Doctors Designing By Bon Ku
End Well Symposium, December 6, 2018

Start of Transcript

[Crowd Laughing]

I earned huge brownie points just knowing my daughter thinks I'm a dork. She's 13. [Crowd Laughing]

This is me back in the day. I was a brand new intern. I joined this army of doctors to save patient lives in a heroic war against death. [Crowd Laughing]

But during my third week of internship, I sustained my first casualty. I was assigned to a small hospital in Central Pennsylvania and I was on in-patient medical service. During a 24-hour on-call shift, I got a call from a nurse in the middle of the night, and because it's my third week after medical school, I panicked. My patient was having difficulty breathing. We put a high full-optional mask on my patient but **[00:01:00]** he would become increasingly agitated, lethargic and I was terrified. We cannot get enough oxygen into his lungs. After a failed intubation, and a surgical airway, he died before dawn. And after I rounded with my medical team in the morning, I retreated to a hospital bathroom and I cried. I thought I made a terrible mistake becoming a physician but I compartmentalised my emotions and carried on.

This line is form the novel *The House of God*. It shares the absurdity of life in hospitals. It is a book that many of us read as medical students or residents. The novel *The House of God* shows us the brutality of medical **[00:02:00]** training. As a resident, I went to go out and take on more patients and many of my patients died during residency but I don't ever remember crying again. Maybe I was just too emotionally or physically exhausted. Maybe I was becoming less human.

As human's death unites us. It is the common denominator. In our society, we have designed the dying experience. Doctors are the principle architects for the medicalization of death and dying in America. Doctors in the past century had become the experts on death. We orchestrate dying as a series of medical events. Symptoms, diagnoses, treatment, admission to the hospital, discharge… rinse and repeat. Doctors tried to extend life at all costs through technology. We value the quantity of life **[00:03:00]** or with the equality of it. Even though we are the architects of the dying experience, most of us have little to no training on what it means to die well.

The expertise on end-of-life care is silo to a handful of specialists in the palliative care community. But why can't pallia medicine just be called medicine? Why can't every doctor from the orthopaedics surgeon to the emergency medicine physician be comfortable talking about end-of-life issues with their patients? What does it look like to view death and dying as a design challenge rather than just say medical one, we might ask questions like these: How might we medicalise death? How might we change the narrative around death and dying? How might we shift death expertise away from physicians? I believe that design **[00:04:00]** can help us to address these challenges. Design can humanise death and dying.

At my medical school in Philadelphia, we use design-thinking to apply creativity in medicine. We were the first program in the medical school to start teaching medical students how to apply design-thinking in healthcare. We defined design-thinking as an approach to generating ideas and solutions that serve human needs. Design-thinking makes the creative process less

opaque. It helps us to rewrite the rules of business as usual. And I want to emphasise that design-thinking isn't just for designers. Any one of us can take part.

These are the design principles that we apply to our health design-thinking program at our medical school. We teach future doctors to think like designers. And to apply these principles to healthcare, we want the ex **[00:05:00]** -perience of healthcare to be humanised for both patients and physicians.

Anyone working in healthcare knows that it can be a very toxic environment. For example, in hospitals we use a secret language. In the emergency room, you might hear a phrase like this one: It refers to being a fission to diagnosing and discharging patients as fast as possible. I am guilty of using this derogatory phrase and I am guilty of labelling my patients with phrases like these. Working in the meat grinder of the hospital is hard. I've experienced symptoms of burnout feeling, a lack of empathy, dehumanized. Burnout is an epidemic in the American medicine and everyone loses especially patients because burnout doctors will deliver burnout care.

When you experience **[00:06:00]** burnout, empathy goes down the drain. Empathy is a core principle of design-thinking. We can define empathy as the ability to recognise and share the mental state of others. This picture is of a tent encampment in Kensington, Philadelphia. We have many of these tent encampments in this neighborhood. People travel to Kensington from all over the city, even different states, to buy and use heroin. What is the mental state of a human living with addiction in one of these tent encampments and what's the mental state of someone coming to me in the emergency room, overdosed on heroin?

Design helped me to humanise my patients. Instead of asking that patient, "Why are you here again, overdoes on opioids?"

A better, more empathetic question might be, "What happened in your life that led you to do this? In order to humanise **[00:07:00]** my patients, I knew we needed to go outside of the walls of the hospital and to gain empathy to venture into the community.

We formed a team of a dozen architects, designers, medical and undergraduate students to launch a program called *Collab Philadelphia.* Collab, one of the aims of it is to open dialogue in the community and to change the narrative around the opioid crisis. Stigmatizing attitudes towards people struggling with addiction has stifled public efforts to end this crisis. And the strategy to — for this epidemic, is really to overcome stigma. In the similar fashion, the conversation around death and dying is also stigmatized. Adam Hayden, my friend living with the diagnosis of brain cancer states it's important that we bring death out of the shadows **[00:08:00]** of taboo.

Last summer we held a design-thinking workshop on re-imagining death and dying. A design workshop is a structured series of activities that really prompt people to think creatively, share ideas, and to make those ideas concrete to their simple prototypes. We had over forty people come to this workshop. We were surprised by the diversity of participants and how engaged they were with this topic.

We just then share their own beliefs and experiences around death and dying. Because empathy is a essential ingredient to making us successful designed workshop, design charrettes or sprints, I reached out to my friend Adam, again.

Adam is a father of three boys from Indiana. He has a graduate degree in **[00:09:00]** in Philosophy. He found out that he had glioblastoma, a highly aggressive brain cancer at age 35.

Adam recorded with his iPhone a five-minute video with his thoughts on death. And how this diagnosis has impacted his life. We shared Adam's video with workshop participants.

To guess comfortable discussing with our own mortality, we had participants write an imaginary obituary for the *New York Times* and then we led a brainstorming exercise on the problems around death and dying in America. We were surprised and impressed by the rich diversity of cultural perspectives around dying. The invitation to make simple prototypes resulted in ideas arranged from a child-friendly quicklinks, that could teach kids about the cycle of life and death **[00:10:00]** and developing new cultural traditions around death and dying.

We live in a death-denying culture. It's so hard to have a conversation about it. But through our design workshop, we were able to bring forty strangers together and think about how we can redesign death and dying.

This is my son Nolan. He's kind of cute.

[Crowd Laughing]

When Nolan was three and a half years old, we shared a traumatic experience. Death nearly met me as a father of a young son. As a physician I have taken care of many patients who have died but I didn't think death would ever try to visit me personally as though my doctors white coat were a force field protecting me from it.

On a hot summer day, where our family was having lunch at a friend's backyard, and in my peripheral vision I **[00:11:00]** saw something at the bottom of the swimming pool. It was Nolan. I dove in, bottom out, his lips and skin were a modelled blue from oxygen deprivation like the patient I took care of during my intern year. And I began the familiar steps of resuscitation… except this time the patient was my son. Fortunately Nolan was only submerged for a brief moment of time and then he recovered without any harm. He is ten years old now and he vividly remembers this near-drowning experience. He's a funny guy. He jokes about it last month. He say, "Hey dad, I wanna tell you this about that experience."

{{ Shows On-Video Text}}

"I went into death's house, robbed it and survived." -Nolan Ku, age 10

[Everybody Laughing]

What this traumatic event has enabled was for my son and I to have open **[00:12:00]** conversations about death and dying. It's not a morbid or dark conversation. We know that it will come to us and it's okay to talk about it. I believe that in order for us to live well, we need to design how we can end well and this moment that we are all experiencing here, I am optimistic about death and dying. We have the opportunity to reframe our understanding of it, de-medicalized it, and humanised the death experience. Thank you.

[Crowd Applauding]

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