

Our Better Nature By Alexis McGill Johnson
End Well Symposium, December 6, 2018

Start of Transcript

[Crowd Applauding]

Saturday, December 1st, my husband lost his very best friend. His name was Rob Caiberry. He was his best friend of literally 52 years. They met each other in the 5th grade, they talked almost every single day, texted in modern times. I swear it's like every time I turn around they were communicating in some kind of way. If they were black women, they would be Oprah and Gale.

[Crowd Laughing]

They covered everything from Detroit so they talked about the *Red Wings*, they talked about the *Tigers*, they talked about *Aretha*, they talked about work and politics, children, marriage, divorce... marriage-divorce and marriage, again.

[Crowd Laughing]

There's so much that I could say about Rob. My Rob and his best friend, Rob Caiberry but what I really want you to know is that [00:01:00] when we lost our dear family friend, we know that he left this world feeling fully accepted, feeling fully appreciated and that he had a strong sense of belonging. Everybody, all of us, as we just heard, all of us should have somebody who is so irrationally crazy about us. Someone who knows every single thing about us. They understand our hopes, our dreams, our failures, our missed opportunities, our close landings and what may all that makes sense for us. The fact is the more we see, the more we understand. The more information we have, the harder it is to judge. So this idea of belonging becomes really important. I just wanna shout out John Powell who is really helped us center this conversation around belonging. This idea that acceptance, of being a natural member of a group, this [00:02:00] fundamental emotional need that we have to be in relationship with each other. What I wanna add to that is what it really means to be seen, to be understood and not be judged is also critical with respect to belonging.

Imagine someone steals a loaf of bread, we could quickly make a judgment, a rash judgment, say she's just a thief. When we find out maybe she's trying to feed her family, that quick judgment may turn into empathy, maybe even compassion. So imagine the two Robs knowing each other for 52 years! The kind of information that they had about each other, it was really hard to pass judgment. Our brains were filled with just so much information knowing all of those histories and those hopes and dreams had just made it much more difficult to not root for them and to not love them [00:03:00] unconditionally.

How do our brains make meaning? We talked about belonging, this idea that human beings are trying to use each other as groups to make sense of the world. We know that at the end of life, that's what we want, that we're not just seen for all of our accomplishments and our failures but that we are understood in this way. What also makes us human is not just the fact that we will all die, even though our ends of lives will be different, but the fact that our brains are also hardwired in some very interesting ways. Some of us have learned to not see each other and to judge each other very quickly. Because of how our brains are wired particularly with respect to raise, which is what I wanna centre today. Some of us will have an end of life that is far different than many others, and that means [00:04:00] some of us will have an end of life that will be less human.

Before I go into some key studies, I wanna explore — I thought I would just cut, create an experience for all of us in the room so that we understand how our unconscious brains operate. Can you all see the side of here? I want you to state the color of the text together, it's a group exercise. Okay, we could do better. Good morning. Okay great! Right, we're gonna start again. Ready? Go!

[Crowd Yelling a Mix of Different Colors at the Same Time and Laughing]

Oh my gosh!

[Crowd Continues Laughing]

What happened? We have a lot of work to do before we get to our end of life, we just said state the color of the texts. What happened? Anyone wanna tell me what happened? When did it get messed up [00:05:00]? When the word red was in the color black, it got harder, right? Because your brain was completely primed when I asked you to state the color of the text, when the colours were aligned with the words, every time you read them they were consistent, we call it schema-consistent, you were able to stay at it but the minute it flipped, the minute some bit of information was inconsistent with how your brain wanted to see it, it became harder to do. Why is that? Our brain's process 11-million bits of information unconsciously in the same amount of time that we process about 40 bits of information consciously. And in order to do that, in order for us to move very quickly and navigate through the day, we have to create what I call these schemas, these mental structures that help us process information efficiently and consistently... and in that way, part of what we were trying to do was create this [00:06:00] quick categories so we could move through.

Think about the schemas that we create about people. Those are called stereotypes. Stereotypes embedded in our brains, particularly the negative stereotypes, are what we *implicit bias*. It's the automatic instant association oftentimes without our conscious awareness but I wanna say we can actually be conscious of what our *implicit biases* are and still have a hard time overriding that, right? You still have a hard time overriding them. And how did your brain feel once you've realised it was going? Felt like a little off, right? A little off and a little confused. Most of us believe in fairness. We believe that we are treating each other as equals, right? Upwards of 90% of Americans believe in the equality of race and gender. And yet, we see the outcomes, right? We see the [00:07:00] disparity in outcomes particularly in healthcare but also education, criminal justice, and politics. So many realms, we see the disparity. We also believed in this idea of fairness paradox, right? With the idea that we could believe ourselves to be fair and yet not see the outcomes that align with our values. And we raise this questions perhaps the way we've been taught to practice fairness, flawed. Not that we're not fair, but perhaps we've been taught to consider fairness in an incorrect way.

We've been taught for many of us in the kind of a post-civil-rights generation that we're supposed to be colourblind, that we're not supposed to notice race at all and when we do our brain gets a little bit nervous in doing that. We've been taught that we can be fully objective in how we evaluate people and how we see people and yet, sometimes we make mistakes with that evaluation. So what does that mean for end-of-life care? Medicine broadly there has been so much work around understanding how biases [00:08:00] impact patient care. It seems that doctors are fairly — do fairly well in terms of prescribing the right diagnosis of a patient. Diagnosing the patient. And yet, when they prescribed the right treatment or the treatment that may be best for their patient, they may actually... biases may come into play. Perceptions of a person of color who they may think may be less compliant. They may not follow a pill regimen, means that they will involve themselves in more, they will recommend more invasive surgeries

at the end of life. In fact, black patients tend to have more intensive treatments in the last six months of their life than white patients. They're more likely to die in the ICU than white patients. What does that mean? What does that mean for us and [00:09:00] and for how our biases operate? And how does it actually interact with other social psychological phenomenon that could be incredibly important? Racial anxiety. This idea that our automatic brains kind of recognising the fact that they may be noticing race is one thing, but when our brains notice it, how do we actually engage across race and across racial interaction? Racial anxiety is a physiological stress response that we have oftentimes in cross racial interactions where if you are a person of color, you may be concerned that discrimination, hostility... you know, invalidation, you don't really know what you're talking about. "My pain feels like this..." "I'm not really sure if that's what you mean." Says the doctor. People who are white may fear that what they say to their patient or vice versa may be perceived as biased [00:10:00] and so they may kind of pull their punches with how they engage. Racial anxiety can show up in shorter interactions, kind of, you know, if I have a high degree of anxiety, I'm not gonna want to spend a lot of time with you, I may even want to avoid this situation altogether. Awkward connections, right? Patient coming in really wanting to have a conversation or to engage with their doctor on something that's critically important to them and in order to kind of make that patient feel better, something completely awkward comes out. You know? Like "Hey, did you see *Black Panther*?"

[Crowd Laughing]

It happens. "Well actually doc, I wanted to talk about, you know, this really critical thing that's happening to me." I say the brain on fire, right? Because our brains are literally going into that fight-or-flight mode that we are so concerned about navigating it, turns into this cognitive shutdown and becomes really really hard to [00:11:00] override because whenever we experience anxiety, we're more concerned about managing our own anxiety than being able to see and acknowledge what's happening in front of us. Black patients report worst communication with their physicians and that patient-patient-doctor communication at end-of-life actually explains a lot of the studies that I just talked about, that inferior patient-doctor communication because doctors display fewer positive rapport-building kind of cues, they're not able to engage in ways. Bias is not just how we articulate things verbally, it also shows up in our body language. When you see that body language, you also have a response in engaging in it. Leads me to think about the other phenomena that we think is critical to connect to this work which is called *Stereotype Threat*.

So it [00:12:00] seems that we all have stereotypes about our social identity groups, right? We all know the stereotypes about our group. We don't stereo — I know the ones for gender, for women, for being a woman. I know what they are for being a black woman. I know what they are for being a New Yorker, I get it all. I understand that there are all of these ways in which I have to show up and present myself in a way that may challenge or reinforce the way someone sees me. But for patients, patients can have something called *stereotype threat* as well, and when we are in a situation where we are worried about a perception of how we are being seen and actually triggers our brain into a process trying to compensate it and fix it in the other person's mind. And what it can lead to, this is a direct quote from a patient who was [00:13:00] experiencing end-of-life, who's at the end of his life and he was in engagement with a doctor, he said, you know, I just think there's some kind of prejudice of the name. There's just a lack of respect. And they think they can get away with it because here is just another dumb Mexican.

So imagine, at the end of life, you are not seen and you are being judged in such a quick way that you feel it. Not only do you feel it, you feel like you have to overcome it, in someone else's eyes. That you don't have the luxury to spend your final moments, days, weeks, what-have-you, focusing on what you need to feel as though you've lived your best life that you could end

well but that you're managing the anxieties and the stereotypes of group identities that are coming through for other groups [00:14:00].

Imagine a doctor who has *implicit bias* that's making those quick judgments, one that then has racial anxiety as well, that has less interaction, they're not eliciting the right information. And then the patient responding to that by withholding, not even really wanting to adhere to the treatment plan before them. That's the risk that we experience if we don't address the kind of bias anxiety and stereotype throughout that exist kind of broadly, not just in medicine but across many sectors.

We do have the capacity to end well, but we have to start well. Our brains of children, or our children, rather, between two and five, they're just learning how to navigate difference. They're learning how to understand you know, what makes us all unique, right? What color of skin she has, what does her hair look like, how does she speak, does she have an accent [00:15:00], where does she live, all those things are meaningful. They're meaningful because they're helping differentiate, they're helping our children make meaning but they are in many senses denied, they're just ways to describe. Between five and eight, our kids are starting to learn stereotypes, traits, that actually are connected to social groups. They're taking in the media as much as we think that, you know, our wonderful children's programming may be offering kind of a broad, diverse way of thinking of things. We're actually seeing a lot of what I call colorblind-diversity, where everybody is the same but they just look different so we're not creating them meaning that we need to really navigate, we're not building that muscle to really navigate difference in a way that helps us see each other and helps us be seen. Between eight and ten, those stereotypes are being hardened. They're being hardened in a way where we understand hierarchy [00:16:00]. A hierarchy of human value. And then from ten to a hundred, we're being told to unlearn, to unlearn all of those stereotypes. So you think about what it means to actually end well, for me it means we have to build a practice of learning how to live well. And I wanna suggest that we actually can override. I wanna take this group test again, this is the exact same tests, you know what the secret is: that there is no secret.

[Crowding Responding: Blue]

Okay. But I want you to really focus and I want you actually to not read the words, okay? Go!

[Crowd Yelling One Color At a Time In Unison] [00:17:00]

Give yourself a round of applause!

[Crowd Applauding]

What we just did was we overrode our unconscious networks. We took our time, we were slow, we were focused, we were intentional, we did not make quick judgements. We allow each color to be seen and recognised for the beautiful primary color that it was. This for us is the building brick of belonging. How do we create respect, individuation, that practice of recognising someone's social identity because that's meaningful but also recognising the unique [00:18:00] individual that they are. How do we challenge ourselves to have conversations that may feel uncomfortable but do we have those conversations in a way where we are able to focus on the experience that the other person is having as opposed to the anxiety that it's causing us? And how we do it, with a bit of kindness in a way that challenges us to resolve this paradox at the end of life so that we all are comfortable in doing what I believe the gospel according to Matthew asked us to do, which is, "Judge not, lest you be judged." The more information we have about each other, the more focused we can build a practice starting from two to a hundred knowing what makes each individual tick, what helps us see each other as humans and will help us end well. Thank you [00:19:00].

[Crowd Applauding]

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