Reclaiming the End of Life as a Human Experience By BJ Miller, MD
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Start of Transcript

All right. So my job to kind of get us going. So you're gonna hear from a lot of very interesting people who have a lot of ideas and I'm sure you guys are filled with them, too. So I'm just trying to think of how to set us up. What might be underneath, what could gird all that's among us. So we'll just do this sort of a tour that Shoshana pranked on us a little bit. Ask ourselves the basic question. This is probably the best one, my favorite is why. Why we're here, why we're here on the planet, why do we do what we do. In healthcare setting, of course, this is the question we don't ask nearly enough. This is probably the single most wayward question. We do interventions, we do thing just because we can or we make assumptions whatever it is but we don't stop and ask why and for my money **[00:01:00]**, if we just do that one alone, we could do a heck of a lot.

But for all of us, I think it pays to reflect here, so one of the awesome things about this subject and Jethro and I were talking this morning about this, this is not a subject, it's a gazillion subjects, it's all subjects in a way. So you can approach it from multiple angles, all right? So there's the personal imperative. Well, I'm a mortal, I suffer, I love, hopefully I am loved, so I've got my own life to live in a way and there's something about ending well. I've seen it in hospice settings. I see it in hospitals too, where a life that could be so so hard and so unlucky. It's amazing how much can go wrong in a life. And if somehow the end comes **[00:02:00]** together well, it's as though it makes sense of an otherwise miserable life. I've seen folks who had the final days and weeks that finally felt good. And when they finally felt seen and whole, and it's like they made their whole life worth it. After years and years of being misunderstood or unseen or alone.

So anyway, there's certainly a personal imperative for all of us. We're all invested in this subject, professionally and personally. And I don't know how many things you could say that about, right? So, social imperative, there were are social critters, right? We're animals [Chuckles]… and we need each other. I'll talk a little bit more about death but there's certainly a social reason to do what we're doing because we care about others. And then of course there's financial — and this is what I love— you could be the most bean country of the bean counters **[00:03:00]** and be in this room and care about this subject. And what's so fascinating is more and more any of these imperatives are heading you in the similar direction. So there's access point for everybody. Ethical for sure, practical for sure, policy and politics for sure as well and on and on, so I'd name a few here but also to kind of get your minds about why are you here, what's your imperative? What's driving you? So this live from the California Health Care foundation, thank you very much, it's 2011. This one's — you really just spent a lot of time on the content of it, it's just to point out if we're serious about patient-patient-centred care or human-human-centred care, instead of the normal disease-centered care, well, what do people care about? And here's some data for us.

The thing to notice is how few of these things have anything to do with **[00:04:00]** medicine. Some medicine's huge and beautiful and I would be very critical with medicine but I also love medicine. I'm alive because of medicine, I have a job because of medicine and etc. There's much to love in this healthcare system, mostly the people. But it has its limitations and I think it's that part of the reckoning we're all here for. And that's okay because its subject is way bigger than medicine. Medicine doesn't t have to have all the answers. It's perfectly fine. I think we overladen our system, to expect too much of that pattern of relief sometime. So that's one point.

Then I'll also wanna point out this word "burden" comes out a couple of times there. Financial burden, decision-making burden, so yeah this one's a really — this one's a big one for me. I see it since the aide in dying legislation came online here in California, this is a refrain that we often here clinically when folks are approaching us to **[00:05:00]** help hasten their death. You'll often hear these words, "I don't wanna be a burden." And I had to say I, as a patient I have understood this very well, personally. I know I have my own experience with this and it took a long time for me to kind of figure it out for myself and with my friends. But part of what I got figured out was I felt really, you know, feel so bad for just being on the receiving end all the time, as a patient or as a dependent.

The truth of the matter is and we all probably know in this room, we give love, we care not for a tit for tat, you know? It's not — ten years out I finally talked to my friends about this. I felt like I've stolen their college experience and they just didn't smack me like this idiot, we didn't —we weren't kind, you wouldn't help because you would then owe us or we didn't. It wasn't incurred a death so we weren't trying to **[00:06:00]** prove anything. We gained, too. We learned, too. You know? We grew. Thanks to this experience. It was so beautiful and you know, anyone who works in the hospice field and it's particularly it's very pointed in this place at Zen hospital project where it takes explicitly that there's a giving and receiving reciprocity, there's a loop. It's kinda linear or one or the other.

So that's one point about this being a burden but I also hear this as an indictment of society, personally. I think it makes me very sad that any of us were made, be made to feel a burden for things beyond our control. I'm gonna have a pause there for a second. You know I don't — it's as if we refashion this future together, I don't question do we need an enemy. You know in healthcare we go to war a lot and there's a ration out of that and it can feel right sometimes but there's a lot of fallout from going to war, so I guess one challenge **[00:07:00]** I put out to you guys, do we need an enemy? You know? And suffering itself, I'm — we gain from suffering, I wouldn't even wish a lack of suffering on my worst enemy. It was like, it would be there's no way to learn. So I guess for me, I would name — if I have to have an enemy, I would supposed it's shame. We're made to feel the same for things we can't control, this is mean. And we do it to each other a lot. We send the [Inaudible_00:07:32] to the parents and signals and those of us in the disabled community know this one.

But the truth is, in a normal life, they're assemytries. There are times where we need more than we can give and there are times where we can give more than we need. That's just part of the deal. It's interesting like I love this thought, I don't know if it's the right language but being a physician or a clinician or a caregiver **[00:08:00]**, oftentimes the clinician-patient is just the worst. And we just can't hide [Giggling] can't be loved. Oh they think they are sort of a one-way street giving machine that's what we're trained to do, I'm gonna give, give, give, care, care, care, and it doesn't really work very well for very long. Especially because those on the receiving end when you're in the bed, looking up, and everyone's caring at you, because it's overwhelming. It's belittling. So that's the piece to shift back on. Again, I think that's up to all of us. Those were the times where you're just gonna need more than you can give and that's part of the deal. It was gonna time — I think this is also for me a call-bless you. A call to learn how to be loved, which honestly I think is one of the hardest things around and I think that's part of what it means for us.

Last thing I say about this "burden" question which, these are called "action here" is, okay, purpose so it kind of relates **[00:09:00]** to not having a purpose and I think we all could get a lot better if we're purposing ourselves. So right now when you're not maximally productive, we can of like put you in a corner and glide on past and we make room for the next producer.

That's it, that's the shame. So I think helping each other find new purpose is really important and I'll talk a sec in a moment about the joy of purposelessness, too.

Okay, so by the way that's a little bit of a how, again this really is an invitation for you guys to think over why you're here. Those are some thoughts for me. Okay, how. How are we gonna do this? This is also, it's a really good one… coz it really comes down to how. The style of how we do things really matters coz in the end if we're not gonna change a fact that we die, which I don't see us doing anytime soon enough, I'm not sure we'd want to. It's all about how you get there **[00:10:00]**… which is also an invitation of style and to do it your own way. I would say for me this also brings up the idea of an ethos. So I'd think one thing that maybe we could all — it's where in some part of movement together and by the way, I wanna harp on a word Shoshana said, we are activists. You guys know that? You feel that? Awesome. I think it's really a great thing to call out because there's a power in it, there's a drive in it, and there's a —it's also a, at least for me it helps me at the end of the day where I don't feel like or I made me feel like I go a couple steps backwards that I realise that we're doing hardwork. So amen to that. I'm really proud to be part of this activism with you guys.

Okay, back to this. So this ethos… ethos of activism but that means **[00:11:00]** change is in the mix. I mean we're here in a way because we're trying to change something. There's this opposition that the way we've been dying isn't so hot or it could be so much better and even truer still, the way we lived until we die could be better. One thing to call out in this sort of this ethos-fear from where I sit would be kind of highlighted a little bit already which is — I don't, I wish someone to tell me at a younger age that independence is a myth! Have you ever known anyone who's independent who needs no one? Has there even been such a person? I don't think so. Again that poor soul [Chuckles] they're really, it'd be so isolating. But we use is suspension in states, we throw this word around like it's obviously the goal is to be independent. Well, it changes when you make — when it becomes clear that that's not possible.

So one thing I had to get comfortable with is sort of thinking along the spectrums. So there's **[00:12:00]** the spectrum of totally dependent and totally independent, we're all somewhere in the mix. And it's something really important to call out because of this ethos of working together, we're working on ourselves. And that there should be no shame in being somewhat dependent unless you wanna make everyone in the world feel ashamed. So this one's a really cute one for me to call out and there was one I was glad — a lesson — I was very glad to learn. All right, so back to sort of an ethos, well we can draw from medicine.

Medicine has bioethics kind of world to you which I'm still out here as a lot of you guys know it, it doesn't have to be this, it's somewhere to start. But these are the four pillars of bioethics or held intention. I'm just gonna run through them real quick. So one is we've all heard of is do no harm. Sounds reasonable. Try not to hurt each other [Chuckles], I guess that sounds good **[00:13:00]**. And of course we can do better than just not hurt each other, we can actually do well by each other. That's where I think, you know, we've been decent-is on the "Do no harm." At least we talked a good game around that, we're certain I think really healthcare tried to not hurt people. But we haven't done so well leaning forward into the positive side of the whole deal, where we can make life better and we can do well by each other. That's a beautiful notion. Under appreciated. Then there's the third pillar that a lot of us know about which is autonomy. Again, autonomies have implied independence. Implies, where I'm sitting doesn't exist. So this would be a sort of a idealised status that's again intention. In medicine we swung loudly from paternalism to autonomy and now sometimes I always meet young doctors who will gladly just walk you off the side of a bridge if that's what you ask them to do, you know, because [Chuckles] well my patient wanted it **[00:14:00]**! You know. So there's a problem with it. It's again because we're not there is no independence that we as providers are also part of

the decision-making process and Naomi Raymond and Alex Smith and others have called for, yes, person centrism, yes human centrism, or perhaps the not is really relationship-centered care. I think I like that thought. So autonomy is still something to it, I'm all for relative independence and then finally this is the most ignored of the four medical bioethics pillars, justice, coz that smells like rationing and we don't like that so we just never touch it. We don't really look at justice piece. So I, for my money, I would say I like this setup. And again, these are meant to be held intention at anyone's situation and I think it's a very useful framework. We can build on it or dispatch with it, whatever you wanna do, it's here for us. And for my money, I would love for us to lean into the beneficence and the justice pieces **[00:15:00]**.

Okay so what, why, how, what are we gonna do? Well, you know, I mean really is wide open and it's so — this is where problems become really great opportunities. The good news is we've been sort of so closeted on this subject that it's so underdeveloped in a contemporary way. This means we got a wide playing field. And thanks to our demographic-ships, the need for the things we care about is just only gonna balloon and balloon and balloon. So it's kind of thrilling, really. And again I think we can delight in this low bar, frankly. It's kind of funny like in palliative care, [Chuckles] sometimes I love is really is true. You will get treated sometimes in the hospital who's a palliative care clinician, you guys know this like a Christ-figure for introducing yourself **[00:16:00]** or you know for actually taking a chair at the bedside. That is like the most amazing thing that's ever happened, it's stunning.

[Everybody Laughing]

And frankly meanwhile take it. That's great. If you guys wanna love me because I sat down, that's cool! So yeah but this is really good to unchain in our selves, in our imagination, can't change so much of what we are — what we have to deal with change, how we see it, what we do with it, how we play with it, and etc. so again I — this is — I just keep — I always slide this slide in here because it's like a public service. Palliative care is a piece of this puzzle, it doesn't have — it's from where I'm coming from, where I'm coming from, from where I'm coming, sorry, but so I thought up here because I also think it's a great mission statement.

So this is the centre for Medicare and Medicaid services how they would define palliative care. I just wanna point out a couple things again. Bear with me **[00:17:00]** I know most of you already know this but can you read the screen? Yeah, I'll just stop for a minute.

{{On Screen Text Display}}

Centers for Medicare & Medicaid Services (CMS)

"Palliative Care" means patient and family-family-centred care that optimizes quality of life by anticipating, preventing, and treating suffering.

Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and to facilitate patient autonomy, access to information, and choice.

Okay. Well, there's a lot to say here so I won't say too much. I just want to point out how noble it is that there's a field that is totally devoted to access this suffering. That's usually the stuff of contemplative and religious traditions and culture traditions, not a healthcare tradition. I think that's a wonderful idea. One of the reasons I think it's so damn wonderful is everyone suffers, 100%, everyone, every one, every one's a radically inclusive endeavor. And then the best part

about it is suffering is totally subjective! I've a doctor don't get to tell you the patient is suffering or not **[00:18:00]**. Has anyone here had their pain question or second guessed by someone? You must see me violent and that's where the closest I get to violence. It is — that's a real wrong.

And this is I think why we see our subject as sort of so uncomfortable in healthcare because it requires a power to shift. The patients have to tell us their suffering. That's really beautiful, it changes the dynamic entirely. The last thing I will say here is just to remind ourselves that palliative care is not — there's no mention of death, no mention of time, and you don't have to be dying in attempts to get palliative care. I hope that we as a field don't run away from the end of life and playing to that old problem that we continue to include in our sphere but let's all remind ourselves in the next time someone needs palliative care that there's nothing — it could be years away from death to make people afraid of palliative care because it implies that they must be dying soon and so they're **[00:19:00]** kept from the things that's gonna help them.

The last thing I will say is wouldn't it be cool if we just cross out palliative care and put in the word "healthcare?"

[Crowd Applauding]

I love that idea! That this specialty gets to go away someday. Wouldn't it be cool if this was no longer needed to be a subspecialty of medicine? Shouldn't everything that medicine — shouldn't this be our mission statement? So we'll see, I don't know if we're gonna get there. But that's the day I'm shooting for, designing our own upending lessons.

Okay some other things that call out here as we kind of reframe and what we're doing here, well I would suggest that we take healing as or goal rather than curing, I think for obvious reasons to most of you. Curing is great when it's possible. Problem is it's not always possible and then we leave people, we abandon them. That's a problem. Healing, much more internally driven always past what you can die well, when you can die whole **[00:20:00]**. You can be completely messed up and be well. [Chuckles] It's a much — it's a better goal and it also gives a weed of patients more power.

This is a big one. A clock. We do acute care very well. We can run in, you know, trauma and ER work it's amazing! But you — these are, you know, as a patient you really do kind of need to lighten still and be passive and experts come in, do things to you and you really are upending mother nature and its settings. There's just no two ways about it. It is by hospitals and one of the hospitals such from environments, strange environments. Acute care, I'm all for it, no way would the message be "Let's get rid of acute care." The message here is "Let's ramp up the chronic care." The ability to care for each other when there's nothing curable or fixable anymore and the ability to care for each other overtime. You know I think our attention span's are good and I was watching how they response to this **[00:21:00]** in Sonoma County fires, I'm watching it myself. There was this beautiful blush of support and I watched it to myself and others sort of just falls away and are fond of the next thing. This is for an example, when I see the way I'm with patients sometimes. So this building of this muscle to be with each other overtime. Really really keen and I hope that that's one of things we will take on.

Another thing is my favorite. This is really my favorite subject which is the world of the senses. So what dies? The body, I think. And you can start even piercing holes in that definition. Our bodies become host for other things, the body's going into better things. If you can just witness that, it's empirical. But we can agree that this body as it is, this body dies, well I don't know about the spirit or soul thing, I don't know, but the body dies **[00:22:00]**, and so I wanted to go there. I wanted the light in my body while I have it! And for me, so much of that delight is due to

senses. You know? So one reason to believe in delight in this aesthetic realm. By the way, it just means the sensory realm. It doesn't necessarily even mean beauty. It does not come to mean that, it just means a feeling so I wanna feel things while I can. That's why I like having a body. So I wanna honor that, I wanna uptake that.

In the healthcare system very often numbness would be your goal, anesthesia. Let's uptake this piece. Other reason they're really focused on on the central realm, on the sensory realm, it's direct. So for those of us who are gonna — most of us are gonna age with some amount of dementia, and as our intellects fail, our frontal lobes go, just because we can't think doesn't mean we can't be **[00:23:00]**. And we can still feel, it's a direct experience, it's not on behalf of something else, it's for its own sake… which is a very beautiful thing. Yes, we have function and purpose and work on behalf of other things but there's something magical about being at all. I think that's a very good bottom line for us. Again it's direct experience. It does not require time, it does not require thought.

Mystery. This one's a mystery. This one's to put a shoutout to not knowing stuff. That's a really potent force. It's a — can be comforting force, it can be a scary force but it at least drives us to with curiosity if we let it. It's not ignorance. Mystery is not the same thing as not knowing about the same things as ignorance. But it's interesting, right? These days we have a kind of a — this is weird, we're in a weird time. We pretend to not know things that are fact and we tend to know things that we don't. This is very… everything's upside down [Chuckles] So I'm **[00:24:00]** for knowledge. Let's acquire it, let's share it, amen brothers and sisters but also there's stuff we just don't know. And that's fine and cool and beautiful and wonderful and someday maybe we'll know it all and then we can do away with mystery but meanwhile, can we please delight in it?

How many folks here will identify as a patient? And how many of us are living with a disability or a chronic illness? Sometimes, yeah, okay. Thank you. So we know, and most of us can guess, I mean the cool thing about disability is it actually can spark some of the most creative thinking and being. Every designer in the audience knows that there's no design without limitations. We need something to bounce against. You need something intention, a blank sheet of paper like architecture with no gravity and I don't know what that would look like **[00:25:00]**. There's no — you need a force to rally against, to work with, something in other words beyond your control. That's where creative or creativity gets going. This is not all about control. It's about working with what we have. And those of us who are sick chronically are really really natively good at this. One of the gazillion reasons we should be leaning more in our patients than we do, coz they're sitting on all sorts of really cool skills and I think we should begin to see how the illness can spark creativity in us and we can roll with that, we can delight in it, become a big part of our identity.

Okay, who is — this is an easy one— everyone. You know, everyone [Chuckles] that I said. This subject, everyone's affected, everyone should be invited so as we're casting this day together and as we're casting something about movement, let's be really careful to be sure to stay, it's funny to say, radically inclusive **[00:26:00]**, I think that's really key. No one should be left out of this work. All right.

Final slide and I —this is a… a lot of you guys have seen this one and I apologise but I just love it and it makes a point for me. And I… so here it is. It's a painting by Nicolas Busan, it's in the 17th century, 16th century? It's called *Et in Arcadia ego* which is Latin for "I too, dwell in paradise." I too, live in paradise. And that is the inscription on his tomb, so you got these wandering happy hikers and some goddess figure in paradise. And they come across the tomb, and you can see they're looking at the inscription and looking at the goddess trying to figure out what the heck is a sarcophagus doing in paradise! This is the paradise. There's no

death **[00:27:00]** in paradise. Isn't paradise sort of the opposite of death? And for me anyway this point of this painting makes the point for me. I've learned this in our history class, I didn't make it up that the "I", the way the inscription is written, that the "I" is active, this is not "I was here." Like this dead guy was alive, it's "I am here" and the "I" is thought to mean death. So the challenge for us here is to think well, maybe it happens on earth. Maybe death is a part of paradise. And I think there's something to that because we're so relatively wired, I don't think we wouldn't know what the hell paradise looked, or felt or smelled like, if we didn't know sort of the obnoxious cousins of those things. If we didn't suffer, I don't think we'd really know what just passionate joy felt like. If we didn't really know **[00:28:00]** pain. If we didn't know pain, I don't think we'd know comfort. If we didn't know hell, we wouldn't know heaven and so on and so on. So I don't think in ending well, I don't think we have to be a bunch of folks who just love death that says, "Weeeee"

[Crowd Laughing]

Not at all. I mean it might be a little creepy. Let's welcome to — I wouldn't, but I think the point is you're gonna be made over and over again. There really is, the point is death helps us love life. I'll just end by saying if we had a target or an enemy, I would say again I think it's shame, being made to feel ashamed of things we can't control, and I would say if I have a goal, at least personally, my goal in life is to appreciate what I have but while I already have while I still have it. That's the trick. Most of us are really good in appreciating something once we have lost it, you know? And that's poignant and gorgeous and fine but wouldn't it be great **[00:29:00]** if we appreciate it before we lost it, while we still had it? Whether it's a body or a relationship or a thought or an identity or whatever it is. So I just want to end with that appreciation of what death, annoying as it is, offers us something, too. And any fuller view of the subject matter has to, I think, has to include death so anyway that's all I have, guys. I really — you know, I'm really glad to see everyone. Thanks again for being here. Thanks for all the work you're about to do and have done. I'm willing to be a part of all this week with you guys. Thank you.

[Crowd Applauding]

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