When Superbugs Get Personal – From Professional Preoccupation to a Family's Nightmare

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SPEAKERS
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Maggie Fox 00:00
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.

Anyone who's ever listened to this podcast knows that we talk a lot about antimicrobial resistance (AMR), the rise of bacteria, viruses, and other pathogens that defy the effects of antibiotics and other drugs. It's one of the scariest threats we face. Strep throat is a common childhood infection that's cured almost immediately with antibiotics. But imagine a world where strep throat can kill a child in days, where a little cut can develop into a deadly infection, or where a standard hospital stay leads to an incurable illness.

In this episode, we're chatting with Nour Shamas, a clinical pharmacist who's also an antimicrobial stewardship consultant for the World Health Organization (WHO) based in Riyadh, Saudi Arabia. She's also a member of the World Health Organization task force of AMR survivors. Nour knows about the need for better antibiotics, tests, and prevention, not just through her job. She's got personal experience with drug-resistant infections, and she's here to tell us about what happened.

Nour, thanks so much for joining us.

Nour Shamas 01:41
Thank you, Maggie, for having me.

Maggie Fox 01:44
Nour, first off, can you tell us a little bit about what you do as an antimicrobial stewardship consultant?

Nour Shamas 01:51
So basically, I try to bring together my experience as a clinical pharmacist in antimicrobial stewardship and resistance, and my training in health policy, or global health policy. I try to figure out how antimicrobial stewardship can be made simple and easy to implement on the frontlines, and I just try to be creative and problem-solve for different contexts.

Maggie Fox 02:13
And you're also a member of the WHO task force of AMR survivors. What is that?

Nour Shamas 02:19
That's a relatively new task force that tries to bring forward the voices of AMR survivors — people who have either survived AMR infections themselves or have taken care of patients who have had AMR infections. The aim is to show how difficult it is to deal with resistant infections. It's not just one episode, but often multiple episodes. Some people live with resistant infections for a very long time. They end up taking antibiotics for years, which can be detrimental to multiple layers of their life. So, it's not just taking antibiotics. It's not just the price of the antibiotics or the availability, but it's also the side effects and the stigma that's related to it. So, we all have different stories, and we all try to advocate and talk about AMR from our perspectives.

Maggie Fox 03:09
Please tell us about your personal experience with this. Let's be clear: you live and work in Saudi Arabia, but you're from Lebanon, and your mom in Lebanon got sick.

Nour Shamas 03:20
As you mentioned, I am an infectious disease clinical pharmacist, and (I have a) background (in that field). So, I happened to be at an infectious disease conference, and at the time, in 2018, I got a call saying that my mom needed emergency surgery. Since I wasn't there, my family took care of the situation. This was a significant spinal surgery. A couple of months afterward, she started getting recurrent urinary tract infections (UTI). She understands what UTI means, but it was difficult for her to understand why she was getting them recurrently. So, I tried to explain it to her, and she started taking intravenous (IV) antibiotics at home. We had to get a healthcare nurse, for which in Lebanon we had to pay out of pocket, and finding the antibiotics on our own was difficult. I sometimes had to bring the antibiotics from abroad and fly them into Lebanon for her. So, it was tough.

Now, she’s very happy that I'm sharing her story. She wants everybody to know that a UTI is not a sexually transmitted disease and that women get more UTIs than others (men), and she's happy to be part of the story.

Maggie Fox 04:24
I think everybody needs to know what happened. Is she okay now?

Nour Shamas 04:27
She's okay now! But she still gets UTIs. Today, she went to the clinic to get checked for one. She knows the symptoms now on her own, so it's something she lives with. But she's okay!

Maggie Fox 04:38
Can we talk a little bit about how (we) get UTIs? It sounds like she was worried about the stigma that people would think it was sexually transmitted.

Nour Shamas 04:48
Yeah, absolutely. Generally, UTIs, especially in women, are not uncommon because of the physiology — the way that our body is built. Bacteria can climb up through the urethra and create an infection locally, which, over time, if not treated, can ascend further up into the kidneys and cause significant harm. People even die from UTIs, unfortunately.

So, in my mom's situation, she had never had a UTI. Of course, she had it while young, but at her age, she still did not have one until she went to the hospital and got her urinary catheter inserted for her surgery, which is normal. Of course, as healthcare workers we accept hospital-acquired or associated infections for any hospital-related care and explain this to patients.

But in her situation, it wasn't defined as a catheter, associated infection, or associated with her care, because she got her UTI 60 days after her surgery. So, she couldn't understand why she got it?

And she was worried about the stigma of having an 'infectious disease consultation' on her file. (She wondered)"Are people going to think it is a sexually transmitted disease?" Because that's what infectious disease is usually associated with. It took me a while to get her to an infectious disease consultant to come and see her, to accept, and approve her medications, but it was hard and it's still hard for her to wrap her head around this.

Maggie Fox 06:11
Wow, you just said something — you kind of threw it away, "But we accept that you get hospital-acquired infections." Can we talk a little bit about that? You shouldn't go to the hospital and get something new there, right?

Nour Shamas 06:24
Absolutely! That's a good point. We accept it — It's kind of like accepting burnt toast — if you accept that, sometimes you're going to burn your toast, but most of the time you're not— you put in some limitations to try for that to not happen. Of course, we're talking about a very serious situation here, where people's lives get affected, and that's unfortunate, because as healthcare workers we treat it as though it's a normal part of healthcare, it's not ideal.

I think, epidemiologically, we just accept that it's likely to happen and that the patient will benefit from that intervention in the hospital, which is more important than the risk of getting the infection. However, it can be very hard on patients, because, as you said, patients don't come into the hospital expecting to get worse outcomes afterward.

Maggie Fox 07:11
It sounds like it was difficult to get the right drugs to treat your mother after she developed this infection.

Nour Shamas 07:17
Yeah, it was difficult. I don't know how much people are aware of Lebanon and what's happening there, but the economic crisis and the economics in general, impact healthcare.

We know that politics impact healthcare, and so the situation currently is that many medications are not available or are very inaccessible, either because they're physically not available or (because they) are very expensive.

In our situation, the antibiotic she needed was just not available for almost a year and a half. And we're very lucky and privileged because I'm working abroad, so I was able to bring in the antibiotic from the outside (abroad). But most people aren't that privileged.

Maggie Fox 07:53
How much did you have to intervene? It sounds like you traveled — you went and got the antibiotics that she needed.

Nour Shamas 08:00
Yeah, I had to fly it in. I still do what I tell people not to do, which is, “Don't buy an antibiotic before you need it.” But in this situation, I buy it with a prescription, just in case. My mom, of course, doesn't take it until she needs it, but because we must prepare for it, just in case it happens.

Maggie Fox 08:21
Can you tell us a little bit about the infection she has? It sounds like it must be a drug-resistant infection if it keeps coming back again and again.

Nour Shamas 08:28
Funny you say that. Her infection is what I used to consider a not-super-important resistant infection. She had extended-spectrum beta-lactamases (ESBLs) *Escherichia coli* (E.coli). In my practice, I used to think that's not such a big deal, but unfortunately, most of the antibiotics that treat this infection are intravenous. You must take them through the blood, so it's harder to get the antibiotics, and they're not as available.

On the other hand, UTIs and other infections in general, don't have to be resistant to recur. You can get a recurrent UTIs just from a simple E. coli, which is the most common pathogen for UTIs. So even with relatively simple infections, we still have a problem, which is a recurrence of UTIs. And that's what's so frustrating.

That's something my mom asked me once: “As women, we know that UTIs are more common in women than in men, and they are more recurrent. Why is it so acceptable, and why do we have such bad antibiotics for our UTIs?” She doesn't understand why we don't have more research going into the subject.

Maggie Fox 09:38
What do you tell her when she asks that?

Nour Shamas 09:42
The biggest problem is that, and in general, there isn't enough investment in women-related healthcare issues such as menopause, polycystic ovary syndrome (PCOS), or other menstruation-related pain. We can hopefully fix many issues we can hopefully fix for fifty percent of the world, but I don't know why there isn't enough funding for that.

Maybe it's a matter of who funds (these researches) — who is at the top of making these decisions. Perhaps they tend to be men, they don't feel (these issues firsthand). And that's why it's so important to have a female presence in board rooms, in meetings, but also among survivors who can talk about the importance of investing more in women's health. There's interesting literature on this, coming out more and more on the disparities between how likely a woman is to get an antibiotic if she walks into a clinic. How likely is it, in the first place that women are exposed to infections?

Who makes up the largest portion of healthcare workers? They're women — nurses, pharmacists, and physicians. Who tends to be the people going to collect water from different water holes, who are exposed to taking care of an elderly person?They tend to be women. So, there are a lot of things to talk about in social structures and how that impacts women's risk of getting infections and resistant infections.

Maggie Fox 10:57
What do you want people to know or understand about your experience?

Nour Shamas 11:02
First, people need to be medically literate (we should) try to educate patients early on before something happens. I don't think it's good to just wait untill something happens to tell people about the risks, or to explain to them what things are. Especially now as AMR is all around us. For example, if there's more education at the elementary school level, parents will end up picking up on these issues. It may not be an easy, but it could be a potential way to increase medical literacy around AMR.

The reason for that (need to increase medical literacy) - is that my mom had spoken to me so much about AMR before she had her infection, I think it made it easier for her to accept it and to understand it, as hard as it was, and for her to accept that she's going to have to take an antibiotic three or four times a year for an infection that just won't go away. That's number one.

Maybe the other important thing is access to antibiotics — antibiotics shouldn't be a luxury; they should be a healthcare right! It's a right to have access to antibiotics. There are so many politics around that when it comes to the price of antibiotics, their availability, who buys the bulk of the antibiotics, and how they are distributed.

I think people need to focus on these points if AMR is to be tackled.

And diagnostics, of course. I'll just add that we are very lucky because we went to a specific hospital a where they can test for the susceptibility of and identify the pathogen. We're lucky to have the finances to cover it, while a lot of people don't have that option. You just don't know what you're treating, so (you might) just administer random antibiotics untill you know the patient gets better, or maybe doesn't get better at all.

Maggie Fox 12:40
It must have helped your mother a lot to have a daughter who's an actual expert.

Nour Shamas 12:47
We're very blessed, and I'm happy that I could help her with it. But it also makes me feel very frustrated to imagine what it's like for people who don't have that care or access to information on how to deal with such a common infection.

Maggie Fox 13:00
What would you advise someone who's in a similar situation — who doesn't have a daughter who's an expert?

Nour Shamas 13:06
I would hope that their local community pharmacists and physicians would be aware of how to help them manage the infection. And that's why I think we have a responsibility to make sure that people are trained. We need to stop thinking of hierarchies in healthcare delivery when it comes to prescribers and dispensers (pharmacists(, and make sure that everyone is aware of how to manage AMR. So, just as you said, if someone doesn't have access to infectious disease specialists, they still get the same care.

Maggie Fox 13:36
How did this near disaster, I mean, almost a disaster for your mother? How did it affect how you approach your work?

Nour Shamas 13:46
It made me think twice before either suggesting an antibiotic in a clinical setting, stopping the antibiotic, or changing the antibiotic. I used to be very naive about reducing how strong the antibiotic is. So, we used to switch from a stronger to]what we call a narrow spectrum antibiotic, let's say, on day three and four. I now am a bit more careful when I do that, and at the same time, I'm a lot more careful when I start an antibiotic to make sure the patient understands what they have, and why they're taking the antibiotic. What is the likelihood this infection will recur? What can they do to avoid it recurring? What is a microbiome, which is the gut's typical bacteria, and how can they replenish it?
So, I think it's made me approach it a lot more with a different lens, where I can talk to the patients a lot more.

Maggie Fox 14:32
Is your mom taking care of her microbiome?

Nour Shamas 14:36
She is, yes. In Lebanon, we eat a lot of yogurts and labneh, which is full of good bacteria. I think she's learned that this will be part of her diet forever, and she's happy to do it. But I think that very often, a lot of cultures don't have yogurt and (live) culture-rich food in their regular diet. So, I think it's important to talk about it.

Maggie Fox 14:56
Nour, thanks so much for joining us and for sharing this story with us.

Nour Shamas 15:01
Thank you, Maggie. I'm happy to be here.

Maggie Fox 15:05
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owoh@onehealthtrust.org. Thanks for joining us.