The Nature Of Care by BJ Miller, MD
End Well Symposium, December 5, 2019

Start of Transcript

BJ Miller: I don't know, I don't know. These are weird times. I do not know whether optimism is called for or pessimism. I don't know if I should be feeling wonderful or horrible. So, I guess we need to do both. I mean that is sort of what adulthood seems to summon. But more particularly it seems to be what our subject matter demands. You know that there's no, my favorite of Frank Otaseski's *Five Invitations*, the admonitions he gives us. One is push away nothing, which I find the most compelling and it's the thing that death does for us. Everything is invited. You know everything must come to account with the end of life. That to me it's singular, no its greatest charm and the most we have to learn from. **[00:01:00]**

So, we have this inclusion we have to include everything right. But to date and what I'm so why so loved and well, is to date as big as a subject is, it's been rammed through the medical lens. Sort of by default and medicine has been the arbiter of death now for a while. Medicine is a beautiful and wonderful thing; it just can't be everything. So, here we are now mixing and mingling other disciplines and that's so beautiful.

These subjects touch everybody that everyone has something to bring to it, every discipline has something to bring to it. That's beautiful. I will say though it's also true that working across disciplines, I think one of the reasons it doesn't happen so often it's because it's actually really hard. I think it sounds wonderful very exciting to work with others in across disciplines I have found it actually pretty difficult, part because we have a different vernacular, different habits, customs, sort of reading the signs and one discipline is tricky in another. **[00:02:00]**

So, I guess one lesson here system we need a sort of a massive respect, bless you across these aisles. A caution too, a sort of we shouldn't necessarily need to take things on face. I think we have a lot to learn from one another, that includes asking questions. Okay so, I've been -last four years or so I've been out in the world mostly just interacting with the public in a lot of ways. Through public speaking and more recently through a book and it's been really wonderful I mean just I hope I've been listening; I've been gabbing a lot.

But I think I've been listening and what I've been hearing is that there's an understand unmet need that you can just feel dripping from the walls of this country. I think there's a lot of talk that we're in denial that no one likes to look at that. I mean here we are, all together looking at it in some level. So, yeah denial is real but I think there's something else going on which is this pent-up interest in this subject. **[00:03:00]**

What I hear from people, is this need to connect. This very basic sense of connection that isolation is a problem. It's particularly galling when you're isolated before the subject that affects everyone. You're isolated before the subject that is so inclusive. So, there's a perversion in that but everyone also money in a ton of need for help there's a there's a tonnage of need and with our aging population, that tonnage is only going up. On one hand dispiriting in a certain way because just so much unmet need. On the other hand, or on the same hand, it's a joke. That means because this need that means that one way or another this subject is coming. This is not going to be a recreational pursuit or just because we're intellectually curious or interested. This is coming for us in the best way. **[00:04:00]**

Or the hardest way, so we're going to get there. I suppose as part of the message and interesting, out in the world I've also noticed you know there's been oftentimes a schism between some medicine and the public it's trying to serve and I fall in a sort of a doctor, it's easy to bash doctors.

But one of the things that's very interesting is I'm not noticing a very big difference in audiences that are full of health care professionals versus the lay folks. Everyone's hurting in the system that we have now. Maybe especially the providers, you know you'd have to get you to bring these ideals into this work. But the reality of practicing medicine or nursing anything else can be so brutal. So, I think that pain that pain is diffused now in a way that everyone's ready for change. So, basically now I think I've been part of, we've been part

of provocation. You know basically getting out and helping each other think and feel and that's been great. It's been very useful but now, we need to go to action. **[00:05:00]**

I think at some point we could lose ourselves and lose our audience in a way if we just sort of stick around a provocation. We need to do some stuff, so I guess that's sort of the gist of my talk is, is how do we now move towards more action and I don't have answers? But I have something of a framework to help us maybe approach action. But, I'll say one more thing here. One of the words, it's registered with folks out in the world that have been surprised by this. In towns big and small rural red blue didn't matter. I heard a lot of people resonate with this word, activist. I've been surprised by that, but I think it's an important word, it's an engaging word, it's a mobilizing word. I think it's useful for us in part because we are pushing a bunch of rocks up hills.

We just need to acknowledge that, that's activism by caring by daring to talk about the subject, that's activism. By sitting with someone that you can't fix, that's activism. **[00:06:00]**

I mean it's all over this stuff, important for us to acknowledge it to give ourselves a little bit of credit but also at the end of the day doesn't forgive ourselves for somehow not fixing everything, not making everything better overnight. So, I think it's a useful word. But to what end right? What is all this activism heading towards? Is this a movement? If it's a movement, what's its goal? What is the goal of this movement? A good death? I don't know if we can mandate that. I don't know what we could even agree on what that is.

Is it health care reform?

What is it exactly? I don't have an entrance question, but I think it's a useful one us all to think on. For me, I think it has something to do with us crafting a reality, a sense of reality that's big enough to include everyone and everything that happens to us in it. That it's not overly reduced, so this idea that our systems would be responsible for a reality that affects us, that jives with our experience. All right on a more personal level, I think it has something to do with us somehow find a way to not be ashamed to be natural beasts. **[00:07:00]**

Not be ashamed, when my saddest things I see in clinic is when people are ashamed or embarrassed to be sick. You know you have to feel crappy and then be embarrassed for feeling crappy, that's really - that's lame and it's unnecessary. Okay so, to whatever end we're all towards of working. I think it's useful to kind of revisit, why. The 'why' we're doing it. Victor Franko has a lovely quote you know, "Man is not crushed by pain or not ruined by pain, we are ruined by pain with without a reason". I'm paraphrasing but something like that. So, let's think about some imperatives. You may have some others but here are just a handful. One would be the ethical imperative, perhaps the greatest, the moral imperative. You know what is this relationship between ourselves and others? These lights up a lot in this room, I think we all know this is a very porous line. But that's not how our structures, that's not our language. **[00:08:00]**

So, I think it's time we revisit the social contract, that phrase I'm not sure what the social contract is anymore. What do we? What can we expect of each other? What do we owe each other? What do we owe ourselves? That's a big question. I think if we answer it would go a long way. A second would be the money, financial imperative right? So, we've got never mind health care's woes, a Social Security, all our safety, that's all headed for insolvency. Long-term care insurance is increasingly an unviable product and we have some really big problems, the number one concern of people facing the end of life, is it gonna be a financial burden? That's the thing that they're worried about.

I've met a lot of people who want to hasten their death, not because they're ready to die but because it's too expensive to live. They don't want to leave their loved ones with the dead. Number one cause of bankruptcy in this country is health care cost. Seventy percent of those who are bankrupt have insurance. So, this old idea that it's an uninsured and personally insured. it's not real anymore. **[00:09:00]**

Consumer imperative, so human-centered design. A beautiful concept but in this space, it hasn't really taken root yet. Why are the patients and caregivers not in direct contact with the designers? I think you know the phrase, I love this, an example like orthopedic shoes. If you someone doesn't like your shoes, I

say nice orthopedic shoes. It just feels like in that and you can tell right when you see adaptable equipment, one of the tells is because it's ugly. Ostensibly because if you need it, no one's gonna put any effort into it on the aesthetic plane or make you actually want it or attracted to it because they can take for granted you need it. I've watched that with prosthetics shift over time. There's no reason we shouldn't love our orthopedic shoes and if we're trying to pull attention to what we have to live with.

I love my legs. It took me a while to get there, I love them. They're not they're not ugly transpositions of things I lost; these are I think they're just beautiful for what they are. **[00:10:00]**

And they've been therapeutic for me on the aesthetic plane there's something to that. Also, I think the idea of designing for the proportionality among us, the need among us. So, access is a huge issue. Architecture, this plays out. Now we'll design beautiful buildings and then to make it accessible, well tack on a ramp on the side. Why not integrate that ramp in a design? That feels very different on the consumer side. Okay, another imperative would be the technology and scientific imperative. So, today you get the feeling sometimes that we keep spitting out new technology that's supposed to serve us, but in the end, we serve it.

You know that that's really problematic and it's insidious and it happens a lot so this is a problem. I think there's an imperative, we're going to reverse that. I love Gandhi, I think was his nephew he wrote this this list that became known as the seven blunders of the world. One of them was, science without humanity and I think we can feel that. **[00:11:00]**

Cultural, social, political imperative. This is our society in which we live, I think it's time for us to reground ourselves in a shared reality. Here's death can do this for us, we all are mortal beings and we all know we have to deal with the cognizance of our mortality.

That's a great bond and that's something we all face. Young, old, skinny fat, whatever doesn't much matter. So, let's reground ourselves with a shared reality and swirling around and underneath all this stuff is the individual imperatives, aesthetic imperatives. We are sentient beasts, right? I love my body. I'll be sad to lose my body because it feels things. That's it's charm, that's why I like it. It moves me around; I get to sense stuff. So, I think there's something to this aesthetic imperative. It's not something about being pretty, it's about something much more elemental than that.

Okay alright, so there are some imperatives of some reasons to do what we're doing now let's quickly cut to some of the ways to structure some of our action. **[00:12:00]**

I think there are four ways to break this down. One would be sort of in the education and training world. So, healthcare, we don't have enough palliative care folks, we don't have enough primary care folks and we don't have geriatricians or so we need to sort of work on the doctor and nursing social worker chaplaincy, home health care aid, direct care, workforce training you name it.

Outside, we need to sort of revisit that. But also, we need to revisit the informal caregiving world. As one of our speakers pointed out, 45 million informal caregivers in the country doing five hundred billion dollars' worth of business that they're not getting paid for and trying to hold down the job at the same time. So, what about our HR professionals right? What about companies competing to bringing talent by offering a family and caregiving benefit package around sort of training. Because we're all going to be caring for each other, so how about some basic training. How about generous reasonable medical leave? **[00:13:00]**

Teachers, this can start very young. We're supposed to speak to school kids about death. The realities of death at a very young age, all right that's beautiful. Those guys will age differently. We can teach grief; we can teach cycles of life. We can interrelate with nature again. Policy is another big way to activate. It's a huge piece. So, we can lobby our congresspeople. some of us here why don't you guys run for Congress on a platform of health and justice around aging well, (Hi Torrie) about aging well and dying well, that would be a beautiful platform. I can't wait to see someone do that. Policy folks, when you're drafting your policy makes sure to translate it back to reality and look at illness as an experience not as a series of transactions.

Researchers, let's move beyond the randomized controlled trial hegemony. Let's start embracing social science, qualitative research etc. Third bucket, infrastructure, the stuff, the material world. **[00:14:00]**

Help us feel… build things when we're safe to fall apart and help us get access to what's possible. Now the hard part is, patients don't get mad at me for not solving cancer. They get mad at me for abandoning them and they get mad at me if there's a medicine down the hall that they just don't have access to. If it exists, if it's knowable, let's know it. If it doesn't, let's make a space for that to just be an interesting mystery. Social, this is a big sort of chunk here. The social world, the way we interrelate, our musicians, the media folks, language, love, art, you got it. I mean you name it this is where this is where we come alive, help us feel seen.

This is where the Golden Rule can play out. This is where it's so important to discern between pity and empathy. The hard part about being disabled is not just the pain I have to deal with. But it's the projections I have to deal with from the public and I don't think my experience is unusual. For me and my answer to. my own question about what to do is just talking, talking, talking. Sonia Dolan and I, my partner in this, we've just starting a little thing called the 'Center For Dying and Living' the website thecenterfordyingandliving.org. **[00:15:00]**

Basically, the purpose is, we're going to start harvesting a ton of stories from patients directly from patients and caregivers. It's set up for people describing their experience in their own words. So, I don't start trying to substitute my voice for my patients, that happens all the time. If we really want to move towards a patient or person-centered centric system, well we need to hear from our patients and caregivers directly. So, that's what we're trying to set up as a latticework for that to happen and then right and around these narratives will build a body of knowledge, curated knowledge so I don't have to Google our disease and sift through a bunch of junk. Alright? So, anyway that's the little quick hit on what we're gonna try to do. But I would invite everyone here to think through why they're here and how they can move, what they're already doing through some of these angles towards action. That's all, thank you guys very much. **[00:16:00]**