Strikes

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SPEAKERS

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Maggie Fox 00:01

Hello and welcome to One World, One Health where we take a look at some of the biggest problems facing our world. I'm Maggie Fox. This podcast is brought to you by the One Health Trust with bite-sized insights into ways to help address challenges, such as infectious diseases, climate change, and pollution. We take a One Health approach that recognizes that everything on this planet — the animals, plants and people, and the climate and environment — are all linked.

Clostridium difficile, it's a mouthful, so we're going to start calling it C. diff from now on. It's a killer bacterial infection whose very name, difficile, describes its nature. It's hard to treat, and efforts to kill off the infection with antibiotics often make it worse. C. diff causes half a million infections every year in the US alone, and these infections will kill up to 30,000 people. It's so common and hard to track that there's not a good estimate of how many people globally are affected. These bacteria are everywhere — in food, in hospitals, and maybe even on your shoes. They're not usually a problem until the natural and beneficial bacteria in a patient's digestive system get disrupted, usually with the use of antibiotics that don't discriminate between the bacteria our bodies need and those that cause disease.

One of those killed by a C. diff infection was Peggy Lillis, a kindergarten teacher from Brooklyn. She developed C. diff when she was given antibiotics after a root canal. In this episode, we're chatting with her son, Christian John Lillis, who founded the Peggy Lillis Foundation in her name.

Christian, thank you for joining us.

Christian John Lillis 01:40

Thanks for having me.

Maggie Fox 01:43

Christian, could you tell us a little bit about your mother, Peggy Lillis?

Christian John Lillis 01:46

My mom was born Margaret Mary Daly in Brooklyn, New York, in 1963. She was the third oldest of nine children from a big Irish Catholic working class family. She became pregnant with me when she was 19 years old and married to my father, in that order.

Her and my father's marriage was not great. They did have my brother three years after I was born, and around the time that I was five, I remember they split up, and that began my mom's life as a single mother. My dad didn't really do much in terms of supporting us throughout our childhood.

Our mother then got her high school diploma. She went to college and ultimately became a kindergarten teacher. She was just a very warm, very funny person, and (had a) sort of gallows humor. I think because of the difficulties in her own life, she really developed very little tolerance for bullying or mistreatment.

I came out as gay when I was 16, but she suspected it long before that. And then my brother is dyslexic! And sometimes it was like this 24 year old woman, who doesn't even have a high school diploma, trying and arguing with administrators and teachers, ensuring that we are protected and that we got every opportunity that we deserve. And she wasn't just that way with as she was, you know, she was just sort of somebody who always advocated for the best for people. A lot of what we do at the Peggy Lillis Foundation is we try to live her values and to teach her values.

Maggie Fox 03:24

Can you describe when she was diagnosed with C. diff?

Christian John Lillis 03:29

As you mentioned earlier, she had gone to the dentist. And a few days after that, she was awoken in the middle of the night, sort of early Friday morning, with very severe diarrhea. It got out of her bed and she took the next day off from work, and she called her doctor. Being a kindergarten teacher, she did not think much of it; she assumed she caught a bug from one of the kids.

So, it was only when the diarrhea and the other symptoms persisted for four days or so that we ultimately decided to take her to the emergency room. And so, it was at the emergency room that they diagnosed her first with toxic megacolon. She was beginning to go into septic shock, and you know that was the first time that I ever heard the term C. Diff.

Maggie Fox 04:10

And then what happened to her?

Christian John Lillis 04:12

Initially, my concern with us going to the ER was that I thought she was just profoundly dehydrated. So, we took her to a local hospital, not like a flagship big named hospital in New York. And so, following her diagnosis, they really did everything they could to help her. They had not, at that point, really experienced a woman who was 56 years old with such an advanced case of C. diff infection, you know, with toxic megacolon and the beginnings of sepsis. So, over the next 24 to 36 hours, they really did everything they could in terms of consulting doctors at other hospitals. They were very direct with us in terms of how sick she was.

Because she was so unstable when we brought her in, her white cell count was 40,000, and she had a blood pressure of 70 over 40. They really just tried to get her stable before they could really begin treatment. So, overnight, they gave her antibiotics through a central line. They also gave her antibiotics through an enema because of the swelling in her colon. The next morning, in what they termed as an attempt to save her life, they did a total colectomy. For a while after the surgery, she seemed to do better; her vitals improved. But then, by the afternoon, she started to kind of crash again, and her blood wasn't oxygenating properly. Ultimately, she died around 7 pm that night.

Maggie Fox 05:35

And although there's no typical course of C. diff, people often get profoundly ill, as your mother did, with multiple complications that hit very fast.

Christian John Lillis 05:47

Part of it depends on what strain you have and whether or not you get treatment quickly. In my mother's case, she was prescribed an antidiarrheal by a doctor who didn't even examine her. And many doctors said to us that they think part of the reason why she went into septic shock so quickly was because the antidiarrheal was kind of keeping the toxins and bacteria in her system, as opposed to just letting it expel.

Maggie Fox 06:16

How did all this affect you and your brother, Liam (Lillis)?

Christian John Lillis 06:20

We're coming up on 14 years, and it remains the worst thing that has ever happened to me. There's not a day that goes by that I don't think of her, miss her, and wish she was still here. Thankfully, she raised us to be very close, so we had each other to lean on.

It affects us in profound ways. I mean, it changed the course of my professional career. You know, I think it really made us value each other and the people in our lives that we loved. It also made us, you know, really determined that her death would not be in vain. I think if my mother had been hit by a car, if she'd had a heart attack, there are so many things that we could have been like, "Oh, that happens to people." But to lose someone, as I mentioned earlier, she had us very young, and so we assumed, you know, we would have her; her mother lived to be 93. We assumed we'd have her well into our own age, and she'd have grandchildren and all that stuff. And all of that was taken from us! And I am saying, you know, even in my happy things, the best moments like our weddings, the birth of my nephew, there's always a shadow of her not being there.

Maggie Fox 07:22

I am so very sorry that this has happened to you. What made you decide to become an advocate?

Christian John Lillis 07:31

So, I mentioned that my mom was, you know, a sort of volunteer advocate for so many people in her own life. I came out as gay in 1989 at 16 years of age, and the AIDS epidemic was, you know, it was early on in the AIDS epidemic. And there were no treatments. So, I became involved in activism around that. And so, up until that point, I had spent my career in nonprofit management and fundraising, and had worked in the LGBTQ rights movement and healthcare.

And so, as we looked around trying to understand what happened to her, we realized that there was no patient advocacy organization preceding us. Given the skills that I had, and given how beloved my mother was in our community, we just felt like there was something we had to do, that we had to sort of make her death matter.

Maggie Fox 08:25

What role can organizations like the one you founded, the Peggy Lillis Foundation, play?

Christian John Lillis 08:31

So as we've grown, we've done a number of different things. Our mission and our programmatic work breaks up into three sections. The first is educating the public. Only about 40 percent of Americans have heard of C. diff,

(whereas) to give a contrast, 85 percent of Americans have heard of Ebola, and we have had only 1 person die of Ebola in the United States, and that was from our failure to rescue. However, we lose about 30,000 Americans to C. diff every year. So just having people be aware of the disease so that they can be judicious in their use of antibiotics, they can spot the symptoms, they can ask for testing, and inquire if a facility they're going to has high C. diff rates. About a quarter of Americans knew about C. diff when my mom died, and now we're at about 40 percent, so we've made some progress. That's one part of our work.

The second part is empowering advocates. So, people like us who either lost a loved one, or had a loved one harmed significantly by C. diff, or who have had C. diff themselves. We recruit from all over the country, we train them, and we help them learn how to speak to the media, how to lobby Congress. As a result of that, all feeds into our last point, which is shaping policy.

We started the first seat of Lobby Day in 2018. We skipped the year 2020 because of COVID; Congress wasn't going to talk about anything else. But otherwise, we have had a Lobby Day every year since, and oftentimes it's the first time that anyone has ever come to that legislator's office to talk to them about C. diff. So, you know, we really look at educating the public, empowering people who care about this disease to act on their own, and then making sure that those actions lead to changes in policy.

Maggie Fox 10:12

You've also done just a small amount of getting involved in the approval of treatments. I think a member (of Peggy Lillis Foundation) went to one of the US Food and Drug Administration advisory committees. Are you going to do more of that?

Christian John Lillis 10:24

Yeah, about 18 months ago, a new therapy or preventative called Rebyota was up for consideration by the FDA for approval. At these FDA advisory committee hearings, there's an opportunity for public comment. So, we got seven of our advocates and myself, and we all provided testimony during that FDA meeting. I think that played a role in ensuring that Rebyota would get approved. We think it's important that the FDA hear from patients, not just the doctors, or pharmaceutical companies; patient experience is really vital.

Maggie Fox 11:04

Can we talk about this particular treatment that you were looking at with C. diff? Sometimes, doctors take a completely different approach, what's called a "poop transplant," to replace the good bacteria so they can control the bad C. diff bacteria.

Christian John Lillis 11:19

Yeah, so starting around 2011 or 2012, there was a nonprofit firm called OpenBiome that provided stool for fecal transplants. There were a few major academic medical centers across the country that had their own stool banks. So, fecal microbiota transplant became the treatment of last resort for people with recurring C. diff.

For us, we always saw that as an intermediary step because it was considered experimental, which meant that it was not widely available. So, Rebyota was basically scientists and doctors taking the essence of fecal transplant, ensuring the treatment itself is safe and effective.

And you know, it is a complete change in terms of the way that we even think about combating an infection, right? So, C. diff, we need to give antibiotics still to bring the infection down, but because the infection thrives in a gut that has diminished good bacteria or diminished variety of bacteria, this drug then gives back that variety of bacteria and then prevents you, in most cases, from having another recurrence or from getting C. diff again. So,

we're really beginning to not just think about killing bacteria, but about the positive role that bacteria can play in our bodies and protecting us from disease.

Maggie Fox 12:35

What would you like to see happening going forward?

Christian John Lillis 12:38

So, in addition to the increased public awareness that we've already mentioned, we really have two things that we would really love to see. The first is for the guidelines for the treatment of C. diff to incorporate these new microbiome therapeutics and to incorporate them earlier on than we would typically see a fecal microbiota transplant (FMT). Oftentimes, people had to have like two or three recurrences before they get an FMT, and we'd like for this to be like the first recurrence you get this (FMT) because with each recurrence you get sicker and sicker. We've been talking about that.

We just responded to guidelines in the American Gastroenterological Association with our thoughts on that from the patient perspective. And then C. diff is tracked and reported by hospitals, but there are exemptions for certain types of hospitals, and it's not tracked in the population in the community. About half of all infections are now occurring in the community. So, we have been advocating for and are sort of bringing up the heat on advocating for C. diff to be designated as a national notifiable disease, which would require that anyone who diagnoses it reports to their state health department and to the CDC's National Healthcare Safety Network.

Maggie Fox 13:47

Christian, thank you so much for joining us, and sharing your story.

Christian John Lillis 13:51

Thank you for having me.

Maggie Fox 13:52

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Dr Ramanan Laxminarayan 14:13

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