Drug Resistant Infections — More Than Meets the Eye

A personal essay for patients By Kim Neudorf



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The doctor's call

The phone rang and what the doctor had to say caught me off guard. A bacteria known as VRE (vancomycin resistant enterococcus) was found in Mom's urine. She had been home from the hospital less than a day. I was focused on what was important—meeting her basic needs, preventing a relapse of her pneumonia, and ensuring she took her antibiotics. I was unprepared for an additional infection, especially a stubborn superbug, or what medicine calls a drug-resistant or antimicrobial resistant (AMR) organism. The doctor needed more information, but so did we.

The doctor wanted to know whether or not Mom was symptomatic and I stumbled over the question. I felt put on the spot, trying to quickly distinguish any relevant symptoms.

Over the past year, she was losing bladder control. Was that relevant? On the first day of her hospital stay she had sudden urges to urinate and often—in medical terms, 'urgency and frequency.' I thought the cause was the intravenous (IV) that ran at 150/mLs per hour. She was up nine times that night. Once the IV stopped, so did the frequency, and she did not complain of discomfort urinating. She no longer had the fever she had on admission, thought to be a symptom of her pneumonia. She had a history of urinary tract infections, and after seven infections in one year, a prescription for continuing low-dose nitrofurantoin (an antibiotic) stopped the symptomatic infections.

"I don't think so," I told the doctor. I could almost hear a sigh of relief, as the doctor listed unfamiliar antibiotics that would be necessary if Mom developed symptoms. Because Mom did not have symptoms of a urinary tract infection, it meant that she was a carrier of VRE. 'Colonized with VRE' is another way saying it, which means the VRE bacteria multiplied, but did not invade or damage body tissues, as an infection does.

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Our first question was Why?

I asked, "Did she pick this up in the hospital?"

The doctor said, "I don't know."

Enterococci bacteria are normally found in the gut and can cause infections that can be treated with common antibiotics. VRE, on the other hand, is resistant to many antibiotics. Unfortunately, VRE is a common healthcare-acquired infection. It spreads from the hands of one person to the next or from contaminated surfaces, and can cause severe infections. Mom was vulnerable to a drug-resistant bacteria because of her advanced age, frailty, long-term prescription of a low dose antibiotic to prevent recurrent urine infections, and her recent pneumonia, which was treated with more antibiotics. I thought about her stay in the hospital. Did she pick up VRE from the shared bathroom and sink or from the staff? I also thought about the many antibiotics Mom received with a past serious infection, and wondered if there was a relationship. She had a private suite in her retirement home and hand sanitation was expected in the dining area.

During her recent hospital stay, healthcare workers clearly paid attention to infection prevention. They used hand sanitizer when entering and exiting Mom's room. They wore full personal protective equipment until her COVID test came back negative. They took a groin swab on admission to screen for a different superbug. Although Mom shared a room with another patient, the space was divided by a wipeable curtain that the staff kept closed. Different nurses cared for the roommates—they did not cross from one patient to the next. The staff also left blood pressure equipment at the bedside, only used by her. Yet, here Mom was with VRE.

How do we live with VRE?

After the doctor's call, my focus turned to VRE. I purchased disinfectant wipes, returned to Mom's retirement home and watched for specific symptoms. I disinfected the counters, door handles, handheld devices, and her bathroom. Even with these precautions, I did not feel confident in our ability to confine this superbug to her room and prevent its spread to other elderly people living in the home. Mom was vulnerable to a drug-resistant bacteria. Mom's e-health record noted that the urine culture result was reported to Infection Control, Public Health or a Medical Health Officer, and I assumed I would receive a call from public health with a patient education resource. The call never came. In the meantime, I turned to the internet and searched for resources that described how to manage VRE in the home. I felt resources were limited, and it was difficult to know which resource was relevant and reliable. This user-friendly patient resource, <u>Living with VRE</u>, helped, and we simply did the best we could (See 'Resource' on page 6).

Mom says, "I'm happy when I remember to wake up in the morning and go to bed at night." She lives with mixed dementia. Entrenched routines, daily coaching calls from family, and in-person visits support her quasi-independence. A memory is retained for only a minute and she has lost her ability to plan for the future. The lack of insight associated with dementia prevents her from making connections between superbugs, any symptoms she might have, and managing risk of harm from infection. I relied on her normally good hygienic practices to protect others, and took on the responsibility to disinfect her home.

I let my siblings know about the superbug, advised them not to use her bathroom, and to use hand sanitizer. Two family members were already aware of the risk of superbugs from their own experiences of drug-resistance, which has taught us that AMR and its harms are not uncommon. Two weeks later, Mom and I visited a clinic and saw the physician who replaced her former doctor. I explained about the VRE notification and asked for advice on how best to manage VRE in Mom's retirement home. Unaware of the culture report, the doctor scanned the e-health record for verification, consulted with a regional pharmacist, examined Mom, and ordered a repeat urinalysis. The urinalysis came back negative and the doctor advised that no further interventions were necessary.

The unanswered questions

This experience with my mom raised more questions than I received answers for. Where did the VRE organism go? The initial urine culture report identified six medications that VRE was resistant to, but none that it was sensitive to. Was it possible the low dose of nitrofurantoin cleared the infection? Was Mom no longer considered colonized? Did her home still require disinfection? Should homecare service providers and others be made aware?

Because of my background in healthcare and involvement with campaigns to raise awareness about superbugs, I think of myself as healthcare literate, but this experience taught me that my knowledge is limited, like the vast majority of people. I knew little about the practical day-to-day personal management of a superbug and what it means to be VRE colonized. What I needed most was information that would help me understand, respond, and prevent spread of superbugs to those who are most vulnerable and into the community.

When I reflect on our close call, I wonder about the extent of VRE and presence of other superbugs in our healthcare facilities and communities. I wonder if the risks and harms of drug-resistant infections are known, but accepted as normal. I wonder if surface disinfection is done frequently enough, especially since VRE can live on surfaces for months. And finally, each time I hear of the suffering associated with a superbug, I wonder how we can do more to respond to this significant patient safety issue. I knew little about the practical day-to-day management of a superbug.

What can a patient do?

Patient safety requires partnership, where the patient is a critical partner. Advocating for yourself or those you care about is important when you are admitted to a healthcare facility. Here are some ways you can start:

- Be aware that superbugs exist in healthcare facilities and in the community. A clean facility is more than what we see.
- If you have concerns about cleanliness in the care setting, speak up and ask your healthcare team about safe practices that help prevent infections at the point of care.
 - Would they clean their hands before caring for you and again before an invasive procedure? Visitors and family members must also clean their hands upon entering your room.
 - Was the medical equipment disinfected before it was brought into your room, or can certain devices (e.g. blood pressure monitor) be left in your room, for your use only?
 - Is there an outbreak of a superbug on the unit. If so, what precautions are being taken?
 - Will they remove your catheter as soon as possible?

- Do your part to prevent and limit the spread of infections.
 - Clean your hands with soap and water or an alcohol-based hand sanitizer after using the bathroom, using a tissue, and before meals.
 - Do not touch your dressings and ensure any open wound is cleaned and covered.
 - Keep your immunizations up-todate.
- Ask for patient education resources on the management of an acquired superbug in the home and community.
- And always help prevent the emergence of superbugs by using antibiotics only when prescribed and only as prescribed.
- Learn more about antimicrobial resistance and share information with those you care about. Visit: <u>www.AntimicrobialAwareness.ca</u>

Resource

Arizona Healthcare Associated Infections (HAI) Program, *Living with VRE: Learning how to control the spread of Vancomycin-resistant enterococci (VRE)*. 2017. Available here. <u>http://grhc.org/wp-content/uploads/2017/01/</u> Living-with-VRE_general.pdf

Where to from here?

Healthcare providers are often familiar with procedures and practices that help to slow and control drug-resistant infections. Unfortunately, this is not true for the patient, family and the public—those who are most affected and vulnerable. More needs to be done to build public awareness about the prevention and control of drug-resistant infections, as well as how to manage living with a resistant organism in care homes and the community. Maybe the simplest way to start is to talk to one another and share our stories of how these unseen infections are so much more than what meets the eye.

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