

Transcript

Matters of Engagement podcast

Episode: "Engaging in Storytelling (Part 2) – Organizations and Patient Stories"

<https://mattersofengagement.com>

Jennifer 00:05

Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

Emily 00:13

And I'm Emily Nicholas Angl.

Jennifer 00:17

So this episode is part of a special miniseries we're releasing this week. It's called Engaging in Storytelling: a 3-part collaborative podcast series with SPORCast, Matters of Engagement and PEPtalks. We each cover a different angle on patient stories and storytelling. And together, the three episodes provide a rich picture of some of the challenges, concerns, and also opportunities when it comes to engaging in storytelling. We're each putting out all three episodes on our feeds. So this is number two of three, and it's produced by us! If you're listening in order, the SPORCast episode was released yesterday, and tomorrow, we're releasing the PEPtalks episode.

Emily 01:03

We have two guests, Carol Fancott and Daniel Buchman. Carol is currently the Director of Patient Partnerships and Engagement at the newly amalgamated organization that's brought together the Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute. Carol did her PhD on how healthcare organizations use patient stories and storytelling. And we chatted with her about her research and some of her thoughts on storytelling, not about her role as director. And Dan is a bioethicist and independent scientist at the Center for Addiction and Mental Health, and an assistant professor at the Dalla Lana School of Public Health at the University of Toronto, as well as a member of the University of Toronto Joint Center for Bioethics. We talked about ethical considerations surrounding patient engagement and storytelling in the context of organizations.

Jennifer 01:55

We have a lot to share and want to get into it. But like with all of our topics, we need to sort out some of the language and definitions. At first, we thought it would be kind of straightforward. I mean, what could possibly be complicated about the word story? Well, turns out a lot. When we refer to our own story, as in, I tell my story, it means both what happened and how I experienced what happened. It's personal, and it's my own interpretation. The story is something that belongs to me.

Emily 02:31

Right. And there's another way we hear it too. Instead of "my patient story" or "your patient story", which is very specific, we also talk about "a patient's story" or in the plural, "patient stories". In this instance, we're not

just talking about multiple individuals - we're talking about a category or a type of narrative for conveying some kind of teachable moment. "Patient stories". They're more like fables. They get passed around, referenced, utilized, and in a way they're dissociated from the actual patient behind the story.

Jennifer 03:07

Yeah, I think of the difference as being either "person first", where there's one person who has any number of stories, which is usually how patients think about it, or "story first", which I think is often how organizations think about it. There's a particular type of story that organizations are often looking for, and any number of patients could fit the bill. Stories essentially get commissioned for some kind of teaching purpose, or maybe to showcase something about the organization.

Emily 03:39

Yeah. And this whole conversation reminds me of the times I've been involved in conferences or meeting planning, and the draft agenda just says "patient story" - they're yet to find someone. It's sort of like "insert here". Or especially in my earlier engagement work, organizations would always say it's good to start a meeting with a patient story without really discussing why.

Jennifer 04:05

Now patients may also be thinking about using their story, to educate or to showcase something. But I think there's a whole lot more going on as well. There's a sense often of wanting to be seen and heard. Patients want to be recognized for what they've gone through. And going back to previous conversations about expertise...this is our currency. As engaged patients, our experience is what legitimizes our knowledge. Having a big story is like hanging a degree on the wall.

Emily 04:36

And it's not only having the story, but telling it. Patient storytelling is often a live event, but one that's set up by an organization. A patient is asked to tell their story to an audience, which may be in the context of a meeting or at a conference or maybe a fundraiser. This is usually a moment or event created by the healthcare organization. And the story is solicited or arranged for that particular occasion.

Jennifer 05:04

There's also storytelling from the patient perspective. There are forums and platforms now where patients write, perform or record their stories completely outside of being asked to do so. One of the other episodes in this miniseries is about digital storytelling, where patients learn how to think through and develop their story in their own way. And there are many reasons why patients do this. Perhaps to make sense or meaning of their own experience, or to share something they think others can connect to or learn from. Or maybe it's simply to document an experience. Regardless, in this type of storytelling, the crafting of the narrative and the distribution of it is entirely within the patient's control. And the end result may never be used inside an institution.

Emily 05:52

So we've done all this careful parsing of language, but we're not going to dwell on it. We really just want to make clear that, as is often the case in patient engagement, the terms we're using don't necessarily have

straightforward definitions. And also that here in this episode, we're mostly talking about stories and storytelling in the context of the healthcare organization. We get into some complex stuff around how stories can be elicited from patients to serve a purpose, and how patients are sometimes put on display. And it's maybe debatable whether there's good reason to do so. But none of that is meant to cast doubt on the sincerity of patients, the need people feel to tell their stories on their own terms, or the connectedness people feel when sharing their experiences.

Jennifer 06:40

Right, we all have stories, we can certainly value them however we want. But in this episode, we want to think about how organizations in particular value them, and what that might mean for patients. We'll get to some of these big questions. But first, let's hear from Carol Fancott, whose PhD focused on patient storytelling. We asked her to summarize the scope of that research.

Carol 07:04

So the study that I did was really looking at it from an organizational perspective, and thinking about it in terms of what is happening when we are engaging patients in this way through storytelling, asking and inviting patients to come in to share their experiences to share their stories. And does this actually impact? Or does it actually affect change and learning within organizations?

Jennifer 07:34

So that was Carol's PhD, which was primarily focused on the organizational perspective. Carol is also deeply interested in the patient perspective.

Carol 07:44

I will say in the work that I do now in my organization, it's not only the thinking about stories, but more and more thinking about them from the perspectives of patients, and what does it mean to tell your story. And what impact does it have on the storyteller. And certainly, many of the patient partners that we've been working with speak about taking a trauma-informed approach - the vulnerability that they feel in sharing their stories, and often the re-traumatizing through telling the stories. And that's something that we are certainly exploring more and more within our organization and being much more attentive to how we're using stories.

Emily 08:29

One of the things Carol reflects on when thinking about her PhD research is that not only is there the power of stories, but what she calls the "power to story", which means having the opportunity and platform to create, elevate and share stories. Organizations definitely have that power, the "power to story". But when thinking about it from the patient's perspective, Carol sees an opportunity for patients to reclaim some of that space, by being involved in deciding how their story is shared. And what happens to it afterwards.

Carol 09:04

The empowerment may come for patients as they're sharing their story, actually as an outcome through which they are continuing to be involved through the sharing of their story. But what happens in the aftermath, after

they have told their story, and how they will continue to be involved? And that's really where the partnership comes into play. And I think where perhaps the shifting of power may actually start to happen.

Jennifer 09:37

So the very premise of patient storytelling in the organizational context is founded on a power imbalance. And I definitely have felt that. I haven't usually been much involved in thinking about how an organization is going to present or use my story. I've usually just made a presentation and then left. So yeah, if patients want to be more involved, I can see how that would give some of that control back to the person who's been asked to tell their story. But there's still an unknown factor. And that's the audience. How people listen to our stories is usually beyond our control.

Carol 10:15

As listeners of stories, we hear things. There are things that we hold on to through our own filters that resonate with us. And then we share the story of a patient in our recounting - it's actually through our own filters, our own lenses of what we felt was important, what resonated with us and that story. And it becomes "a story of a patient", it is no longer "a patient's story". And those are little nuances, little tweaks in language, that actually make a difference and how we're thinking about stories, how we're reflexively sort of realizing our own implications in the story. It's a very, you know, what they call that dialogic nature of stories, especially when someone is in front of us sharing their story. Often, the sharing of the story is how we are reacting to it as well. And how then the storyteller will continue on then in a certain vein, or continue wanting to elaborate in certain areas, based on our responses to that the audience response to it.

Emily 11:28

I think Carol here is calling attention to how the shape of a story is often influenced by whatever interaction we're having with the listener or with an audience. But as we're talking about power, it's interesting to consider that a person telling a story may have more influence on how their story is being heard. If the activity of storytelling is more interactive or dynamic, where there's more of an engaged dialogue with the listeners, instead of just a one way presentation. That kind of storytelling is all too common in health care, where someone tells their story, and everyone else watches. Carol referred to this as spectating.

Carol 12:09

These are people that are invited to go up and to share their experiences. And as an audience, we are spectating, we are listening, we are hearing them. And I think those are the kinds of stories that are more open to the appropriation or co-optation, where people take in the story, take what they want from it, and may use it for their own purposes and different settings or reflect on it. But you know, potentially may have impact or intense, but it's taken on by the listener. And the intent may not be that of the storyteller.

Jennifer 12:52

Even though we typically get to decide ourselves what we're going to talk about, and we might work very hard to present our stories in a particular way - we have no way of knowing what people are hearing what they're learning, or what they're taking away from what we said. It's definitely a risk. And we all know the pitfalls associated with putting too much weight on just one story. Or assuming that one story is typical, or perhaps

representative of a group. Now this risk can be mitigated somewhat by what's known as a "mosaic of engagement". Carol talked about not relying on one source of information like a patient story, but rather looking at many points of input.

Carol 13:35

The story is one input. And the organizations that use stories effectively had many many inputs for patient experience coming in, which may not have been through stories exclusively, but could come in through different informal ways of leadership walkabouts, where leaders would go on to units and be having conversations and getting feedback in the moment real time feedback from patients and the experiences that they were having in care. It could come from other formalized means of patient surveys, patient experience surveys, and through patient (and I hate using this terminology) but patient complaints and patient incidents that might have been coming through. So they had structures in place that were funneling in many ways of gathering patient experiences, but also through more formalized mechanisms of patient storytelling.

Jennifer 14:38

Carol is differentiating here between formal and informal inputs. Now either way, there are types of engagement that don't count as research per se, and maybe even don't really count as engagement. She mentions sifting through complaints, walking through the halls, doing patient satisfaction surveys. These are all ways that organizations interface with patients, and they don't necessarily generate data that they're going to immediately act upon. But they function as a way to get a read on how things are going. Or maybe they stimulate some creative thinking. This is probably helpful in a number of ways. The organization may hear anecdotes that validate something they already knew. Or maybe they learn something in conversation that triggers an idea they decide to look into. There is a kind of serendipity to these sorts of inputs, which might provide insight that would otherwise get missed.

Emily 15:32

Whether done formally or informally, patient stories are commonly thought of as being impactful, even transformational, especially if the story is shared in dialogue. Drawing on the work of Arno Kumagai, a professor at the University of Toronto - we've actually cited his work before - Carol considers how dialogue stimulates different types of learning. In this context, we're moving beyond storytelling as a spectator sport. And instead, we're considering how patients, the organization and even the audience can all somehow engage together to intentionally co determine what has been learned. And by the way, we put some links in the show notes to Arno Kumagai's work.

Carol 16:16

So it was that notion of putting legs to stories, those structures, those processes, where they were very intentional about how is it that we are learning from the story. And so when organizations would continue to have dialogue with patients and families after the sharing of their story - that intentionality of the effect of learning, the cognitive learning and the experiential learning that can happen through that dialogue, that then would lead to more intentional change that would come out of the patient's story. And I think that's where I started to see, you know, to me what I would consider effective ways of learning through patient stories. But that would then have an impact on change through then other engagement mechanisms of bringing in the

patient storyteller, and other patient partners that could then work with the organization on those changes together.

Jennifer 17:20

Honestly, to me, this sounds like a rather idealized notion of how storytelling can go. Let's call it aspirational. And I say that because in my experience, organizations aren't necessarily setting aside the time and resources to work through this sort of co-created experience. But of course, that's not to say it never happens. Perhaps in the context of education and learning, where people are focused on method and process, I can see that some of this could be put into practice more effectively.

Emily 17:52

Well more often than not, I think storytelling in the organizational context tends towards being inspirational, or set up to provoke an emotional response of some kind. Carol also spoke about what she calls the "galvanizing story", which aims to rally people in a particular way. At one point, Carol gave an example of an organization using a patient story to illustrate the importance of a fall prevention initiative - she's referring to it again here.

Carol 18:22

So it can play many roles. But I think in many cases in the stories that we hear, and hear again and again, are often those stories that are catalysts for change. Oftentimes, what leaders might want is sort of that galvanizing story that's going to help elevate it to different levels of the organization. Now, I will say, you know, and I'm using this as an example, the senior leaders are going to know the importance of fall prevention within their organizations, and they're going to want to be preventing this. But sometimes it's galvanizing others staff members of why do we need to follow these best practices, these new protocols or the screening tools that we're now trying to implement, to prevent falls - and sometimes it is those galvanizing stories that might get pulled out, and where a family member or a patient can then talk about what happened to them to try to inspire others than to make the change. And so they can be used in very different ways and in different trajectories of, you know, organizational journeys to what they're trying to accomplish.

Jennifer 19:41

And this gets to the heart of what we talk about a lot on this podcast about engagement generally - what is it we're trying to accomplish with engagement activities? And this is especially important when it comes to stories and storytelling because of the personal and intimate nature of what's being asked of patients. Carol referred again to an organization's "power to story", noting that certain voices tend to get elevated and others may get silenced or excluded. Awareness of this dynamic is really important, but is sometimes missing.

Carol 20:16

And it's that reflexive nature that I think often hasn't happened for conference organizers for people that want to bring patients into the fold that understand there is great power in that, but may not necessarily be reflecting on the power that they're holding in determining which story and whom is telling that story, but also to what audience and for what purpose.

Emily 20:45

Again, for Carol, one way to mitigate this power imbalance through dialogue, ensuring that the patient retains some control or at least has influence over the shaping of their story, what gets highlighted and how the story is utilized afterwards. Carol also sees this as a way to maintain authenticity of the patient voice.

Carol 21:04

And there needs to be that dialogue back and forth, that can help tease that out and to ensure that it remains the authentic voice of the patient. And it really is the experience that they want to highlight and feel that they need to highlight in the circumstances. And, and that there again, it goes back to that authenticity - that it's not the power of the organization that is necessarily sort of shaping the story or saying this is the kind of story that we want, but that there is a common purpose for why are we sharing this. But also that invitation to continue to engage with the organization to then think through what what should be done, what could be done, how do we work together to improve this issue, so that the experiences of patients will never replicate that experience that the patient has now shared with us.

Emily 22:03

What Carol is saying here actually goes beyond just ensuring the patient is involved in the shaping and use of their story. Here, she's talking about starting from the foundation of the patient's experience, and the patient then continuing to contribute to the improvement process and help ensure that other patients don't experience the same thing. If this is the case, the story becomes just one aspect of what a patient might contribute. And in this context, we're talking about a collaboration where the organization works with a patient to develop the story and how it's used.

Emily 22:39

But that's, of course, not the only way that patients tell their stories. We talk briefly about modern modes of storytelling that are developed entirely by the patient, in particular, digital storytelling. Carol was clear that this is not her area of focus. But from what she's seen, it can be empowering for patients to develop their own stories outside of the organizational context. But because her research has been about impact through storytelling, she was curious about the effects of stories told in this way. And the risk that online stories get used in ways that weren't intended by the storyteller.

Carol 23:16

What happens with that story? And and who takes it on? Who uses it? For what purpose? And I mean, to me, that's a whole fascinating other realm. That, you know, in some ways, it's very liberating, because there is no organization selecting and inviting different people to share stories, and filtering in any way. It's somebody very, you know, authentically wanting to share and putting it out there. But I do question what the impact of some of those stories become, and I know some, you know, get hundreds of 1000s, millions of hits that are shared, but then do they affect change? And I would say there are probably educators out there that are pulling those kinds of stories out using them in class to illustrate different things. But the storyteller no longer has that kind of ownership about what's happening. And that's where I worry about some of that co-optation, and appropriation.

Jennifer 24:22

I think these are valid concerns. And this goes back to what Carol was saying earlier about spectating stories. I often use the word "edutainment" to describe the performative nature of the patient telling their own story before a live audience. I've actually stopped telling my own stories because of a deep self-consciousness, a feeling of being on display and a self-imposed pressure to be entertaining, and to hold the attention of the audience. It's way too stressful and no amount of compensation makes up for that. And I think there's something awkward for the audience to seeing a patient tell the most intimate details of their experience through a PowerPoint. Sometimes fighting back tears as they try to be professional but also trying to deliver the emotion they know that people are wanting to see. It's definitely my own discomfort speaking here, but I find these performances kind of exploitive. And I'm left wondering what I'm supposed to do or think about what I just saw. Carol's work actually touches on this. She doesn't describe it like I do, obviously! But she talks about how the audience hears what's being delivered, and makes a distinction between spectating and bearing witness.

Carol 25:37

So I had been talking about, you know, that notion of, and again, I'm talking about within the confines of my study, the kinds of stories that were being shared in person, to various audiences. So this notion of the spectating stories, which is an interesting concept of, you know, we are all sort of watching what's unfolding. But if there is not the ability, or the intentionality to actually reflect and to think about the learning... Again, drawing from Arno Kumagai in terms of the affective cognitive, experiential learning that can come from stories... but the way that it has often been framed is rather than a spectating story, how is it that we bear witness to stories? And that in bearing witness that intentionality of how is it that we are learning, reflecting, and hopefully then taking action as a result of the story. And so I think that that is an important element in distinguishing, you know, the kinds of stories that are brought to bear.

Emily 26:48

So this is really interesting. I imagine it takes a certain amount of priming of the audience, like providing instruction on how to listen. Carol talks about this as creating a safe space, not just for patients, but for the audience.

Carol 27:03

So we talked a little bit about the safety for patients in being able to share and what is it that they need to help support and to ensure that they're well prepared for what's going to happen for the, for the audience that they're sharing with,. But also the creating of safe space for the audience that what they're going to hear, how are they going to take it in? And again, I guess it goes back to the intentionality of not wanting to set this up where people hear these experiences and move into a defensive mechanism, which often is the case: "Oh, that is someone's experience. But that was not the intent that I had in delivering care." And, you know, misinterpretation of "that's not what I said, that's not what I meant". And people's natural reactions, which might be a bit more defensive, but opening them up to those elements of empathy of understanding through someone else's eyes. And then what is it that we do with those feelings and that empathy, to then reinforce learning and dialogue that can happen after. So all of those pieces that need to be put in place to really support the learning from stories.

Emily 28:23

So again, the perspective of Carol's research was how organizations use stories for learning and impact. And now Carol is in a role where she works to develop ideas and support for patient engagement and partnership, which means bringing the patient perspective much more into the foreground. This conversation brought to mind some of the ideas from our episode with Miles Sibley of the Patient Experience Library. Their report "Inadmissible Evidence", talked about how patient stories are thought of as anecdotal, and aren't valued in terms of how we think about patient voice or patient experience. This issue came up in our conversation with Carol. And she noted that she counters this by changing how she talks about stories.

Carol 29:07

So storytelling has become a lexicon unto itself. And again, it's part of our human existence of telling stories, and particularly in the indigenous way, storytelling is a method and is a form of knowledge. And I hear you in that often, when we say patient stories it becomes relegated to anecdotal. And it becomes thought of as not a legitimate form of evidence. But I often flip my lexicon because I think of these as patient experiences - in my particular world, they're experiences of care, the experiences of receiving care within the healthcare system, and that is, what they're sharing. And that it may come in the form of a story, but that it is in essence it's the experience. And maybe I'm using that language because in my head I think if I'm sharing an experience is that helping to legitimize this as a form of knowledge, whereas stories aren't necessarily seen as that.

Emily 30:24

That was such a rich conversation with Carol. And normally this would be a more than sufficient amount of material for an episode. But at the same time, we were thinking about storytelling, we were also interviewing Dan Buchman, a bioethicist at the Center for Addiction and Mental Health, about how bioethics might have something to offer when thinking about patient engagement programs. Because patient stories and storytelling were fresh on our minds, we couldn't help but ask him to give us his thoughts.

Jennifer 30:55

Dan is not a patient engagement expert, but he does participate in patient engagement activities in his organization. And his skills and knowledge as a bioethicist are helpful in understanding how we might think about patient engagement through an ethics lens.

Dan 31:09

I think that bioethicists can help contribute to the overall design of the program, think about considerations around informing patients, you know, how to minimize potential harms of patients sharing their illness experiences. You know, the patient experience and the illness experience are very different, or can be different. And I think that there's those kinds of nuanced distinctions in patient engagement programs are something that a bioethicists with a particular background and training can identify and be thoughtful of.

Jennifer 31:49

We then shifted to talking about storytelling. And Dan had all the same questions I do right off the bat. And this makes sense, as I naturally bring my own bioethics training and thinking into these conversations. But it was

validating to hear Dan as a much more experienced bioethicist raise many of the same issues that we're considering here.

Dan 32:09

And this may come up when we're thinking about what are we asking patients to do. What are we asking them? What are their responsibilities? What do we expect from them? Are we asking them to share their testimonies and their illness experiences? Are we asking them to share their patient experiences? Are we asking them to share other aspects of their complicated and complex lives that that, you know, can enrich discussions? And what does that look like? And what does that mean? Who's benefiting from these interactions? Who's being harmed by them? Are we treating people fairly and equitably? And this this may go to areas such as, are we compensating people for their time? Or are we providing people other aspects of recognition of their expertise and their work and their time. So I think that there's very good good intentions amongst folks that are working in this area. But because there's a very, I think, very strong moral underpinnings to the whole idea of what engagement means, in terms of, you know, duties to another, that this aligns very well with various forms of ethics, content expertise, that a practicing healthcare ethicist within an institution can bring to those discussions.

Emily 33:28

There are a lot of nuanced aspects to this discussion. And we're going to highlight only a couple of them here. We'll focus on ones that are maybe not as frequently discussed about storytelling.

Emily 33:41

So when I think of the word "story", and even "storytelling", it sounds pretty cozy. In my mind, I jump right to the event of it to the person telling their story. I don't really think about the invitation itself, and what that moment of invitation might look like and feel like. But Dan does. He talks about the potential for that feeling of wanting to give back...giving way to a feeling of obligation.

Dan 34:09

From my understanding, when patients volunteer or or agree to be patient partners, to share their story, it's largely because people want to give back. There's that norm of reciprocity. They maybe have benefited from the institution in a certain way, and they find that there's a way to give back. So this is one way in a role as a patient they can give back. But I think we need to think about in healthcare - how we're presenting these opportunities to patients to tell their stories? Are we you know, making people an offer, they can't refuse in a way, right? Is this undue influence to potentially on [inaudible] to the point of coercion, where people feel they cannot say "no" to showing up and making themselves vulnerable in this way.

Jennifer 34:57

So in terms of everyday usage, the word coercion is pretty strong. And Dan's not suggesting here that people tell stories under duress or under threat. It's more about a sense of obligation or a feeling that you can't say no. I know what he means. Especially in the early days, when I was asked to tell my story, it never occurred to me to say no. And there were times when I'd said yes and wish I hadn't, and felt I couldn't back out. There's definitely

pressure. Not necessarily created by people and the things they say - but it's inherent in the power dynamic, and even just in the request itself.

Dan 35:37

Now, this is with not being said that there are people may not find benefit in doing so. And there may be a lot of benefit to the person, benefit to the organization, and a lot of positives from this experience. But I think, you know, given the power that institutions hold in designing these programs, and inviting people - institutions need to pay particular attention, I think, to this issue as well - I think as part of maybe even the informed consent process, that people who are engaging as patients need to understand as well is how is the story going to be used? How do folks around the table intend to use it? Is it a matter of just understanding who's around the table a bit better? Is it to be used in PR programs? How is that story going to actually be used to help affect decisions? Again, these are the ethics all the way down. This is normative decisions. I think patients need to understand that as well.

Emily 36:33

So this was interesting that Dan mentioned informed consent. Well, some people might bristle at this idea in the context of patient engagement activities, but if we think about it: telling your story at say, a conference, is not much different than allowing your photo to be taken. It might make sense that there be a consent form or media release form. Something that expressly states how this story might be repurposed or shared. This isn't applicable in all situations, but certainly in some cases.

Jennifer 37:06

We often return to the idea of power, which in this case is about who is controlling the environment and the opportunity. Dan reflected on the inherent power imbalance between patient and healthcare provider, which persists I think, regardless of what role the patient is occupying,

Dan 37:23

I will first say that I think institutions ought to strive for flattening a hierarchy - not just in terms of patient engagement, but in other areas of structure. That's something I think is a worthwhile goal, to try to minimize power dynamics as much as possible. But I don't think we should fool ourselves into thinking that power and hierarchy, power hierarchies or even epistemic hierarchies, can be completely flat. And people have talked about this for a long time in terms of let's say, the patient physician relationship. And a lot of the discourse over the years has looked at more of that, you know, shared decision making, supportive decision making, and trying to flatten or move away from that traditional paternalistic model of the relationship. But, no. To be a patient is to, by definition, to be vulnerable. Patients are accessing healthcare professionals because of their particular knowledge and expertise. They place trust in them in their content and their competency, and that they will do what they say they're going to do, and not leave them worse off. And so there is an inherent power imbalance there. And so we, you know, even if we use language of "patient partners", which I think is an aspirational goal, I don't think it is necessarily the reality.

Jennifer 38:48

Dan elaborated to say that this inherent power imbalance is inherent only because of how our system currently functions. With organizations determining the rules of engagement, he noted that things could potentially look a lot different if patients were actually in positions of power, or at least employed on the same level as healthcare decision makers. Things being what they are, however, he sees room for negotiation.

Dan 39:15

We ought to do things to be equitable, such as you know, considering to have more of a negotiation relationship. In terms of the relationship, the dynamic, I think there's lots of things that can be done but we can never completely minimize that power hierarchy, because that always will be there. It will always be there, too, in terms of whose knowledge counts and how it's being used and how it's being integrated and informed or what role and purpose does it play. But at the end of the day, you know, stories are powerful and can hold a lot of power. But if the institutions are still dictating the terms of that story, and the boundaries of that story, and how the story is used, there is still a hierarchy there and so it is not quite a true partnership.

Emily 40:13

As part of his role as a bioethicist, Dan spends a lot of time thinking about ethics and research methods, including the way we collect and utilize patient data. Of course, Dan recognizes that organizational improvement activities are not held to the same standards as research activities. But still, he has concerns. If patient stories are not just stories, but in fact, important ways to learn something through someone's experience, well, we should be thinking deeply about how we are going about eliciting stories and deriving meaning from them.

Dan 40:51

There may be a sense from folks that are working on developing these policies or guidelines that, you know, let's ask patients what they think how this should look? Or what are some of the values or principles patients think should underpin this policy? And then we'll go back and we'll use those. And so maybe folks without any training in data collection, without any training in survey design, without any training in qualitative interviewing, for example, or quality improvement, may go out and find someone sitting in the lobby and say, "will you answer a few questions for something we're developing?", and the person very well intentioned, may be completely transparent about what they're doing. But the person from the healthcare institution may or may not have that specific kind of training. There's some potential harms there. Like, we would never allow that in a research context. We would never have untrained or unskilled people collecting data for various reasons.

Dan 41:57

But it's also a data quality question. Because if people who do not know how to design survey questions are designing survey questions, and then asking patients for their responses, there could be many problems. And any of us who work in research know how difficult it is in designing a survey or even just crafting a research question - then going out and collecting data, let's say about certain values and principles that should underlie a, you know, visitors policy or a access to certain resources within the hospital policy. And then those findings from this quality improvement initiative - very well intentioned - are then taken back and used as evidence of what the values that patients hold, and are generalized as such.

Jennifer 42:48

We think this is relevant to storytelling for a number of reasons. As Carol has mentioned, stories and storytelling are important inputs that inform decision making, as well as training and education. And if the shaping and use of stories is something that is potentially negotiated and co-produced with patients, the ways in which organizations go about this is really important. As Dan describes here, the outcomes of a poor process may have lasting implications.

Dan 43:17

This is where I have concern about some of these methodological pieces that seep into engagement practices with folks who want the best and want to improve patient care and want to improve the quality of patient care but don't have those skills on the tools and how to do this. And maybe done in some cases without adequate ethical reflection. And then we get... I'll call it a "pseudo scientific authority" of what the outcomes are. And we may have a situation where this poor data quality, which could have potentially caused a lot of harm, is now given, as you described Jen, the "ideology of patient engagement" in health care institutions, prioritized and given a lot of weight in institutional programming and perhaps extended well beyond the initial intention of what it was designed for. And I don't think that benefits anybody.

Jennifer 44:19

Hi, Emily.

Emily 44:20

Hi, Jen.

Jennifer 44:23

I'm really glad we got to spend a lot of time on this topic. Storytelling is so embedded as part of patient engagement and partnership activities that I think it just kind of washes over us as a given. It's not usually thought of as controversial. In fact, we often understand it as a kind of entry point into engagement. It's seen as a good place to test the waters and see if we enjoy it. I know many patient partners have started this way, including myself. Telling your story is like the ticket "in".

Emily 44:54

Yeah. And there's something even more fundamental about stories. You know how Carol interchanges "patient story" with "patient experience"? Now, she was doing it to remind people that stories are credible sources of knowledge... but overall, I think it's a fairly common understanding. I think for many people, it's like patients are "walking stories". And in fact, that's why they're there in the first place. I mean, to be really reductionist: the story or experience is what makes the patient. So yes, telling our stories is one form of patient engagement. But if we equate stories and experience, well, then stories are a fundamental part of being engaged. I think that's partly why we really like engaged patients to tell their story in whatever form they appear - meetings, conferences, making introductions - it establishes them as a proper or legitimate patient.

Jennifer 45:56

Yep, we really do love stories. And, you know, honestly, I'm not making fun of that. It's a tradition as old as the ages. Stories humanize. They put a face to numbers and they inspire or galvanize, as Carol mentioned. They

move people in ways that help us all feel more connected. And they also offer teachable moments. Stories are vehicles or devices. They're instrumental to conveying something important about or for the organization. And it goes deeper too - something kind of intangible. You mentioned earlier, this idea of "insert patient here"? Well, this is amusing, of course, but it also speaks to something kind of earnest. It's the assumption that all patients have a certain wisdom, and it doesn't matter who. And if you lean in and listen close, maybe something magical will happen.

Emily 46:48

[laughs] Yeah, I've been caught up in that special feeling, both as an audience member and as a storyteller myself. It's like the "event" of storytelling - a real life patient being seen and heard - has its own sort of value. Even if you remember nothing about the story itself, there's a sense that something important has happened. And on a more practical note, as Carol says, stories are everywhere. So for the organization, it's a readily accessible way to add impact or value at virtually no cost. So there's a lot to love about stories!

Jennifer 47:29

Yeah, which means we don't always use our critical faculties when listening. I mean, we both have a lot of experience telling stories. And one thing I know for sure, is that I spend a lot of time constructing what I want to say. I want to sound real and authentic. But I also don't want to freak anyone out with some of my darker thoughts. I want to be relatable and provide enough detail to paint a picture, but I don't want to be boring or gross. I want to stand out, I want to seem typical. I want to be emphatic, but not scary. It's such a fine line to walk. And I navigate both consciously and unconsciously. At some level, we're all presenting a version that we want people to see. And considering all of this, it seems a bit much to call it authentic.

Emily 48:17

Right. Well, it gets complicated. I mean, all we have is words and language to convey an experience. So it's not like there's some other way to easily communicate what we want to share. But yeah, it's not like our stories are static objects just waiting to be collected. We create them. And we do it with all of our human impulses to present things in a way we feel comfortable with. We also don't usually create them out of the blue. Someone asks us to do it, and we make assumptions about what they might want from us. And at some level, we tell them what they want, or what we think they should hear.

Emily 49:00

Also, thinking of my own experience - well, I'm sure the details of my story have somewhat shifted over time. Sometimes I wonder if I'm remembering what happened, or remembering the last time I told the story. And as Carol spoke about, the way the audience reacts, the questions they ask or the anecdotes they laugh or cringe at - those things definitely influence the way we describe how things happened. So I think stories are useful in many ways. But they're also more complex than we tend to think of them.

Jennifer 49:36

Yeah, and this is where Dan's comments are really relevant. Gathering and understanding patient experience requires a very specific skill set that's usually found in the research world. And we're so adamant that engagement activities, including storytelling, aren't research. It's hard to reconcile that with this other

perspective that says patient experience is evidence, is an important input into decision making, has significant impact on system improvement and policymaking. And I'm not saying it has to be either/or - it's just that if we're going to take patient stories seriously, we should be extra mindful about how these invitations are extended, what context patients are being invited into, and for what purpose. And it has to be said: if we did have more of a research approach or mindset, we might be more reflective about the questions of power that keep coming up.

Emily 50:30

Yeah, I'm not convinced that some of the things we've talked about in this conversation actually lend themselves to evening out power imbalances. I mean, sure, if patients are developing their stories and dialogue with organizations and helping to frame how their stories are going to be used? That definitely makes for a more pleasant collaborative experience, and one where it's kind of like a win-win feeling. But it still serves the organization's purpose, and it's still extracts the story out of the patient for their own gains. I think it can create a sense of empowerment for the patient. But well, I mean, certainly reflecting on my own experience with telling my story, the organization's really given up nothing and gets to reward itself for listening, even if nothing changes.

Jennifer 51:19

Yeah, I'm with you on that one. I don't think we can collaborate our way out of systemic power imbalances. I like Dan's thoughts on patients negotiating terms of engagement. But that has to happen much further upstream. And I don't think it can happen effectively patient by patient. But that's the thing about individual invitations to tell your story. It's flattering. It's very personal, and it feels like important work. And in many ways, it doesn't seem like it has anything to do the wider patient engagement landscape.

Jennifer 52:52

I remember when I first started commenting publicly on patient engagement, there was a point where I felt a bit of imposter syndrome. Like, you know, what do I know about any of this? But my partner Carsten looked at me slightly bemused and said, "well, you're the ultimate engaged patient!" And at the time, I totally didn't get it. But he was right. I had been telling or writing my story and all of these healthcare forums for a decade or more. I was a super-contributor. And what's come of it all? What impact did I have? I don't know. It's pretty varied and nonspecific.

Emily 52:30

I certainly resonate with all of that. Well, okay. So where do we want to leave things? I know, for me, one thing I'll take away is that there really is a difference between patient experience and patient story. Experience is something we can come to understand through a variety of means. And the story itself, whether it's shared on stage or as part of a meeting, well, it's a person's version of their own experience, or even just a fragment of their experience. That has its own value, of course. But we should always consider that there's a context, a framing, and that the story is rarely a complete story.

Jennifer 53:14

Yep. And I'll just add as well: patients should be mindful that an invitation to tell their story comes because the organization wants something. And they usually want something pretty specific. And we see all sorts of frameworks and guidelines and best practices now about how to tell stories effectively and for maximum impact. Well, we need to ask, effectively for whom? Impact for what? We know that everyone has a story. But not everyone is asked and not every story is appropriate. There's both a deliberate and unconscious selection process going on. And I think we'd do well to make that more explicit.

Emily 53:59

Thanks to our guests, Carol Fancott and Dan Bachman, for sharing their insights with us as we puzzle through yet another complex topic. We're always interested in your feedback. If you have any comments or questions, please get in touch through our website at mattersofengagement.com.

Jennifer 54:19

This episode was written and produced by Jennifer Johannesen and Emily Nicholas Angl, with generous financial contribution from the Ontario SPOR SUPPORT Unit, or OSSU, which is jointly funded by the Government of Ontario and the Canadian Institutes of Health Research, or CIHR. The views and opinions expressed in this episode belong solely to the producers or their guests, and are not to be considered endorsed by OSSU, the Government of Ontario, or CIHR.