

Bonni: [00:00:00] Today on episode number 149 of the Teaching in Higher Ed podcast Rebecca Hogue talks about giving voice and face to the illness experience.

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Bonni: [00:00:22] Welcome to this episode of Teaching in Higher Ed. I'm Bonni Stachowiak and this is the space where we explored the art and science of being more effective at facilitating learning. We also share ways to improve our personal productivity so we can have more peace in our lives and be even more present for our students.

Bonni: [00:00:49] I have been so excited to be able to talk to today's guest. It's been something we've been working on coordinating for a while. Rebecca Hogue is a Ph.D. candidate at the University of Ottawa in Ottawa Canada. She has a professional background and instructional design and also software quality insurance. She holds a Master of Arts degree in Distributed Learning and a Bachelor of Science degree in Computer Science.

Bonni: [00:01:15] Her passion is for creating innovative education solutions that I have seen that from even just what little bit of glumes as I've been able to catch into the work that she does I'm super excited to talk to her today. Her Ph.D. research which she'll be sharing with us today involves looking at the educational afford insoles of illness blogs. And she teaches instructional design for online courses at the University of Massachusetts Boston.

Bonni: [00:01:42] Today she'll be sharing a bit with us about her experience in June 2014 of becoming a breast cancer warrior and this unexpected twist in her life she shares helped serve to highlight her desire to explore connected communities and how education and our life experiences are enhanced through connections. And I feel like my life has been enhanced by being

connected with her and I'm just so excited to welcome Rebecca Hogue to the show. Rebecca, welcome to Teaching in Higher Ed.

Rebecca: [00:02:16] Thank you. I'm looking forward to our conversation.

Bonni: [00:02:19] Me too. We were talking. It's been more than a year since I first started to get on the show and I know you've had all kinds of stuff going on and I even appreciate now you're taking time away from guests that are staying in your home. I really just appreciate your spending time today in conversation.

Rebecca: [00:02:34] Yeah I'm looking forward to it.

Bonni: [00:02:35] You're the first guest to I've ever had on the show that I had to go into a little bit more depth as to how to read you how to refer to you because I know you have all these different identities that you have to consider kind of what space you're in and what context it is. Could you talk a little bit about some of these identities and some of the complexities involved there.

Rebecca: [00:02:58] Sure sure. So one of the agencies I carry is that I teach at the University of Massachusetts Boston. I live in California but I teach in Boston Boston online. So I have a presence as an online instructor there but I'm also a Ph.D. student and I'm a breast cancer survivor. And so for the longest time I had separate identities for different spaces. I'm a blogger in many spaces. I have a travel blog. I have an academic blog and a breast cancer blog and so my my spaces were very different for a long time. You know I really sort of compartmentalize. Some of that. So unless you've dug deeply you wouldn't have seen fit to be connected.

Rebecca: [00:03:47] But now that my research I'm researching doing an autoethnography and looking at my breast cancer blog as a data set and with that my identities had to emerge. And so for the longest time you my students and professionally I would be Rebecca Jay Hogue and you can google me as Rebecca Jay Hogue and get you know some of that professional view of who I am.

Rebecca: [00:04:10] And my blog was my breast cancer blog was Becky and it was just Becky it was like I didn't have a first name or last name. BCBecky.com and that blog it was just that. And there was no combination between the two of my students were no look up or they wouldn't necessarily know right now that I'm doing research in that area and the two have merged and I really had to think sort of deeply about that in some spaces because there are risks

associated with exposing yourself as a cancer survivor in an employment situation. It just gets really complicated.

Bonni: [00:04:47] Tell me about the significance of June 14th 2014.

Rebecca: [00:04:53] Oh wow that's it. So I went back with my diagnosis day. And I had just moved to California. And what happened was of course shortly after moving to California I found a lump and I was went through the diagnosis process and I started my blog within. You know I hadn't even had my full put biology. So I started my blog like two days after I was told I had cancer. You know that was my outlet and my way of you know processing and getting through it but also telling everybody but you know it's funny because I couldn't wait.

Rebecca: [00:05:35] I had seen if I was going through I had seen blog post like I'm a blogger. Right. You go through life and you knew your experiences become blog post and so you see blog posts in your experience. And so I saw that I went through that sort of process. You know one of the first things that went through my mind is if I get treated at Stanford do I get to wear the sweatshirt make me wear the University sweatshirt for a university you didn't go to. Right. Like doesn't seem right to me.

Rebecca: [00:06:08] Sort of like well going through this if I go through there then I think I qualify because you know going through this process with a master's degree. Right. So I get to a history where the Stanfords lecture because I can say I went to Stanford it was in a different way.

Bonni: [00:06:25] At the time who did it feel like you were writing to or or. I don't know if writing for is the right way to ask the question to or for.

Rebecca: [00:06:34] You know what's interesting is it changed at some point too. And so originally I was writing. For myself and to a small group of friends I actually did well some of the rise of 14 folk because we were in the middle of that when I was diagnosed. So it was actually my online friends that I was writing for.

Rebecca: [00:06:58] So it starts off with you know for me with friends or family because the other thing I couldn't do was I couldn't talk about it at least for two weeks. I could not say the words I couldn't talk about it but because I had moved down here and my family is all of a sanitaire being so far away they

needed to know what was going on and I couldn't be on the phone all the time I couldn't talk about it.

Rebecca: [00:07:20] And so it just gave me that outlet. But what was interesting and what I saw with my research is not very long before my audience changed and it became fellow survivors and it became an education tool for other people. So I was sharing my experience to help other people and I had some very moving comments on my blog and e-mails from people that were fellow that were not necessarily bloggers but were reading my blog saying things like you know this really helps me process what were what I went through or helped me understand what my sister went through or help me help me talk to my doctors.

Rebecca: [00:08:01] So I got lots and lots of that kind of feedback and so my audience really did change. Friends and family were always there and that was always there that always became an issue too because when you're writing about some of these things and you know there's a lot of anxiety there's a lot of negative feelings that happen. And you write about them but you have to worry about your family reading them.

Bonni: [00:08:23] Yeah yeah.

Rebecca: [00:08:24] And knowing that they're going to read them. And so it's like. But on the other hand I wanted to make sure that I was brutally honest because I always had the back of my mind that I might be doing research on the right this dataset. That is my blog. That is a useful research tool.

Bonni: [00:08:40] One of the themes that has come up probably more than any other in over 150 episodes is the issue of vulnerability and just what is required to be pursuing excellence in our teaching is just the sense of risk and we might fail and the wrongness with which so many of us work at trying to pursue this mysterious craft. I'm curious though for you it has to have been a new type of vulnerability.

Bonni: [00:09:16] And I'm just curious how you sort of respond to that do you. Did you sense vulnerability in your teaching before diagnosis did it take on something new after your diagnosis and then and then also just to really be a terrible interviewer and ask 13 questions at once. What did you decide with your students what you would share and wouldn't share in a classroom. You know I know it's teaching online but you know in the online classroom environment.

Rebecca: [00:09:41] In the online classroom environment it's even more of an issue because your students are more likely to Google you. And so your students are more likely to see your foliage in the in the on my face I think than in your in the face to face basis because my face to face face they see you in that area whereas an online you know sort of your sort of your online identity.

Rebecca: [00:10:05] And I really had to think about it because I also offer a course on blogging. I very specifically have people before they start blogging thinking about how much they want to expose themselves. There was an article I read early on in PHD that talks about academics and how some people are in here share people and other people aren't. To some people just by their nature hold things in and keep that privacy thing and some people are more public than I am.

Rebecca: [00:10:34] I've always been one of those more public people. So for me sharing it didn't bother me that much. The bigger worry was because I'm an adjunct at this point in our time professor the risk of whether or not I'll get hired or rehired into job because when I put myself out there my cancer identity does show up and that you know how does that affect employability. That is a huge issue for young survivors when you're younger and you know you've got a whole career ahead of you or a life you know a time ahead of you. The risk of exposing your cancer history to the world. And it does cause an interesting thing in teaching because I don't I don't intentionally mention my cancer experiences when I teach.

Rebecca: [00:11:30] But it does come up and sometimes it comes up because I bring so one of the things I like to do in my classroom is I do synchronous sessions where I bring in guest speakers and so when I do that I'm reaching out to a lot of my online friends to come and visit my classroom and talk about it. The cancer thing sometimes comes up in that context because my friends know both identities and they don't you know they don't separate the two. And as a result of that you know it does come up sometimes. And I've had students in private emails come up to me and talk to me because they've gone through similar experiences. And so in it's an interesting dynamic but it helps us remember that world people we're all human in this process.

Bonni: [00:12:19] I came across a new word as I was reading everything I could get my hands on before we talked. And that is pathography. What can you tell us about pathography.

Rebecca: [00:12:30] Pathography is sort of like people are familiar with biography and autobiography where you're talking your life history or memoir graphy is the memoir of a person through illness. So where illness is the focus of the memoir.

Rebecca: [00:12:49] It's become a really big genre in writing actually there's a lot more you know memoir of breast cancer experience. There's a lot of books in that area and those are considered pathographies and in specifically in the field of sociology. They do a lot of research of looking out what people share in their probabilities what they look like and sort of what what is the struggle. But is that the illness or different illnesses. What's interesting in photography is also considered pathography when a caregiver writes and tell the story. Because again it's still about the illness becomes is one of the key focuses of the story.

Bonni: [00:13:32] In your case with your Ph.D. research you're doing an auto ethnography and would you share a little bit about your Ph.D.. And I'm actually a little bit about how we could learn more about your research if we wanted to.

Rebecca: [00:13:45] So I am actually blogging a lot of my research because you know I'm inherently a blogger can't help it. And so I blog my research at living's the founder of the dot org. And so I used the word pathography I think blogs is a living pathography in that most pathographies that are some Bagchi when people study pathography they're studying books that have been published right. So they're very post-process the issues of people when they write their pathography.

Rebecca: [00:14:13] They go back and do what I'm doing with my autoethnography and that's the re-experiencing of things and pulling things out from a retrospective. Right. Because you have the benefit of hindsight when you're writing at this point. But the blog itself you don't have that benefit of hindsight when you look at a blog or write a blog. It's a raw data as it happens. So I think a bit more of a living thing. And so in studying blogs I'm looking at budding sort of a living experience as it's being experienced rather than the retrospective experience. That that that's sort of a with the name Living Pathography came from.

Bonni: [00:14:53] So a lot of our talk on the episodes around cultural competence have brought up examples of micro aggressions and we've had people of color sharing about ones that have been inflicted upon them and then also we recently had Steven Brookfield share about his experiences as a white man where he had found himself reflecting back and realizing he had

inflicted a micro aggression on his students. And I'm curious is there such a thing in your mind as micro aggressions that those of us who are less educated about cancer cancer survivors that that we inflict on people without realizing it. Do you think that there's a is that the right use of this word in this context.

Rebecca: [00:15:39] Oh there's a lot identity is actually such a huge aspect of it even even the term survivor is a loaded word for a lot of people if you have met a static you that you're not considered a survivor right because you're going to die from cancer in your hand. So you don't get to carry that identity and make it just seems very weird. And then there is like when you get the call yourself or Survivor is like from the day the last thing the cancer comes over the day life is sort of when you take on the different identity becomes a huge issue. It's it's a self-reflection and a lot of ways. And I use the term survivor for myself not because it means anything to me but because it means something to other people. It's the easiest way for me to explain it. And I know other people don't. They call themselves worriers. They're here. You're your. Battle metaphor again.

Bonni: [00:16:42] Can we go back to that for a second because I did read a little bit about that but I can't even trace back to where it was. But just this this critique calling saying cancer is not a battle. Tell us more about that because I think that's probably misunderstood by most of us.

Rebecca: [00:16:57] It is in part of it is because it puts a winning and losing mentality. Right, you win in battle or you lose the battle but it isn't. But that isn't that isn't even a good. It isn't a good metaphor for what it is because you live with cancer. Once you've been diagnosed the rest of your life. Right. It's not something that. Generally goes away. At least with breast cancer in particular it's not a disease that you ever stop living with once you had it. But the battle metaphor put something on that I means the patient. It sounds like you did something wrong. Right. They lost their battle because they didn't try hard enough or you know it's that guilt that happens.

Rebecca: [00:17:44] The positive attitude one is another one that comes up a lot. Right. So people are always like oh but if you put on a brave face you know you'll do. You know if you just have a positive attitude you'll do better. And that just puts it back on to the patient to get your back into the making the patient behave a particular way so that the healthy person feels better about it.

Bonni: [00:18:08] I was thinking about it. I think I saw greeting cards that were written by a cancer survivor and now I'm going to be sensitive to the use of that word but that were really humorous as if like most of the people that actually

made greeting cards knew what it was like to have cancer this is what they would actually make for those greeting cards.

Rebecca: [00:18:27] You know there's actually a book. She actually wrote a book called *Healthy Crow* and it's a really good book and it's *There's No Good Card for This*. Is that the key title. It's a really just recently launched the book and I went to her book reading Mountain View and she's such a powerful person and an amazing speaker. She's a breast cancer survivor herself but she does. She talks about how you talk to somebody with a critical. And you know cancer in particular because a lot of people just don't know how to talk to people you know and they're afraid to talk to people.

Rebecca: [00:19:07] But I stumble over what they say and in many cases you know I'd rather you tumble with a good meaning and not try at all. But she actually gives a lot of really good advice on things like how you can help somebody when they're going through things because that's another area where people sort of put it on the survivor it's sort of like the you know I want to help you tell me how I can help you. Animal like. But now I have to think about how you can help me you know. And so she positioned it and the how are you QUESTION That is always like the worst question in the world right. Especially because you don't know what people are. Asking when they're How are you.

Bonni: [00:19:51] Well and that's such a societal thing of how are you. Oh I'm fine how are you. And it's just that sometimes you can have that without even having to ask the person how they are but they're just so used to that being the first greeting.

Rebecca: [00:20:03] And often it's like I can't even say it because it's like how are you. I said I'm not well. Right. So it is a really hard thing. And actually her advice was really brilliant and she just said she you know put context to it. How are you today. Is. Suddenly something that you can't answer. Well today I'm feeling pretty good. Or today. I'm not doing so well. But just as I worry you with just such a big loaded question and I just think it's brilliant.

Rebecca: [00:20:33] Like she just created this book and it's an easy read it's not not a difficult book to read or it's not you know but it's got so many so many good bits of advice for how to handle it. But they also have some great greeting cards.

Bonni: [00:20:48] Rebecca in what ways were you able to find humor in your experiences and just one of the examples I have of many was just the post that you wrote about what boobs to wear today.

Rebecca: [00:20:59] It's you know it's kind of funny because that was that was actually one of the very first post I wrote very early on in in part because what what you know when you're going through it. Humor is a release and you use that and as a blogger of course and I want to share that. And so I had watch at one point a TED talk from this woman whose name I can't remember who had artificial legs.

Rebecca: [00:21:25] And she had different legs for different things so she could wear you know she'd change her height based upon which leg she was wearing. So if she wanted to wear a dress she might wear one pair of legs and you know just fascinating that sort of. And I had taken that of course.

Rebecca: [00:21:42] I'm somebody who likes the you know I take things from different my different and then we merged them together and so I often see things when I'm looking at health or related things like I see things through education and how they can come together. And so for that one you just sort of came to the idea of I was facing a double mastectomy like cancer on both breasts and going through that process of. Oh my God what am I going to do. But what did they humor parts of it I thought of. Like I could you know have different for different day.

[00:22:15] And then you know just how would people react if one day I come out and I miss double the Cup or the next day with a cup right. And then this idea of having different boobs you know based upon your outfit. But also for different circumstances. I just thought that was absurd. And so I wrote about that in the basement of apology. A little short story called Window shopping but it's humor in the moment that gets you through it. Right.

Bonni: [00:22:49] It's such an interesting thing just to think about how we look at things so differently when we go through such hard experiences and we ask actually maybe it's not even that we look at things so differently from hard experiences but just from our life's experiences.

Bonni: [00:23:03] I am one of the things I try to do with my young kids is try not to get impatient with them if they're being slower or something like that because so many times if I just can get inside their little minds it's because they are able to pay attention to things that I long ago forgot to pay attention to and they'll see

things that I will completely miss in a day. And your context totally changes on experiences like this. That's such such an interesting thing to think about.

Rebecca: [00:23:31] Yeah I found you know and the other thing I found was that the nature and I remember blogging about nature having more beauty in life little things like I would go for a walk along the trail which was up my house at the time and it's just sort of follows this little water water way and you know there would be grits and might be futile for birds that I would look at.

Rebecca: [00:23:54] But then you know one day I'm walking and I notice the snails. And you know just with these little things that I'm like wow and I'm just in awe of the beauty of these things. I went through that for a little while and then I'm kind of loosing it again I'm known. Notice I'm starting to lose that same sort of sense of everything being beautiful or everything you know seeing those little details. And it's exactly like like as you were saying as much as a child sees things. They see all those details and they have to process them. And when I was going through treatment it was the same sort of the world slows down and and you start to see the little things in a different way.

Bonni: [00:24:40] Well it has been great hearing a little bit about your stories but I'm also going to encourage that people go check out all the links we're going to have in the show notes which are going to be at teachinginhighered.com/149. And this is the point where we get to share some recommendations and today I'm actually handing over my recommendations duties to Adam Croom who's going to tell us a little bit about an upcoming conference he wants to share.

Adam: [00:25:07] Hey teaching in higher listeners is Adam Croom, director of digital learning at the University of Oklahoma where I play a lead role in the domain of one's own initiative. OU Create. I have an opportunity for you that Bonni has so kindly let me pass along. If you follow open education within education technology you've likely came across the domain of one's own initiative which started at the University of Mary Washington and affords each of faculty staff and student their own web domain to build a digital identity on the open web. No this isn't your told us spaces of yesteryear domains offer technologies that allow students to install popular applications like Drupal, Wordpress, and Omega create their own subdomains and even host their own email.

Adam: [00:25:57] What's even better is that because the domains are registered in their name they fully own the content and can take it with them beyond their

tenure at their respective institution. Unlike the learning management systems that most of our institutions have adopted and this thing has blown up domain initiatives have taken the world by storm with more than 40 institutions now offering domains.

Adam: [00:26:20] OK so here's where you come in in June specifically June 5th and 6. The University of Oklahoma along with reclaim hosting is hosting the first annual domain's conference which is dedicated to exploring domains and other open web technologies in the classroom. And we would love for you to come join us in Oklahoma City join a community of folks like Jim Groom, Alan Levine, Martha Bertus, Jesse Stommel, Jon Udel, you tell Laura Tob and many others who will be leading sessions. If you're passionate about student ownership, Ed tech, the open web, digital literacy, open pedagogy, this is the conference for you learn more about how you can begin your India approach to edtech today. Register at domains.reclaimhosting.com. I hope to see you on June 5th in Oklahoma City, Oklahoma.

Bonni: [00:27:22] Oh that sounds like such a great conference. Adam thank you for sharing it with us. And I'm going to pass it over now to Rebecca what do you have to recommend.

Rebecca: [00:27:31] You know what I'd recommend one would recommend a couple of things I want to recommend a book written by Kelsey Crowe and Emily McDowell called *There's No Good Card for This: What to Say and Do When Life is Scary, Awful and Unfair to People you Love*. It's a really great book to help people you know sort of reach out and talk to people when they're going through things like cancer. And it's it's an easy read. So it's not not hard to read but it has to some really really great advice in it. And so I'd highly recommend that.

Rebecca: [00:28:02] The other thing I want to recommend they're called empathy cards and you can see them at EmilyMcDowell.com And she writes these really really great cards that are you know they sort of say wait what's really hard to say in a really really nice way. There's someone that just says there's no good cards for this. This makes it easy you know and that makes it easy. It makes it easier to reach out like you know I'm so sorry you're sick. This sucks right. And if it's what their nice they are great cards and I would definitely recommend taking a look at both of them and the book.

Bonni: [00:28:43] One says I promise never to refer to your illness as a quote journey unless someone takes you on a cruise. You're not a burden. You're human.

Rebecca: [00:28:56] Yeah. They're just they're so beautiful. You know when you're trying to reach out to somebody and you want to say something but you don't know how to say it. It's a great resource to figure that out.

Bonni: [00:29:07] And so much of what you said earlier just in terms of the micro aggressions is just when we as potential listeners get in the way of ourself because we want to fix that other person because they're making us feel uncomfortable. It's kind of like actually that's not really your role you can't fix this so as soon as you give that up and can just be present for another person things seem to go a lot better.

Rebecca: [00:29:28] Yeah exactly.

Bonni: [00:29:30] Well Rebecca thank you so much for sharing all of this. And just for your ongoing vulnerability that's required to do the wonderful work that you do. You've certainly helped so many others and so many of that that you'll never know about that hopefully they'll pop up somewhere in the comments mentioned. But but so many just that you've touched their lives without them ever knowing it. And just thank you for that and for being on today's show. I'm so excited to finally get in to talk to you.

Rebecca: [00:29:57] Yeah and thank you for having me. I'm actually really excited. I'm looking forward to hearing the podcast when it's done.

Bonni: [00:30:05] Thanks to all of you for listening and to being such a great part of the teaching in higher ed community. If you'd like to connect on an even deeper level with the community you are always welcome to check out our community. You can find out more at teachinginhighered.com/slack.

Bonni: [00:30:23] And speaking of the community if you want to not remember to have to go to teachinginhighered.com/149. These resources from every week's show can come into your inbox automatically. If you go to teaching in higher ed subscribe and that it will also get you a copy of the ad tech tools guide 9000 tools that will help you use technology in both your teaching and also your productivity. Thanks so much for listening and I look forward to seeing you next time. It's going to be episode 150. It's an all recommendations episode and you'll get to hear from some past guests and some other members of Teaching in Higher Ed community. So make sure and download it next week and I'll see you then.

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