Transcript
Matters of Engagement podcast
Episode: “Moral Distress in Engagement Professionals, with Mark Weir”
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Note: this is a replacement file for the original episode, which contained an error about Mark's training.

SPEAKERS
Jennifer Johannesen, Emily Nicholas Angl, Mark Weir

**Jennifer** 00:07
Hello, and welcome to Matters of Engagement, a podcast exploring the complex world of patient engagement and partnership. I'm Jennifer Johannesen.

**Emily** 00:15
And I'm Emily Nicholas Angl.

**Jennifer** 00:19
We've had a few episodes now that feature the experiences of engagement professionals - people whose jobs are to organize and conduct engagement activities on behalf of healthcare organizations. Way back in Season One, we spoke with Francine Buchanan at SickKids Hospital and Aman Sium at Holland Bloorview. Then in Season Two, we spoke with Katherine Dib and Katie Burnie of Kids in Pain, and Kelli Dilworth, at the Centre of Excellence for Child and Youth Mental Health. Each of these guests highlighted different aspects of the work - whether it was the complexities of relationship building, or the emotional toll of failed experiences, or the questions that arise when occupying a role that requires lived experience. So we've covered a lot of ground. But I think we've really only just begun to scratch the surface in terms of how these roles can be experienced.

**Emily** 01:10
Yeah, and as you mentioned, there are a lot of factors at play. I imagine part of the issue is that it's challenging to even develop clear job descriptions for these sorts of roles. It's hard to capture the spirit of what is essentially relationship-building in a list of deliverables. So it's up to the person in the role to just figure it out. There are advantages to this as the person can shape the role to some extent, but it also potentially creates additional responsibilities and burdens that don't get acknowledged, or even seen.

**Jennifer** 01:44
Yep, and working for large organizations can mean lots of constraints, protocols, regulations, a lot of moving parts, you're typically part of a long chain of events and processes, which means you don't necessarily know how, or even if, your work is going to be used. There are a lot of aspects you don't have control over.

**Emily** 02:05
Well, particularly in healthcare, this can lead to experiences of moral distress, which is what our conversation is about today. We tend to think about moral distress more in terms of clinical practice, but it relates to patient engagement as well. Moral distress is a term first introduced in nursing practice in 1984 by Andrew Jameton.

Originally, it was defined as "knowing what to do in an ethical situation, but not being allowed to do it." This applies to a wide range of situations and contexts, including end-of-life care, scarce resource allocation, and various types of health care decision-making. And in all contexts, there seems to be an overwhelming sense of powerlessness that drives the distress.

**Jennifer** 02:53
Well, a timely example is around COVID-19. Healthcare professionals face issues of: health system capacity; policies that affect schools and businesses; equitable access to vaccines and testing. People working in these spaces experience not just physical exhaustion, but immense disappointment, frustration and anger with how decisions are being made. This is a good example of workplace related moral distress, where there's an additional emotional toll because of factors that aren't really related to the actual job responsibilities. And we've come to accept it. But delivering good health care shouldn't have to include this kind of distress.

**Emily** 03:33
Right. And because of the interpersonal nature of patient engagement work, it's definitely not a stretch to imagine that moral distress can be an issue. Our guest is Mark Weir. He's the Director of Strategic Planning and Community Engagement at Woodstock Hospital in southwestern Ontario. Back in the fall of 2021, he presented a workshop on moral distress at the IAP2 Canada conference. IAP2 is an association for professionals in the field of public participation.

**Jennifer** 04:04
The workshop was called Weighing on our Shoulders:  Moral Distress and Compassion Fatigue in Engagement Professionals. We learned about it on twitter, actually, and we were keen to find out more. This conversation was really interesting on a number of levels. I mean, first of all, we appreciated the opportunity to hear from someone who was so committed to his work. Mark clearly cares about engagement and believes in its importance.

**Emily** 04:29
I think even just the fact that Mark is attuned to moral distress... ? Well, it indicates a level of sensitivity and self awareness that probably makes him well suited to this work. So it was interesting to get a glimpse of his experience. But we were also interested in this discussion from more of a macro level.

**Jennifer** 04:48
In Mark's presentation, he defined moral distress as feeling stuck and wanting to do the right thing but constrained due to barriers. And he mentioned systemic or institutional barriers as examples. Now, just to be super clear, Mark's not talking about the emotional toll it might take to build relationships and trust with patients. That's not moral distress. The moral distress Mark is referring to seems to be caused by workplace and environmental factors, which are beyond his control. And to us, this is an opportunity to take a closer look at the context of engagement in general. What are some possible causes of this distress? And what does it say about the overall project of patient engagement? Emily and I try to sort through these questions later in the episode.

**Emily** 05:37

Okay, well, let's hold that thought for now and get to our discussion with Mark. Our conversation started with getting a better understanding of how patient engagement relates to or differs from community engagement, and how moral distress plays a role. Here's Mark:

**Mark** 05:53
I find when you engage the people who either have already been served or are kind of in the process of being served - patients, families, caregivers - it's a different conversation. Slightly different. When you go out into the broader community, the more general public, a lot of people reflect on different experiences that they had - but they also look to your organization as part of their community. They want to know that those services are going to be available when they need it. But they may not really appreciate or understand maybe some of the inner workings. The kinds of questions that you might ask definitely differ. We will open our doors and invite people in. But when you do community engagement - like, you're going to their meetings, you're going to their settings, and you get a much broader perspective on what your services mean to the community.

**Jennifer** 06:45
As director of Strategic Planning and Community Engagement, Mark's role encompasses engagement with people and groups that certainly includes patients, but may not be limited to patients. This gives Mark a broader perspective, and perhaps a heightened sense of responsibility.

**Mark** 07:02
It helps you appreciate that you do have responsibility. Or you're stretching your responsibility beyond just people once they enter your walls. Like, you're needing to think more about how people access care. How do people even get to the hospital? What about when people are discharged? Do they have a plan to get home? You do pick up on definitely some tensions that can weigh on you. Because you realize some of the systemic barriers more so between institutions and across the system.

**Mark** 07:36
Focusing on the public can sometimes need even bit more clarification in terms of, you know, sometimes people will think more of the public in terms of their role as a taxpayer, and the kinds of questions that they have about where their taxes are going, how they're being utilized, resource allocation, those sorts of broader public services kind of questions. I think when we talk about public, we're not always crystal clear on like, what are we actually really trying to understand from their point of view? And to your point, it may have very different stakes.

**Emily** 08:11
Throughout his career as an engagement professional, Mark has been primarily working in the healthcare sector. However, many of his peers work outside of healthcare. And he finds that opportunities, like conferences for engagement professionals, provide a chance for him to network with colleagues and learn from their experiences and other sectors.

**Jennifer** 08:30
Right, like the IAP2 workshop we mentioned earlier - that's what he's referring to here.

**Mark** 08:36
Yeah, I've had a real interest in speaking at those groups, because it's quite therapeutic in a way - like, they're conference presentations, certainly, but, you know, it's a chance for that peer to peer support and knowledge exchange. And when I decided to put together an abstract that talks about some of the issues that I've wrestled with through my career, is that I think as a practice, we're really good at sharing the work that we do. But I don't think we're always as good about talking about the impact that that has on us as practitioners and our ability to sustain our motivation and enthusiasm. And, you know, battle some of those demons around just, you know, disillusionment.

**Mark** 09:18
You know, there's an opportunity at those conferences to go beyond just the work that we do. But to talk more about, how are we taking care of ourselves? How are we continuing to advocate for strong engagement work that will allow for those sustainable decisions? Because we don't want situations to have to escalate to the point where people are lobbying for change, or there's having to be so much organized advocacy in a sense, where it's very diametrical.

**Jennifer** 09:47
So this goes beyond what we commonly hear about when we talk about challenges in engagement. Often, it's about trying to build capacity in the patient population, or trying to navigate organizational growth. processes and systems to ensure support for engagement programs. Or maybe we talk about managing interpersonal and group dynamics...

**Emily** 10:08
Right. So these conversations are usually about tactics or implementation. There's something bigger here. Mark is acknowledging that there's more at stake than just gathering patients together and asking for good ideas. He recognizes that patients are seeking outlets to be heard in a way that's satisfactory to them. Otherwise? Well, that's where Mark talked about wanting to hopefully prevent escalation of issues to where there might be conflict. So the moral distress is heightened by also feeling responsible for keeping patients happy. It's a lot to bear. And so Mark is looking to colleagues to see if there's a way to support each other through, as he says, disillusionment.

**Jennifer** 10:52
Mark continued with describing some of the ongoing work of navigating patients' needs, and finding ways to incorporate or learn from their experiences.

**Mark** 11:00
And then when I say like, you know, "diametrical position" it's not to say that they're needing to be a difficult person or challenge everything and whatnot... it's just that maybe they're gonna find more satisfaction by setting up a bilateral meeting with somebody - to sort of put this as this is my position and this is the kind of change that I think needs to happen. But there's other routes for some of that, too, within healthcare. I find sometimes a Patient Relations route, or maybe that it's helping direct them to, say, a different level of the

system that is the actual where change perhaps is where it needs to happen, rather than where it's lived out. Anyway, it's a very important central tension of this work. And it's not something that is formulaic. It really doesn't need to be explored and address with with each person that you're looking to engage with. I think at the end of the day, everyone is trying to affect some kind of change - you're really just trying to find the right match for a lot of thos avenues and sometimes... [fades]

**Emily** 12:04
For Mark, the engagement role is more than recruiting patients into committees. He's actually in a kind of facilitation or brokering role, where he's welcoming a patient who might have something to contribute - whether it's feedback, or a suggestion... maybe they want to volunteer, or they might be really upset about something and they're looking for the right place to bring their complaint. Mark is kind of on the front lines of customer service, which comes with stresses or tensions that might not be present in other managerial or administrative roles.

**Mark** 12:34
You can feel a push and pull from both different sides as well. In creating that vulnerability for... speaking with patients and families.... like, they're sharing with you incredible personal journeys of hope and being let down and, you know, feeling like they've got a second chance at life. But then other people who have had great tragedy. And in a way, you're kind of trying to help them... not "make sense" of what they've been through, but try to find a way that it's not all for naught. That starts to weigh on you a bit. Because in order to create that vulnerable space, you as a practitioner have to become vulnerable yourself. I mean, I've shared lots of personal things about myself to folks, you know, including my own personal health journeys that have been, frankly, chaotic and confusing and frightening and disempowering at times - also been really, you know, great at times, too. But yeah, it certainly... you internalize a lot of that. Folks will maybe say like, "oh, you know, do you just kind of have to keep it separated", and all that sort of stuff. And it's just not... it's not possible. And it's not, frankly, I think, a good way to do engagement work, especially with patients and families. Because when you create that vulnerability, you bring some of that story of theirs in with you as you try to find the right places within the health system about where is that idea... the best place to effect some change.

**Jennifer** 14:15
Mark has training in genetics and health ethics, and has been working as an engagement professional for many years. But like many who do this work, he also shared with us that he's been an engaged patient himself. So he has a sense of what it's like on the other side. He brings a natural empathy to the role, which is undoubtedly helpful. But I wonder if it also ups the stakes of it, increasing a sense of distress when things don't go well?

**Emily** 14:43
Mark also mentioned vulnerability a few times. This is language more commonly heard in sort of more therapeutic sessions. I suppose that's how many people experience engagement in health care. People share details, thoughts and feelings about being a patient and those are usually very private. Trust plays a big part of whether people want to share or not.

**Jennifer** 15:06

Right. And it's not just the vulnerability of the patient that Mark is talking about. He's talking about sharing his own experiences as well. And that's fairly common in engagement work, people are often hired, at least in part because of their lived experience.

**Emily** 15:22
Yeah, and for a lot of reasons that can be really valuable. But we know from other conversations, that there can be mixed feelings about how much to share once you're hired into a role. I know I've experienced them. Some people will want to share and relate and others feel it's just not appropriate. But since shared vulnerability helps with building trust, as Mark has experienced, it might actually feel like a job requirement, whether it's stated or not. Which, for some of us, can create some inner conflict.

**Jennifer** 15:55
I imagine that can be tough to navigate. And for the patient, trust is not just about feeling safe in the moment - although that's a big part. It's also about knowing that the person you're talking to is going to take what you've shared, and do something good or productive with it. All of this combined? Well, it's a lot.

**Mark** 16:15
You know, you're dealing with all these things that are moving parts, and there's different timeframes for different policies and initiatives. And, you know, another analogy I might use is I kind of feel like an operator where you're taking a call from the patient, and you're understanding what is at stake here. But then you're also trying to find the right receptacle for it, but all those receptacles are moving. And you know, the person on the line is really kind of counting on you to help them, to help others, by taking that insight and applying it to the right place. So it does create moral distress, because you do feel like you can let people down very easily. You just feel terrible, because, you know, you want to try to move things to a better place. You want them to help move things to a better place.

**Jennifer** 17:09
I thought this was an effective visual that Mark described, trying to make connections like a receptionist and not being able to put people through to the right person. And actually, if we run even further with that analogy, it's probably more like being a 911 operator, but you can't access emergency services. You can take the call and talk people through something that's really difficult. But if you don't actually have a solution to offer, well, it can be highly distressing.

**Emily** 17:36
Yeah, and Mark's not saying it's 100% of cases where the connection gets dropped. But it's enough that it weighs heavily on people in this role. I mean, he's not using the term moral distress lightly.

**Jennifer** 17:50
No, that's right. And it's not just barriers within the organization. He alludes here to much wider systemic and societal issues, which might include racism, discrimination, and other forms of systemic mistreatment that result in patient distrust.

**Mark** 18:07
Every once in a while it comes to your awareness - but not all the time - of again, these systemic barriers that maybe have nothing to do with you or your institution or the way you're engaging. But say you're trying to engage audiences that have, just, there's a complete lack of trust, because of, you know, generations of neglect and lack of service or the service has caused harm. You know, organizations are wanting to take these next steps to engage with those audiences. But I found myself at times in a situation where it's like, now I am the face of not just the organization, or the system, but it's like the whole historical setup of how healthcare has been organized. And it's all of a sudden now like me as a person trying to go and have these conversations where you know that it's not going to be a simple thing. And in many ways, you're just trying to start with building a relationship, rather than try to get to some deliverable.

**Mark** 19:10
That places great strain on you, because you want to do a good job and you're trying to be as thoughtful and down to earth and authentic as possible. But you realize, sometimes it is so much bigger than you. You can feel a great strain on yourself to all of a sudden now be the person who's putting that responsibility onto your shoulders, because you know there's still so much learning and relationship building that needs to happen that so many levels.

**Jennifer** 19:41
I imagine that what Mark's describing here doesn't show up in job descriptions. He's talking about not only shouldering the weight of current and historical grievances, but also having to be the interface or the buffer between the patient or community and the organization. Now that's a tall order, to have someone on the frontlines absorb all of that pressure.

**Mark** 20:06
You're no longer just an engagement practitioner - you're also like a coach. You're trying to work with many subject matter experts who have many different disciplines, many different educations, many different worldviews, frankly, about what is knowledge? What is valuable? Whose values are we trying to serve? And, you know, so many organizations in the health care are evidence based, so then you get into lots of different discussions about well, what is this is? What is this engagement work? Is it evidence? Is it information? Is it more advocacy, that kind of thing?

**Mark** 20:50
You know, you don't want to make all these decisions based on assumptions, it's better just to ask the people who are really impacted. But there's still this growing pain of knowing what to do with that information, and how does it stand up alongside clinical evidence and economic evidence? And, you know, should it inform decisions? Or should it help to make decisions? And... [fades]

**Emily** 21:11
Okay, so, I think Mark just asked all of the questions about engagement we've been wondering throughout this whole podcast series! It's a really challenging role to be in, especially if you're sitting with all these unknowns.

**Mark** 21:25
You know, there's so many growing pains along the way, where, again, I think it's just sometimes a matter of, as I mentioned, those kinds of moving targets that you keep trying to hit. Sometimes it just doesn't line up. And it's just, it's painful, because you realize that the train has left the station on something, and then it's like, you've got this great input that can't really affect anything. And then, frankly, you know, the organization may look bad, because it's like, "oh, they didn't listen" but it's actually just that there's so many trains moving in and out of the station that it just, it just doesn't look good that, you know, we've taken the time to do this really thoughtful work. And it's like, it never really went anywhere. And it's like, your role as an engagement practitioner is then to try to work within the organization to say, "Okay, next time this train is even being assembled, can we start to talk to people, rather than wait until it's, you know, getting full steam ahead."

**Mark** 22:25
So there's a lot of that interplay that you're doing. And again, with these massive organizations, it might just be you or a small group of you who are trying to keep on top of this massive machine of all these different moving parts. You wear that responsibility - you feel like, you've been that bridge that somehow collapsed. And then it's just, you know, you're kind of get disappointment, all around. And, you know, part of it too, I would say is that I'm trying to also work with colleagues who they who they themselves may not always know how everything works. We're all kind of working together to try to find the right route for some of this input to actually filter up into how decisions get made, not always knowing what are all the other factors that decision makers are weighing up. But it certainly weighs on you, who is trying to be this bridge, this conduit, to all the people who are impacted and being served by the health system.

**Jennifer** 23:34
Mark is trying to manage a lot of things at once - managing patient expectations, while building capacity within the organization, all while trying to navigate through processes and decisions that aren't transparent to him. In addition to the moral distress, there's also the risk of a kind of burnout or compassion fatigue. In this kind of job, like with many other frontline roles, where you're interacting with patients on a regular basis, you just can't have a bad day without potentially impacting others

**Mark** 24:04
Working with people and their stories - you can almost say that distress there is a bit more compassion fatigue in a sense. And, you know, real concern that you know, you're trying to help somebody make sense of sometimes a senseless situation or set of circumstances. And the last thing you're trying to do is re traumatize somebody, that sort of thing. So that I think, can definitely be addressed a little bit more through again, some more proactive... I have gone to a couple of workshops here and there around empathy and, you know, sort of the self care and asking appropriate questions - and when it comes more to the systemic tensions, and that sort of thing, I do think that that is something that is perhaps shared a little bit more across sectors beyond health care.

**Emily** 24:54
Mark raised an interesting point here about the engagement profession in general. It's a much wider field and just health care, of course, and many of his peers are working in sectors that don't include this sense of

partnership. In many cases, engagement means stakeholder consultation, which may take the form of things like public surveys, or town halls, information sessions. Well, this is quite a bit different than patient engagement, where there's an expectation of relationship building, collaboration and co-design. So even though there's a wider community of practice in terms of public engagement, the healthcare context presents some issues that are unique to the space.

**Mark** 25:33
You have colleagues that work in more like environment and energy. And, you know, when I talk to him about all these compassion fatigue things, they're like, "What are you talking about?" But when it comes to systemic challenges, we're like, right on the same page. And, you know, trying to talk about understanding a system, talking about.. you have to understand all sorts of frameworks and legislative and regulatory components and that side of the system - I guess, there's no real roadmap for like a clear path of like, how do you address some of that? And especially, you know, how do we address again, some of those systemic barriers that patients and families encounter?

**Mark** 26:19
Societally, we're, we're facing now a lot of these question marks about how do we address systemic challenges, systemic barriers, and I don't think it's just gonna be engagement work that moves us forward. I think we're an important role of it, I think we have to help - not just always build the trust...? But say when an organization builds trust, that trust is then bestowed upon us to go and have conversations that we need to be very cautious and careful around trying to not erode that trust further and needing to be very good listeners.

**Emily** 27:01
I think this is actually where institutional patient engagement practice has perhaps improved the most. Far from perfect, of course, but there is a notable shift in terms of creating a welcoming atmosphere and trying to provide some kind of... platform? .... where patients can feel heard. Whether that's on committees, or advisory panels, or perhaps one off projects. Again, not across the board, but some engaged patients do really feel engagement activities give them a space to feel heard, even if they still harbour suspicions that it might not lead to actual change.

**Jennifer** 27:36
Right. Well, obviously, just listening isn't enough. Trust can be hard to earn, or can be easily broken, if there's no follow through.

**Mark** 27:45
It's just not sufficient. I think that's where folks would maybe feel like, okay, you're listening as the engagement professional, but I'm not really seeing any change happen. I would say again, like that's where you feel that responsibility as the engagement professional because you're furiously trying to find those different receptacles for.... you know, as the operator, you're finding all these different receptacles are moving around and you have an appreciation for the complexity of different organizations and where this one idea may actually really be valuable. And so you're trying to create those channels where that listening can happen. And it's not like we all went to school to become engagement practitioners. I think there's more formal education coming and it's

evolving. But I don't know, I'm not sure there ever be just like a single course on "Okay, now you take this, now you're prepared for everything." A lot of this is experienced by living through it.

**Mark** 28:41
And I think just needing to get people to pause and not just keep forging ahead, and then later on feeling like completely drained or have breakdowns to say, "I just can't, I can't keep doing this the way I'm doing it." You know, I guess another kind of part of the role certainly is being an advocate for good and thoughtful well-designed engagement. I do have conversations with other colleagues who say they want to do X, Y, and Z. You know, I'll chat with them and say, "Okay, help me understand, like, what are the timeframes you're working with? Where is your project going? You know, how are we gonna explain this to the people we're engaging, so we can, you know, make sure that they're clear." It's really important to help, you know, make sure that you are not setting something up for failure. And you might end up taking, say, five steps back by doing X, Y, and Z.

**Jennifer** 29:37
This is the capacity building piece of the job. As Mark mentioned, there's just not a lot of training for these kinds of roles. And even though organizations are carving out departments and programs, they're still quite inexperienced. Mark is trying to shape how people think about engagement, so that there's actually somewhere to integrate the input he's tasked with obtaining.

**Emily** 29:58
Yeah, and I imagine it's quite frustrating. Well, we asked Mark if there's room for refusal. When you see something being done poorly and you know the risk of causing harm is high, can you just say no or push back?

**Mark** 30:12
There can be a bit of a reluctance to push back or to your point, like, you don't want to be the obstacle for progress and what people want to do. But there's incredible value in managing those expectations internally to say what the risks are, what could potentially arise and what your past experiences have been when things maybe have been rushed or inauthentic or not clear - those sorts of things. But I do think this kind of, you know, bringing out these ideas of moral distress and getting some conversation about it, etc, is ultimately trying to empower practitioners to have that confidence so that when we have those conversations, they don't just feel like them against the world, but that there's actually, you know, a whole association or practice that feels like this is something that we need to advocate for.... [fades]

**Emily** 31:15
Right, so it's not just about building capacity within the organization. Here, Mark is talking about shoring up the confidence and skills of engagement practitioners, so they can advocate for better engagement within their organization with the support of a wider community. Which is where the conference workshop comes in.

**Mark** 31:32
There's no straight line in this practice. There are good days, there are bad days, there are challenging experiences. But as I mentioned, exhilarating ones to where it feels like you're opening the window, and there's a breath of fresh air. And it's just like, an aha moment where things are clicking, and it's amazing. But if you

don't have some of the awareness, I would say, of some of the moral distress that comes along with this work, it can kind of creep into your sense of being. And it's happened to me, it's why I want to create a space where that conversation can happen. Part of the culture change within organizations is simply getting invited to those meetings. And again I've been in three inaugural roles. And sometimes folks just don't know to invite you to certain things. I don't think it's intentional to leave folks like us out of it. But sometimes it's just not top of mind. Trying to name and deal with some of the... work through some of the moral distress and challenges through this work is then to empower practitioners to have the confidence to speak up at those meetings.

**Jennifer** 32:46
Well, I can see why it can be a heavy burden sometimes. Mark is a fairly seasoned engagement professional at this point. Yet each of his healthcare related engagement roles have been inaugural ones, meaning he was the first person to occupy that role in the organization. And that's a lot of culture change, he's been trying to impact. But Mark remains optimistic. For him, the good outweighs the burdens.

**Mark** 33:11
I am very much on the "it is worth it" side of things, especially because this is a field of work that really is still growing into itself. For all the work that you're doing within an organization, it also feels like part of the motivations for doing the work is that you are growing a field of work. You're trying to take it to the next level, and you're willing to go through some of those growing pains. You know, beyond just myself and being in these inaugural roles, I do think that organizations that create engagement roles do need to support their staff. I think that they want to, maybe they just don't really know how to completely yet? Maybe in part because again, we're so focused on these best practices that it's sort of seen as like, there's a lot of just the great things out there. And there are great things, I'm not trying to detract from any of that. It's just to say, we need to appreciate the toll that, you know, the vulnerable space that some of those people get into.

**Mark** 33:48
I just appreciate that I've been able to have a great experience through this career, but it hasn't been without things weighing on me. I think I'm not alone in that. And, again, I want it to be done thoughtfully. You know, we often hear about the word meaningful engagement. Like for me, I think meaningful can mean a lot of different things for a lot of people, but for me, it just has to be authentic. Are you fully present when you're engaging? Are you bringing some of yourself? Are you creating that vulnerable space? I think we need to do that in order to make this successful. This experiment....this engagement field of practice, but there's a bit of a trade off with that. I guess there's a bit of a side effect of that. And it's not like it's not worth it.

**Jennifer** 35:08
Hey, Emily.

**Emily** 35:10
Hi, Jen.

**Jennifer** 35:12
So I don't actually have a lot of further comments on the specifics of our conversation with Mark. Mostly I'm just appreciating how thoughtful he is about the work and how much he's wanting to help improve people's experience of the role.

**Emily** 35:25
Yeah, I agree. We had a follow up call with Mark after the workshop - sounds like this really resonates with people. And there's a lot of interest in the peer support he's talking about. I think this concept of moral distress is only just starting to take hold. So it makes sense that Mark is first trying to gauge if this is a shared reality. I'll be interested to see what might come next as Mark and many others continue to build a community of practice for engagement practitioners.

**Jennifer** 35:56
So for our part of this discussion, let's think a bit wider about the organizational context and this idea of moral distress. I think what makes the patient engagement role somewhat unique, amongst other administrative or managerial roles, is that it's a bit nebulous. Often the people in these roles are given some leeway to shape the responsibilities and activities. And often they're by themselves, like Mark, in a department of one. So they're kind of alone in their mission. And without a wider frame of reference.

**Emily** 36:28
Right. There are always going to be workplace frustrations and challenges. But this feels different. It's like patient engagement is a little silo that operates on its own. And as long as there's activity and some kind of feedback loop? Well, from the organization's perspective, it's maybe working as expected. But for the people on the inside, especially those who care and who want to make a difference, it can maybe feel like they've just been left on their own to sort it all out. And not just on a practical level. On an emotional one, too.

**Jennifer** 37:02
Yeah, I think we're in a particular cultural moment right now where we tend to look inward to see how we can take ownership of our experiences, or whatever. And organizations encourage this through their wellness programs, or mental health support, or talking about work life balance. But all of this puts the burden on the employee, right? The very definition of moral distress is that you want to do the right thing, but you can't, because you're not allowed or enabled to do so. So for engagement professionals:  you're hired into a job, have lots of compassion and energy and want to do right by patients, and find that you're kind of walled off from the rest of the organization. But because you're often the only one and the job is so loosely defined, well, it can feel like your own fault if things don't go well. Or if you feel that you've been ineffective.

**Emily** 37:57
Yeah. And then it becomes a kind of internal advocacy campaign to inform and teach the rest of the organization about why they should not just listen to patients, but actually change processes and decision making to incorporate patients. It's a hard sell. And it keeps people very busy, I think.

**Jennifer** 38:17
Right, which on some level IS the job. It's hard to measure making a difference. But you can measure activity levels. So maybe part of the role is to just be busy doing engagement. In other episodes, we've touched on this idea that patient engagement serves a purpose for the organization, unrelated to actually including patient perspectives in decision making. It helps organizations look more engaged, and whether they are or not? Well, it might not matter so much. If they're always trying and always improving, and they're always saying, "well, it's not perfect, but we have to start somewhere." Well, there's no finish line.

**Emily** 39:00
There are a lot of other things being accomplished. The patient engagement role kind of acts as a buffer. Mark talked about sometimes finding himself as the face of decades of systemic mistreatment, which he's then having to navigate as one of the primary interfaces to the hospital for the role itself is put out front. And part of its responsibility is to absorb and maybe diffuse patient discontent.

**Jennifer** 39:27
Yeah, I think conscientious people like Mark would certainly find this unsatisfying, and even dismaying. But you know, in other episodes, we've also reflected on the notion that the point of engagement seems to be engagement. So an example would be convene a group, do an activity, talk through experiences and develop some insights. And then everybody goes home. We've seen time and again that that's where engagement begins and ends because the purpose is served once you've held the meeting. At least, according to the organization. There is more pressure now to show impact. But often it's fairly inconsequential. Or the value in saying you did something is higher than the value of the thing itself.

**Emily** 40:13
So the moral distress is caused by thinking you can make a difference when in fact the environment or conditions don't allow for that. There's no getting around the fact that the engagement role is part of the organizational hierarchy. And ultimately, it serves the goals of the organization. So part of the job is to represent the organization and help explain its shortcomings - perhaps fend off or manage patient dissatisfaction. If you have a patient advocacy mindset, going into a job like this, it can be really disheartening to discover the limits of what you can achieve.

**Jennifer** 40:47
Yeah, so it makes sense that people in those roles often find the interpersonal interactions so rewarding. It's almost therapeutic. Which makes sense. I mean, there's maybe personal relating and connection, perhaps catharsis, gaining a new perspective. It's the affective aspect we've talked about before. Engagement can actually be experienced as something quite meaningful for the people involved. And the organization also gains because these activities, well, they potentially defuse antagonistic or oppositional energies.

**Emily** 41:22
Yeah, well, while that might be true, it's interesting to note, yet again, that large organizations with complex bureaucracies - like hospitals, universities, research institutes - they don't exactly make it easy for people to do the work they've been hired to do. A lot of these themes just keep coming back!

**Jennifer** 41:44
Okay, let's end there for now. Big thanks to Mark Weir for his participation in this episode.

**Jennifer** 41:54
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