S3 - Conquer Silence

Transcription

Narrator: [00:00:00] I want to do a little experiment. Behind cancer and heart disease, what would you guess is the third leading cause of death?

Man: [00:00:14] Oh, I don't know.

Woman: [0:00:12] Lyme disease?

Man: [00:00:16] Heart disease, cancer, diabetes.

Man: [0:00:24] Probably respiratory.

Narrator: [0:00:27] The third leading cause of death in Canada? Remember that question later. When you hear about something like this, you want it to be kind of a one-off, just a remote case, total outlier kind of thing. And I guess I'm curious, how common is what happened to you?

Woman: [00:00:51] Yeah, I'm not alone. I'm really, really not. There are unfortunately, thousands, perhaps millions of young people out there, people under the age of 50 whose symptoms were dismissed and who are now – well, I'm stage four now. And in fact, though I was diagnosed stage three, subsequent investigations revealed I really was stage four all along. Their delay is going to take my life. And there was no need of it.

Narrator: [00:01:24] Canadian Patient Safety Institute presents *Patient*, a nonfiction medical podcast about the people trying to fix modern health care from the inside out. My name is Jordan Bloemen.

[0:01:52] Robyn Magee is about the most qualified human being you could come up with to try to navigate the health care system. And I say this because there are going to be points in her story where you start to try to think about what you would do differently. And the unsatisfying thing I kept bumping into is there really isn't. Robyn is a psychologist. She knows the medical system. She was relatively young. She spoke English. She was not, as she puts it:

Robyn: [00:02:18] They are young, they're elderly, they're frail, they're sick, they're bereaved.

Narrator: [00:02:23] Robyn was well equipped to face a complicated and formidable health care system. Her story starts with a lot of doctors and a family history of a very specific illness.

Robyn: [00:02:35] In my search for a diagnosis, I had an immediate family history of colorectal cancer, and I had active symptoms which were progressively worse. So I had actual rectal bleeding, so actual, you know, worsening bleeding. And I saw four doctors – three family physicians and one general surgeon – each of whom dismissed, belittled, sort of scorned my presentation.

Narrator: [00:03:03] Why didn't they believe what you were saying? Why didn't they believe what they were seeing?

Robyn: [00:03:08] Because all of them were of the fervent belief that people under the age of 50 cannot get colorectal cancer. I was 46 when I first presented to doctors and I was 48 when I was diagnosed.

Narrator: [00:03:21] There's two things about colorectal cancer you need to understand for this all to make sense. The first is that if you catch it early, the survival rates are comparatively high.

Robyn: [00:03:30] Colorectal cancer is one of the most preventable cancers there is if it's detected early. It's like skin cancer that way: the longer it goes untreated, the worse the outcome, and I was past the point of no return.

Narrator: [00:03:43] The second detail is most people – over 90 some percent, most numbers say – who get colorectal cancer are over the age of 50. That one is really, really important because when Robyn showed up at the hospital with symptoms of colorectal cancer and a family history of colorectal cancer, you really start to wonder why doctors didn't take more seriously the possibility that it was colorectal cancer. The reason why? She was in her mid-forties.

Robyn: [00:04:15] Disturbingly, doctor four, the general surgeon, had made it a policy not to triage her own cases and had left that responsibility to her high school-educated receptionist who was guided by the screening standards at the time. So doctor four had ripped out the screening standards out of a journal, pasted it on the secretary's desk and said, “When people phone up with rectal bleeding, you triage them using this.” So it says right at the top, symptomatic people should go on to assessment. However, the secretary, not knowing any better, said, “Oh, this woman's under 50. There's no screening for people under the age of 50, therefore no endoscopy for her.” So I could not access a colonoscopy or any kind of endoscopy through that path because of this egregiously bad practice around surgical triage.

Narrator: [00:05:12] So Doctor four doesn't give Robyn a colonoscopy because their secretary, following the criteria provided to them, made the decision that Robyn was too young to have that disease, which, amongst a lot of other questions, naturally raises one about what exactly was happening with doctors one and two and three.

Robyn: [00:05:32] It's one of the issues that arose in the course of this whole thing is that each doctor assumed another doctor would take responsibility for the case. So in the end, none of them did. So each doctor did their thing but failed to communicate to the next one. So, for example, the third doctor, I had a positive cancer screening test. I had a positive result. So a positive test should instigate appropriate investigation, but the doctor just didn't hand it on.

Narrator: [00:06:04] Robyn received a positive test screening indicating her illness, and her doctor didn't hand it on to a specialist. So here's where we're at. Robyn Magee goes into her doctor showing both symptoms and a family history of colorectal cancer. She's handed from one doctor to the next to the next, which is normal enough. But during this process, she receives test results that confirm that she does indeed have colorectal cancer, with which nothing is done. She's not allowed to receive other tests due to her age. And today, as of the moment I spoke with her, Robyn's cancer, which otherwise has a relatively high survival rate, is, to borrow her words, going to take her life. So what exactly happened here? When we talk about the leading causes of death, though, only one typically gets listed. A person can fit into multiple categories. Robyn has cancer. Which is the number one cause. But this brings us back to that question at the very start of the show, the third leading cause of death in Canada. Here's a hint: it's not a disease. It’s what happened to Robyn.

[0:07:28] We discuss preventable health care harm and the silence that fuels it, the third leading cause of death in Canada, after this message. *Patient* is brought to you by Canadian Patient Safety Institute’s Canadian Patient Safety Week. This year's theme is, in keeping with the episode, hashtag Conquer Silence. But it isn't just running this one week. Throughout the year, CPSI invites patients, providers and the public to record your health care harms story and share your advice to help others learn from your experience to help spread the word and conquer silence. CPSI will be tackling topics all throughout the year with advice from people across Canada and resources to help battle systemic silence. To share your story or to listen to others and to learn more, visit ConquerSilence.ca.

Abby: [00:08:20] Hi there. My name is Abby Hain and I'm a registered nurse. I have been for about 30 years now. And I am researching the health provider’s experience of a serious adverse event. And I'm trying to look at it from a growth perspective and how health professionals can grow professionally and personally through these experiences.

Narrator: [00:08:46] A serious adverse event. End of the last segment, we evoked a pretty startling statistic. So it's worth unpacking what exactly patient safety advocates mean when they talk about silence and preventable harm in the health care industry and the relationship between the two. Not a lot of Canadians realize that every year 28,000 of us die from preventable harm when receiving care in the health care system. And these patient safety incidents are the third leading cause of death in Canada, behind cancer and heart disease. They are so often born of miscommunication and misunderstanding and so rarely discussed after they happen, that they're considered a silent epidemic. Silent and cause and in response. Robyn was a victim of such a silence, silence between providers who could and should have been working with one another. Abby, who we just heard from, is researching the other side the impacts of these events on health care providers and the system itself that allows these events to occur.

Abby: [00:10:04] There is a lot of silence around these experiences, an immense amount of silence, actually, and it becomes very difficult for people when things go really wrong and everybody kind of goes into the place of self-blame. You know, “I screwed up. What did I do wrong?” You know. And this whole idea of when you're in the health profession, you get into it because you want to help people. And you certainly don't want to harm anybody in your work through something that you may have done or something that happened in the processes of the care.

Narrator: [00:10:45] Yeah. When you have to still go to work the next day or week or whatever, knowing that what happened happened.

Abby: [00:10:52] A lot of people talk about this idea. When you're a health professional, it's not just your job; it's your personhood, you know. Like when you become a nurse or a doctor, you identify as a nurse or a doctor as a human. So when it fails, when something's failing in your work, you feel like you're failing as a human being, you know. And how do people work through that? How do we learn from these incidents and get past this silence of the shame of it?

Narrator: [00:11:28] Today in Canada, every 17 minutes, someone dies in a hospital from an adverse event. One out of 18 hospital visits results in preventable harm or even death, and that's about 28,000 people each year. There could be roughly about 400,000 average annual cases of patient safety incidents costing around $6,800 per patient and generating an additional 2.75 billion in health care treatment costs per year. These statistics are from a report by Risk Analytica commissioned by Canadian Patient Safety Institute and from the Canadian Institute for Health Information. The patient safety incidents considered and the costs incurred are all preventable. So when you've heard a story like Robyn's and you have a person like Abby with

her expertize on the line, the question that you naturally want to ask is, “How do we fix this? Is there a silver bullet?”

Woman: [00:12:27] [Inaudible]. I've been doing this working in the safety world for about 15 years now and we always want that silver bullet, you know. And I see from what I'm understanding in the study and learning – and that's why the kind of approach I'm taking is a really deep dive into single stories. Like, I'm doing a narrative, qualitative kind of thing because I really want to get to the depth of it. Definitely, there's systems things we can put in place and there's been some good stuff around culture, you know, just culture stuff. Absolutely, some of the human factors, engineering to stop the systems from failing. So putting locks on med pumps, those kinds of hardwiring. But I tell you, it's also within the human, you know, going deep into a person's journey with their profession and what called them to their profession and how they want to be in that work and face themselves and others when everything's not going great and something horrible has happened. It's really interesting. There's a wonderful speaker who's Margaret Murphy. She's an Irish lady. She's a patient advocate. And what a lovely and feisty lady she is. And she lost her son, Kevin, to a serious event. And it was this whole notion, as you mention, of these moments of missed communication or missed sharing or even eye contact, you know, and sort of understanding what's going on. And her son died unnecessarily. Should not have.

[0:14:18] And she speaks eloquently of this idea of how she was abandoned because of the notion that people were just having such a hard time to look her in the eye. She was sent away. There was a lot of denial. But then she met the medical resident in the elevator. She was coming back to talk to sort of senior people about the incident. And she met the resident who'd been involved. And she looked at him and he looked at her. And it was a moment of silence, but so much was shared. And his shame and pain and inability to actually talk to her was very evident to her. And he sort of rushed away. And she came to this idea of shared abandonment, which I felt was incredibly deep of her to look at both sides of the experience, you know. And this idea that everyone's reeling after something like this and the front line person is sort of standing here on the sharp end feeling so alone, you know?

Chris: [0:15:27] So I would say for people, if something feels wrong, if it looks wrong, if you know it is wrong, you just need to find your inner voice and speak up.

Narrator: [00:15:40] That's Chris Power, CEO of Canadian Patient Safety Institute. In response to kind of the big question at the heart of all this, what can normal people be doing to prevent this silence, to prevent this specific kind of harm?

Chris: [00:15:55] I was talking with people earlier this week about the whole idea around “conquer silence” and finding your voice and having the strength to speak up. And as I was talking about it, I said to him, “Everybody has a story. Everybody can remember at some point in time when they should have spoken up because it just didn't feel right.” And after I was speaking about this, at least 10 people in the space of about 15 minutes came up and told me their story and said, “I wish that either my mother or myself or my friend or whoever it was who just didn't feel comfortable enough to speak up,” and they said, “if only they had, because what a difference it would have made for them.”

Narrator: [00:16:39] But in that room, with a health care provider who you've gone to for their knowledge, to question them, to speak up, to ask hard questions is so, so difficult for people.

Chris: [00:16:51] So it is a cultural thing. There's no question about that. In health care, we've always deferred to the authority of physicians or nurses or others and felt that, you know, we weren't on the same playing field at all. But if you think about it in the sense of something that you do in your everyday life, like if you were going to buy a car, for instance, you would ask questions. Even though the person selling the car knows way more about it, you know that this is something that's near and dear to your heart. You're going to make a big investment in it. And so you ask those tough questions; you just don't take that for granted. So there is a culture shift that needs to happen, but we need to put that same lens on our health care. Nothing is more important than our health, right? It truly is. Nothing is. And so we need to start to feel comfortable. And it works both ways because this is working with care providers, the doctors, the nurses, the pharmacists, to help them to speak in everyday terms so people don't feel that there is that big gap between the knowledge and that they can't speak up.

Narrator: [00:17:58] We've talked about silence at the root of the problem, but there's another silence that Robyn spoke with me about and that's – I guess you could call it the silence of the aftermath. After one of these events, something like what happened to Robyn, how do we break that silence? How do we talk about these events when they're so hard for the patient and so sensitive for the provider?

Chris: [00:18:20] Yeah. So at CPSI, we've been working really hard with governments, with policymakers, with leaders, with people who are providing care all across the country on the whole disclosure side of things. So how do you talk to patients and families? How do you talk to the public and to media after an adverse event happens, after harm happens in the health care system? And it is really difficult. Many of our health professionals are advised through lawyers, et cetera, not to say anything. And so we're trying to move past that to say, “We need to apologize. We need to let people know exactly what happened. And we need to continually

keep them in the loop, not just that time we disclosed and then nothing else happens." But I think we are seeing breakthroughs. We are seeing some excellent examples of where organizations, people who are working in organizations, are really trying hard to work with patients and families to help them through this after so they don't experience the kind of thing, that silence that Robyn and other patients who've been harmed by the health system, have in the past.

Narrator: [00:19:30] Which brings us back to Robyn. Figuring out how to respond to such a systems failure is this puzzle in and of itself. In some cases, Robyn went through the hospital system; others, complaints; and others, she went through the legal system. But after all of that is said and done, what do you do? Robyn has, since her experience, dove into the world of patient advocacy in a pretty remarkable way. She's spoken at events. She's spoken with journalists. She wrote a book called *The Cancer Olympics*, which you can and should look up online. Right now, as I'm chatting with her, she's headed to Italy.

Robyn: [00:20:11] So I've rented a villa in Florence and we're all flying there on Friday. So this is something, when I was sick as a dog on chemotherapy and was just like a shell of a human, and I would spend hours, you know, pining for – you couldn't eat. I couldn't even drink water, it was so painful to eat. So I would watch endless Jamie Oliver videos about Italian food. And I thought, "When I better, if I'm ever well enough, I'm going to buy time with my family in Italy." And so we're going. So we're going to go. We're going to do that and we're going to do that.

Narrator: [00:20:53] But there's this one thing that she said to me that I want to share with you. I asked Robyn why she spent so much time on advocacy when – and this is tough to ask someone – being terminally ill means that time for her is a very precious thing. And I'll be honest, knowing that she's a psychologist, I was expecting a very specific answer, an answer about harm, about preventing harm from happening to others. And that was definitely part of it. But it wasn't the entire thing. I'm going to leave you with that in Robyn's own words.

Robyn: [00:21:32] Yes, I can tell you that exactly: because it gives meaning to my suffering and to my death. That is why. Because I'm going to die anyway. The harm has happened. We're all going to die anyway, but I'm going to die sooner than I would have otherwise because of this, because of these errors. And for my death to have meaning and my suffering, the extraordinary physical suffering that I've undergone, I have to make it mean something. And the way I make it mean something is I make sure that I'm out there doing my best to say this can't happen again. People have to examine their practices to find the loopholes that result in this kind of thing. And also, if there are loopholes and if they have an adverse – you know, no doctor wakes up in the morning saying, "Let's kill this patient." If you have made an error, just apologize and do your

best to fix the system so that the kind of inadvertent errors aren't repeated and so that other people needn't suffer and die.

Narrator: [00:22:45] This episode of *Patient* is produced by the Canadian Patient Safety Institute. For more information on projects people like Robyn, Abby, and Chris are working on to improve patient safety, visit PatientSafetyInstitute.ca. *Patient* is produced by Dan Costigan, Cecilia Bloxham, Scott Winder, Christopher Thrall, and myself, Jordan Bloemen. Thanks for listening.

[0:23:14] *Patient* is brought to you by Canadian Patient Safety Institute's Canadian Patient Safety Week. This year's theme is, in keeping with the episode, hashtag Conquer Silence. But it isn't just running this one week. Throughout the year, CPSI invites patients, providers and the public to record your health care harms story and share your advice to help others learn from your experience to help spread the word and conquer silence. CPSI will be tackling topics all throughout the year with advice from people across Canada and resources to help battle systemic silence. To share your story or to listen to others and to learn more, visit ConquerSilence.ca.