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Introducing Kenneth Goodman 00:55

I'm deep in the mine of learning on the journey toward best health – a deep and rich mine with many veins. My extensive connections across many lives and disciplines allow me to extract the ore with my guests one load at a time. I have worked with laypeople, care partners, parents, researchers, clinicians, bosses, administrators, policymakers, and thought leaders. Today, I'm fortunate to speak with Dr. Ken Goodman, a bioethicist and Director, University of Miami Miller School of Medicine Institute for Bioethics and Health Policy. Ken and I met when we worked together at the Patient-Centered Clinical Decision Support Learning Network. I was looking for a guest who worked as a teacher, policymaker, and clinician in bioethics. Ken sits in that sweet spot with people at the center struggling day-to-day with the ethical tensions of healthcare navigation and management. Let's listen to the conversation.

Health Hats: Good morning, Ken. Thanks for joining me. How do you introduce yourself in a social situation?

Kenneth Goodman: I say, Hi, I'm Ken. Nice to meet you.

Health Hats: And in a professional situation?

Kenneth Goodman: I try and do the same thing. If it's appropriate, I'll say, I have the privilege of directing the Institute for Bioethics at the University of Miami Miller School of Medicine.

Health Hats: Where were you when you first realized that health was fragile?

Kenneth Goodman: I got sick and was worried. You hope against hope that there's some pattern here that an expert would recognize. But the fragility of it, the idea that there are forces at work, which you also know, by the way, parenthetically, that every once in awhile, someone gets sick and dies and they're not old. So, it means that no matter what those forces are, we haven't mastered from yet. And, you realize, here's the source of potential incapacity. Here's a source of potential limited movements, or just some source of potential limited cognition. Here's a source of potential death. I was lucky enough to be a generally healthy kid, but we all have either misadventures or bad luck. If you're a kid and you're a thoughtful kid, even the chickenpox will be enough to shake you awake out of those slumbers.

Leavened by experience 03:44

Health Hats: Did those experiences influence you in this line of work?

Kenneth Goodman: Yes, but only after I got into the line of work. I found myself having the opportunity to teach and practice in a world of bioethics. One of the issues that have come up as an issue in the profession and working with colleagues is that of empathy. One of the things that I've discovered is this beautiful part of empathy - if you've ever been sick and had someone bring you a tea you understand how very much it can matter to be supportive and helpful and caring for people who are sick. Sick onto death in many cases. So, it didn't guide me. However, it has leavened me.

Health Hats: That's a good word, leavened you. I like that. I spent four or five years of my career, working at Boston Children's Hospital. I led the Patient Family Experience Initiative there. In that process, I was impressed that children are not just children. There are neonates, babies, children, and young adults. The challenges were so different. When I thought about ethics in those situations, my first aha was autonomy and self-determination as people got older. As a parent, a nurse, a person, I am fascinated with autonomy and control, being a master of my own life. Watching the variation and the progression of that is a fascinating study. But at Boston Children's, I became aware of that point, where young adults are transitioning to more control and the misalignment of law and regulations with that autonomy. What's the bioethical angle on that?

Celebrate autonomy at any age 06:23

Kenneth Goodman: That's a great question. We have come over thousands of years, I guess, but certainly in our moral frameworks, our legal systems, and now what we do in the world of bioethics, to recognize and celebrate self-determination. Autonomy, if you will, or Autonomics, to be self-governing, is something that free entities enjoy simply by having free will and a brain. The challenge, of course, is that you don't get that from the get-go. As a child, through all the stages you mentioned, see a creature who very, very slowly manages to acquire more autonomy simply by the root faculty of human development. Kids need guidance. They are not self-governing. Parents and guardians govern them. That's as it should be. We've learned, and this matters a lot in practical ethics, that as you achieve autonomy at different times, depending on the biology of it, especially if you worked in a Children's Hospital, you will see 15, 16, 14-year-olds and even younger, have extraordinary insight about their maladies. And you've seen 35-year olds who can't pour water out of a boot. So, it's a part of individual variation. Then you have our cultures. Our cultures have several other and different criteria. We want to

be able to point to a number. In some cultures, it could be 13 and others, and it could be 16; sometimes, it's 18 unless it's 21. That suggests how very tricky it is to get this right. You're not going to have a social system or a culture that's going to get it right for every individual, which is why, in a lot of cases, we muddle through. But the law is sometimes not very nimble about this, because when you have a 15-year-old who's got her bolts in tight, the law still wants to say that there needs to be a parent, and yet we also know of adults who really could use some grownup assistance themselves. How do we take the privilege, the right, the brute cognitive sack of self-governance or autonomy and apply it? Well, decisions involving reproduction, involving a medical procedure, involving life and death can be so challenging. It's one reason I have a job, but it's also one of the reasons that, or one of the sources of why my job is so interesting. We want to get it right and being virtuous doesn't help you get it right. We need to do a critical analysis. A lot of evidence and data are brought to bear to make the right decision.

Health Hats: What are some of the more common dilemmas related to the young adult that are brought to you for help?

I'm 14. Growing into my autonomy 09:18

Kenneth Goodman: Well, there's one right now. Danny, this constitutes what might be one of the greatest challenges I've faced. People who do what I do are generally in hospitals to do three things. One, we educate people. Two, we develop institutional policies. And three, when we're asked, we do ethics consultations. Right now, I have been struggling with a policy that is among, if not the most difficult policy I've had to work on. It involves new technology. For years, if you were a parent, you would walk into a hospital or your doctor's office or clinic and say, I want to see my child's medical records. And they would give it to you. We've recognized in some jurisdictions where that might be inapt. You might have a 17-year-old or for that matter, a 15-year-old, or even a 13-year-old who has confided in her physician or his physician, something that's quite intimate - usually involving sex or drugs. We also know that if you, for example, were my nurse or my doctor, and I know you're going to share what I tell you with my parents, I'm going to look you in the eye, and I'm going to lie. So how do you write a policy in the 21st century, that governs parental access to my records through an electronic portal? Right now, we almost all have access to personal health records, usually through the electronic health records at a hospital or a clinic. So, if I want to look at and double-check my anti-hypertension drug dose, I log in. It's got all my drugs and may have other information about my visits, my medical history and that sort of thing. I also, in principle, will be able to do that for my daughter or my son. And what we know, given what I said earlier, is that that has the risk of being wildly atherapeutic. If a child knows a parent or guardian's going to get the records, the child's incentivized to deceive her clinician. So, we're trying to write a policy that allows children or minors to say, "I don't want mommy and daddy looking at my record and I'm not 18 yet. At 18, I can have control over that." That's true for all those jurisdictions in the United States and Canada. But it means that if I'm 16 or 17, how can we come up with a policy that allows me to say, "I don't want them seeing at least certain aspects of my record?" That's a challenge, one, for how you meet it and at what age do you start communicating that option to your patients? Two, having communicated the option, what sorts of things can be hidden from parents in the records? Because it would be weird to say, I don't want my parents to see anything, including the

results of the surgery. In other words, it's legitimate for our parents and guardians to need to know somethings. Given the fact that we live under the unhappy fact that we are in a country with a dysfunctional healthcare system, no matter what I want, someone's going to get a bill. And that's going to give up the game. So, the challenges we're facing involved one, at what age do you do this? Two, do you have the ability to write the software that will partition off, for example, birth control, from neurosurgery, and three, how do you manage that as a policy, so parents don't utterly freak out. Because some of them will freak out. They'll say, "it's my kid. How dare you? I'm paying the bills. I get to see the records," when the right answer to that is actually, "yeah, you're paying the bills, but no, you don't according to best practices, get to see the records because we want to make sure that this growing, evolving, autonomous being can enjoy some privacy and confidentiality." Getting that right is hard.

Health Hats: Yeah, that was a big topic at Boston Children's when I was there. Not that I remember how we dealt with it. It's been a while.

Consent while losing my autonomy 13:23

Let's look at the other end. So many of us are caring for somebody. Increasingly we're caring for our children, and we're caring for a parent, or we're caring for a sibling. We were talking about people who were growing into their autonomy. Now we're talking about people who are declining in their autonomy. What about that in terms of the frame of an ethicist? I can think about it practically, in the sense of my parent has growing dementia and I'm increasingly making decisions for my parent. On the other hand, I want to respect their wishes as I understand them. Again, it can be such a mess. It's not clear cut.

Kenneth Goodman: A fair point. No, it's not clear. And it is sometimes a mess — one of the greatest challenges that we face. Overwhelmingly in an aging population. You see people who lose their autonomy, or they lose it bit by bit. Or what we've learned from our colleagues in behavioral health is sometimes we lose it this morning, but not this afternoon or vice versa. Incapacity and dementia sometimes vary during the day. Trying to honor and respect self-determination in a hospital situation can be exquisitely tricky. For example, one of the things that we've learned over the years, especially as modern biomedical sciences, have made it possible for us to live much longer. We will see ourselves treating people in hospitals beyond their ability to consent to it. The foundation, the core value in the 20th century, 21st-century bioethics, is that a valid consent?

Notice I'm saying valid consent, not informed consent, because what we've also learned that consent has three parts to it. One of them is, I must be adequately informed. Two, I must be able to make a decision. And three, I need to be able to understand and appreciate the information to make that decision. So's there are three components. I might be adequately informed, but I might've been incapacitated at the time you informed me. So informed consent was the phrase we use. Well, this gets one of the three legs of that stool. In a hospital situation, when we correctly insist that before we treat people, we get their permission to do so, how do you get permission from somebody who's lost capacity? And the answer is, well, it's very often you don't. That's why we turned to surrogates and why

we entreat, cajole and begged people for hospitalization to designate someone to be their surrogate. Often, many people do not. That's a weird kind of avoidance behavior, denial, or selfishness because it means strangers are therefore going to be making life and death decisions for you, quite literally. Because if you haven't identified someone, we're going to have to appoint a proxy. Most states have a list of proxies, but sometimes we can't find a family member or close friend, in which case we're going to get a stranger. And that stranger, while he or she is going to be obligated under ethics and the law to decide based on what we believe you would have made.

Substituted judgment, best interest, reasonable person, oh my 17:08

That standard, by the way, is called [substituted judgment](#). You do what you think the patient would say if they could say. If you can't determine that, then what do you do? At that point, the next set of standards which are an example of the collaboration between ethics and the law. The next standard is [the best interest standard](#). Okay. Well, the best interest is hard to decide for somebody else. I don't know what's in my best interest sometimes, so that can be tricky. The third standard, which I tend to like a lot, it also is used very frequently in the law, is what a reasonable person would do the circumstances? It's [the reasonable person standard](#). Although in some extreme cases, does a reasonable person want to be permanently unconscious or be allowed to die peacefully? I believe that reasonable people would say the point of being alive is not simply not being dead. I enjoy talking, looking, sharing, feeling, touching, not simply not being dead. If I to do all those other things, you know, I'm conscious. I would argue, I am not differentially abled at that point. This is not a disability argument. This is an argument from somebody far, far, far distant, I believe. I want to enjoy such as I can. And if I'm unconscious, then I can't participate in anything. I stopped being a differentially able. That's the permanently unconscious. In that case, the most reasonable people would say, "I'm done."

Health Hats: We've talked about kids, young adults, and aging is agency, autonomy. As an ethicist, there must be other dilemmas that cross your table or cross your desk. What are the other big issues that you deal with from a practice and policy point of view?

Kenneth Goodman: Mind you, the criteria for valid consent, give us three domains. One of them is how do you communicate with people? We try to teach nursing and medical students about how to communicate sometimes very complex facts to people who might not be able to understand. So, communication ends up being a great challenge. In many places, Miami, where I get to work, is one of them. This show, I know, is in Boston and increasingly many places around the country, I might not speak the same language you do. If I'm not able to do that, then there impedes communication.

Similarly, while language can be a barrier, so's culture. You've just heard the lesson that you need to provide as part of the consent process: all the risks, the benefits, and the alternatives and the possibility of dying. Some cultures never talk about dying. There are some wonderful examples we've heard about in Southeast Asia, of cultures where the common belief is that if you discuss something bad, it increases the chances of it happening. So how do you talk about that? So, communication ends up being one. Capacity and managing its various forms are called [cognitive capacity](#). The third may relate to medical technology.

Ethics and medical technology 19:15

Most of our greatest modern ethical challenges exist because we have a machine that we didn't have so a few years ago. That machine will be able to push air into your lungs when you can't breathe. That machine will be able to keep your heart beating when otherwise would stop. That machine will clean your blood. That machine will do all sorts of things that are needed to keep your whole heart. We have machines in popular culture, the best known of all of them, that will restart your heart after it's stopped. So, the appropriate use and appropriate users of this technology, I think, may be the greatest challenge we face. In terms of resuscitation, everybody who has watched more than three television shows has seen somebody who's had a heart attack, fallen, had somebody come over a white coat under a special incantation that you say after you rub the defibrillator paddles together. You may not know about what a virus is; you may have mystical beliefs about end of life care; you may think that eating cheeseburgers daily for the rest of your life is good health - all false beliefs. But you know that before you put the defibrillator paddles on, someone's going to say, "CLEAR" cause you've seen that on TV. And once you also believed from TV is that every time they do that, they succeed in bringing back the dead. As somebody who's worked in healthcare knows, this is overwhelmingly false. Cardiopulmonary resuscitation was invented for people whose heart attack or whose heart stoppage was a surprise. Mainly, they nearly drowned or had been electrocuted. That's why we invented CPR. Not to try to forestall the inevitable when you're 114 years old with metastatic cancer, end-stage renal disease, and congestive heart failure. What that means when your heart stops is you're dying. And the right thing to do overwhelmingly is protecting your right to a peaceful and dignified passing, not beating the crap out of you for a few minutes right before you die so that the relatives don't feel guilty. Anyway, that's one challenge. Another is dialysis. We have situations where the machines that clean our blood, which, by the way, didn't exist when I was born. That's how young the technologies are. The idea is, here's a new technology that was invented for people, comparatively younger people with renal failure, when transplants were rare and hard to get. Now dialysis is a bridge to transplant. But dialysis might not be appropriate if it's not for any larger medical goal or treatment. I mentioned organ transplantation. So, there's a technology that sometimes people hold out hope for. But which is sometimes inappropriate or because it's a scarce resource, I might not be eligible. Another technology we now have a tool to put oxygen in the blood when the heart and lungs are not able to. It's called [extracorporeal membrane oxygenation](#) or ECMO. ECMO was used when you're fixing to die, your heart's failing, and we're waiting for a heart transplant. So ECMO used to be a [bridge therapy](#). We're going to do this for you to oxygenate your blood, but we're going to put you on the list and try and get you through to a heart. What's happening at some of our institutions now is that ECMO is no more bridge therapy. Now it's becoming what's called [destination therapy](#), where you once put on this device expected to work on it for the rest of your life. You will never leave the hospital, but you also won't be dead. Some people value that a lot, even if they're not able to interact with their care.

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Ethics and artificial intelligence 25:23

Health Hats: Let me shift it a little bit in this technology angle. One of the things that I see with artificial intelligence, the processing of lots of data, leading to making decisions through sifting that data and the likelihood of outcomes is that often with the programming that goes into the algorithms of artificial intelligence are created by white people, a dominant culture, that is not necessarily representative of the exquisite variation of cultures. Is that an area that bioethics gets into?

Kenneth Goodman: Without question. The third technology was going to be information technology. We all got excited about artificial intelligence, which raises some of the issues you mentioned which I'll get to. We have known for a generation that computer programs can make diagnoses that are more accurate than human experts. Let that sink in a second. Computers make diagnoses that are consistently more accurate than humans. By the way, at the end of life computers can make a more accurate prognosis. In other words, with enough data, the computer program can predict whether and when you're going to die more accurately than human experts. Before there was artificial intelligence, we can do that with just the question, what numbers we had available? You don't need artificial intelligence - usually, it's a very large database and a robust computer program. Now, fast forward to 2020, and we have algorithms, which, as you pointed out, are our computer programs. They've been around for quite some time, thank you very much. The other way algorithms that we use in machine learning, which is a branch of artificial intelligence, is [machine learning algorithms](#). I've been around for a while; they haven't evolved very much. We are now in the bioethics community trying to make such observations as you've made, as well as recommended corrective action. So, right. Biases work into the algorithms not only because the people writing the programs were straight, abled white guys, but because the sets of data they used to train or tune the algorithms are from people who had access to healthcare, that their records are already in the chart. And there you're going to find overwhelmingly that they're going to be white. You may find out, depending on the malady, they're overwhelmingly male. That sort of thing. That is a risk. The people who write algorithms care about this a great deal. There are ways to write algorithms that anticipate the risks of bias and reduces influence. In other words, the proper response to a technology that might be faulty is to improve technology, in my opinion. One of the reasons you want to do that is one, you get more accuracy. Two, there's a thread in artificial intelligence and healthcare literature saying that if we get this right, we can reduce health disparities.

A weird, balkanized, for-profit, atherapeutic system 28:19

Let's be concerned about what might be the greatest bioethical issue of our time as it's been in many jurisdictions many times: namely, we don't share very well. That access to high-quality health care is not

available to everyone. And that in some countries that have kluge and dysfunctional healthcare systems. I'm thinking of the United States of America, for example.

Health Hats: You don't have to look very far for that.

Kenneth Goodman: We have a weird, balkanized, profit-driven system that is atherapeutic, discriminates daily, and doesn't provide the high-quality care that all of our institutions brag about in their advertisements. Our healthcare system is corrupt and broken. It is parenthetically dispiriting that our good faith efforts to improve it are now being undermined. That's, by the way, a purely empirical observation, not a political one. If we can use information technology to better identify, for example, social determinants of disease, that will be a very helpful thing to help us reduce those disparities. That identifies people who need help. A computer can't fix everything that humans have broken, and we've broken quite a lot. But information technology, when appropriately developed, when appropriately governed, and what appropriately used, I think, is an exciting new technology. I think we can use it appropriately and bend it to our values, which, when we are at our best, are not the values of selfishness, corruption, privilege, but something entirely different.

Listen to your patient 30:31

Health Hats: When I first was diagnosed with multiple sclerosis, my neurologist, who, when he said this, I fell in love with him. He said that he was an expert in the medical treatment of populations with multiple sclerosis, and he didn't know crap about me. That my job was to learn more about multiple sclerosis, and his job was to learn more about me. I loved that. When I was preparing for this conversation with you and I was thinking about the range of ethical dilemmas, this is one of the things that came up for me. The difference between what research says under these circumstances - that A is more likely than B to be effective - doesn't necessarily say anything about me. How does that come into your work?

Kenneth Goodman: It's a happy transition from discussions of information technology. We have known for thousands of years that humans tend to respond similarly. The signs and symptoms of a disease that allow a nursing or a medical diagnosis - whether or not I respond to a particular drug or treatment - is going to tend to be consistent, right? They're going to be a lot of exceptions and we're going to be able to find ways of managing that. Your physician, by the way, you're right. He's worth falling in love with. Getting that right, finding out how any individual fits into that constellation of zillions of data points is what makes the practice of nursing and medicine so interesting and profound. How do you, Patient Danny on Tuesday afternoon at one o'clock right there, fit into that constellation? It's why we for years, taught nursing and medical students; you need to know about the health of populations. Learn what tends to make people sick and what tends to make them better. Then find out how the patient before you will be able to respond to what you come up with. It shaped evidence-based practices. It was a movement. It's still in place now, although some people have objected to it for just the reason you're mentioning, gather more evidence to learn what works. We don't use that evidence to override what you think of the pathophysiology of the patient in front of you would call for. In other words, listen to your patients, not the research summary of all of them or the computer summary of all of them. Listen

to your patient. She will give you important information about your diagnosis and treatment plan. But at the same time, you need to know what the population is showing. Knowing that might help you when you're listening to her give a more accurate diagnosis. A transition I wanted to make was this requires information, data, a lot of it. One of the challenges we face, another large issue that comes up all the time, is that of privacy and confidentiality. If I tell you a secret and you're my nurse or my physician, you're duty-bound to keep that secret. Well, what they mean is you're not going to tell my roommate or my kid. You are still going to put it in the chart and other people are going to have access to that record. Is it permissible to analyze health records for the sake of population health? If the answer to that is yes, must you obtain valid consent every time? I think one of the greatest challenges we face is the challenge that goes to the difference between an individual patient on the one hand and the needs to practice better and smarter population health. At the same time, it challenges our notion about how much permission I need to give to studying my de-identify health records. I'm of the view that I've benefited in ways I can't articulate from analysis of health. System records included your information. You don't know about that. I don't know that it was your information and yet I'm better for it. This is how public health surveillance works. If I get influenza and I go to my doctor, then she puts plus one in the counting of influenza this year. Plus, whether I got vaccinated or not. Plus, how old I am. Plus, what the outcome is. Are those data points private? I would argue that it would be perverse of me to say, "Oh, I don't want you to share that with the public health people cause that's my information. That's private information." I think that would be perverse. I think that, in as much as I've benefited from the de-identified analysis of other people's data, I must share mine, too. I do it gladly, by the way,

Health Hats: So interesting. What should I be asking you that I'm not?

Kenneth Goodman: I see we're out of time. That's a great question.

Health Hats: It took me a while to get that.

Call to action: Do something 25:58

Kenneth Goodman: One of the things I hope has happened is that you and your listeners have acquired the belief if you didn't have it already, that the attention to values in health care is really interesting. I also hope I've communicated a little, the idea that it's not merely identifying problems to savor them. We need to solve them. And applied ethics or bioethics, being a branch of that, when it's at its best, here's how we can solve this problem. This problem of access to care. This problem of privacy, confidentiality. This problem of communicating for the sake of a better valid consent process. Those aren't hypothetical, and those aren't abstract philosophical concepts. This sort of thing comes up every day, a zillion times. So, what else must be done? I wanted to answer by saying, "well, if you think this is interesting, learn more. The web is full of free courses and information about bioethics and medical ethics. If you're concerned about disability, go to credible websites and read about disability. If you're concerned about end of life care, worried about advanced directives, living wills, and how you, despite your future incapacity will be able to try and govern what your nurses and doctors do after you're no longer able to communicate, learn more about that. If you're interested in genetics or an exciting and controversial new technology when it comes to interventions, learn about that. As much as we talk

about health literacy for ordinary people, I'm trying to think of what it would look like to improve health ethics literacy. Know about your autonomy and the power that it carries with it. Know about how you don't lose that power and those rights when you lose capacity. But to protect them, you need to do something. It doesn't happen magically. To honor or protect our rights, we need to put our shoulders to the wheel. If you're concerned about disparities, we still live in a democracy where our voices very often don't rock the world, can move the needle a little bit. And so, taking responsibility, especially in complex and peculiar times, make sure your representatives know that wherever you are on the political spectrum, you believe that healthcare is a basic human right. Indulge me, parenthetically, the famous libertarian health economist, [Hayek](#), look it up. The libertarian says, "of course, we weren't talking about healthcare. Every civil society needs to provide a basic level of healthcare." That's from the arch-conservative, limited government, libertarian genius who says healthcare is not part of what we're talking about. That's important. It means that civil societies need to do a better job helping us take care of each other. And if you care about that, make sure that the people you voted for know that that's your belief.

Health Hats: Ken, thanks for taking the time. I appreciate it.

Kenneth Goodman: Thank you for including me.

Reflections 39:03

Autonomics, substituted judgment, the best interest standard, the reasonable person standard, bridge therapy, destination therapy – my head hurts. Bioethics, the term first coined by someone (who is a controversy) in 1971, includes four principles – respect for autonomy, nonmaleficence (do no harm), beneficence (for me, on behalf of me), and justice. Ken spoke about two of the four principles autonomy and beneficence. As with much when you start peeling back the layers, bioethics are not simple, not black and white, rather shades of grey. With my family, we're fortunate that we talk about issues of autonomy as parents, as children of parents, and of people certain to die sometime. It's made the dilemmas easier to handle when they inevitably happen. In one stage of my career, I sat on an ethics committee for a year or so. Many of the scenarios Ken discussed came up. None were easy or straightforward. What bioethical issues are you dealing with? Please share as you feel comfortable.