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Knocking on Heaven's Door: The Path to a Better Way of Death

Dr. Maurice Pickard:

I had always heard, if it isn't broken don't fix it. The book we're going to discuss today and that I've read caused me to pause and to think about fixing our health care system. I'm your host, Dr. Maurice Pickard, and you're listening to Book Club on Reach MD. And with me today is Katy Butler, the author of the bestselling New York Times book, Knocking on Heaven's Door: The Path to a Better Way of Death. Thank you very much for joining us today.

Katy Butler:

My pleasure, Dr. Pickard.

Dr. Maurice Pickard:

What caused you to write this marvelous book?

Katy Butler:

Well, I love my parents deeply, and they had lived very good lives, and I think they unconsciously planned to die good deaths as well. They had signed living wills and durable powers of attorney, and they were both very healthy, very intelligent, and very well-educated people. And what I watched was that my mother actually did end up dying a pretty good death, by which I mean a meaningful and empowered death. But that was not the case for my poor father.

Essentially he had a major stroke which really destroyed his happiness, and then in a very rushed decision a year or so later he was given a pacemaker which my mother and I then much later tried to get turned off as he was descending into dementia, and failed. She and I failed, we completely lost control of our family's medical autonomy. And I was already a journalist, and a baby boomer, and I just knew that what was happening to our family was not an isolated case, it was actually medicine as usual.

And that led me to really delve into the problems in our current health care system that had created such a bad death for my dad. And so I would say the reason I wrote the book is I wanted to empower other families, and doctors and nurses, to start speaking up about this epidemic of unnecessary suffering that's occurring on the way to the deathbed now, most of it the result of overtreatment or badly thought out treatments in those last five year of life.

Dr. Maurice Pickard:

You touched on something that I'd like to come back to. You said the hurry-up decision, and you really touched on consent and what it involves, and that it isn't a yes or no, and that it's often a longstanding or certainly a prolonged discussion about the pros and cons. What do you think can be done, especially when you consent to a procedure that has long-term implications for the patient and the family?

Katy Butler:

I'm sort of horrified to say this, but I think a great deal of what passes for informed consent in the medical system is actually pretty meaningless. And I think actually the crucial issue here is defining that we now have what can be a prolonged gray zone between active life and active dying. And we have really not developed meaningful terms for this period.

So my father, for example, he was really in the gray zone for six and a half years, descending into dementia and helplessness. And decisions that are a no-brainer at an earlier time of life such as extend life, extend longevity, those decisions are no longer no-brainers, and they become very, very complicated for the family.

Because the family is balancing extending life against other goals such as relieving suffering, or relieving the caregiver burden, or making sure that someone stays as independent and undisabled as possible as they proceed towards the deathbed. And I don't think

we really have much of a language within medicine at the moment for this gray zone and for how goals of care shift when families enter the gray zone.

Dr. Maurice Pickard:

Is this what you call slow medicine in your book?

Katy Butler:

Well, I think slow medicine is important throughout the lifespan. Slow medicine just means quality over quantity, taking time with patients, and being thoughtful and developing trust with them so that you choose very carefully what interventions or tests are actually good for the patient and what actually might do more harm than good. But these slow medicine issues become extremely vivid when people enter the gray zone of that last five years of life, because the risks of an unnecessary surgery or treatment really go up for elderly fragile people and the possible benefits go down.

Dr. Maurice Pickard:

It's interesting, I had not planned to ask you this but there are certainly, in formalized religions it is okay to withhold certain aggressive treatment if the person actually is in the process of dying. And what you're saying in a way is, we should look upon this process of dying as a much more prolonged one than the day or two or the last week of this person's life. And if we do that we'll be much more thoughtful about interventions.

Katy Butler:

Well, exactly. And in that gray zone it's sort of, you're slowly dying in a very slow way. It's kind of a continuum rather than a black-and-white couple of categories. If you recognize you're in the gray zone and you're a doctor or a nurse you never need feel like a failure. But if you only focus on cure and fixing there's going to come a time with every single patient where you feel like a failure.

But if you also have in mind these other goals of care such as relieving suffering for the entire family, postponing disability, these other major goals, you need never feel like a failure, because there's always something you can do to relieve the suffering of either the patient or the psychological issues for the surrounding family.

Dr. Maurice Pickard:

I like the way you phrased that, because as a family doctor I heard over and over again, "Isn't there something more you can do for my parent?" and they're always talking about an intervention. And of course there is something you can always do, but really it has to do with respecting their values, and giving them comfort care, and allowing them to enjoy what time they do have rather than one test after another. You just have to frame it differently.

Katy Butler:

Yes, you frame it differently and both patients, and families, and many, many doctors are really quite ignorant about a vocabulary for how decisions get made in this period of life. You can say to a family, "I think your mother is approaching the end of her life, and the way we need to think about our decisions has to become a lot more subtle now about what we really think is best for her," for example. You have to say that very difficult phrase, "I think your mother is approaching the end of her life."

Dr. Maurice Pickard:

Or, "she's dying." Doctors don't like to say that particular word.

Katy Butler:

Yeah. But in the gray zone people are not necessarily dying actively yet. It's very sad. Half of people who enter hospice are only there for 18 days or less. There's a terrible, terrible pattern in American medicine which is to treat, treat, treat, including treatments like chemo that can be extremely painful and actually destroy quality of life.

And to persist with those long beyond the point where they actually have a chance of doing some good, and then essentially dump the patient into hospice for the period of active dying, that last week or so. And this is a terrible thing to do, both to the patient and the family. Half of these people don't get to say their goodbyes, to express their final blessing, and those are the things that help family members feel less traumatized by the process of dying.

Dr. Maurice Pickard:

What are your hopes for this book as far as our culture? Do you think we'll have a public discussion that could start with a book like this?

Katy Butler:

Well, I think this is already happening, and I've actually spoken at medical schools and programs where after I've spoken they've actually changed an end of life protocol to make things a little bit more humane. So I do hear from a lot of people who either sent the book to numerous siblings or family members and opened up discussions within the family, and also at end of life programs within hospitals that

are desperately trying to change end of life policies that they know are causing unnecessary cost and suffering to patients.

So I believe it's already happening, and as a nonmedical person it is tremendously healing for me, and surprising, to realize what a positive response the book has gotten from people like you, for example, who are within the medical system and trying to produce better more humane end of life medical care.

Dr. Maurice Pickard:

If you're just tuning in, you're listening to Book Club, Reach MD. I'm your host Dr. Maurice Pickard, and joining me today is Katy Butler discussing her thought-provoking and well-written and beautiful book, really a love story if I can call it that, in many, many ways, *Knocking on Heaven's Door: The Path to a Better Way of Death*.

If I can just step aside for a minute I'd like to say something about, what does this mean to you and to the book when I read Bob Dylan's words, "Mama, take this badge from me, I can't use it anymore. It's getting dark, too dark to see. Feels like I'm knocking on heaven's door, knock, knock, knocking on heaven's door. Knock, knock, knocking on heaven's door"?

Katy Butler:

Yes. I played that song over and over while I was writing the book, and especially that line, "Take the badge off of me, I can't use it anymore." That there comes this wonderful terrible mysterious time when we are transiting into something we don't even know or understand. And all those badges, all those interventions, all that striving becomes meaningless. And as a culture I think we need to shift from cure to care at this liminal time of life and death.

Dr. Maurice Pickard:

The other quote that kept running through my mind, and I thought how ironic that your father frequently said, "May flights of angels sing thee to sleep." What did it mean when he said it, and how do you view that particular quote that he said so often in his active academic life?

Katy Butler:

He used to say, "May flights of angels sing thee to thy rest" to me a little bit as a joke but very lovingly when he said good night to me when I was a kid. And it's almost ironic to me that I ended up writing a book about this man that I loved so much and that really the theme of it in some way is, how do we sing each other to our rest? How do we help each other along this major final life passage, especially in a multicultural culture with numerous forms of religion in them?

There once was a time when these rites of passage were more clearly understood culturally and people really had some pathway towards death that they were capable of contemplating ahead of time, and a lot of us don't have that now. And I'm hoping that this book and other books like it will help inspire people to create their own meaningful rites of passage for the deathbed with events, playing Willie Nelson, or singing, or whatever really has meaning for the person who's dying and the family members surrounding them.

Dr. Maurice Pickard:

The thing that impressed me most about the book, or one of the things that impressed me, was how it's a memoir in that you wove so much research into it as far as the medical community is concerned, which makes it really a thought-provoking book for people who've gone through this and also for the physician, which is of course 90 percent of our audience today. How did you go about doing that?

Katy Butler:

Well, I just knew it had to be done. I mean, there are lots of simple memoirs that may be quite emotional about caregiving one's aging parents or facing a life-threatening illness. I hate to say this, but there's almost a thinness and there can be even a sentimentality to those stories if you don't widen the lens and look at the big picture. In our family's case I wrote about a pacemaker but I could have been writing about very late stage dialysis, or a feeding tube, or chemotherapy, numerous other moral dilemmas facing families and doctors at the end of life.

And I wanted to widen the lens and also look at, how did we get here, because family members and doctors have been complaining about overuse of the ICU for example for over 20 years, and yet nothing changes. And so I really felt like I had to look at issues like the history of medical innovation, how lobbying has shaped reimbursement policies so that we keep favoring these fixes even when fixes are futile and neglecting families' other needs for caregiving and all kinds of other support that really make a difference in quality of life toward the end.

So I wanted to empower people, and I also wanted to zigzag back and forth, because I felt like the family story alone could become too heavy if that's all you read, and certainly the medical policy material could have become frankly boring if it hadn't been alternated with a deeply-felt family story.

So that was my intention, and it made writing the book bearable for me frankly in some ways, because I would often be in tears writing

about how my father had suffered, and I would really need a break. And writing about the history of the pacemaker or how Medicare funding helped promote the overuse of the pacemaker, both of these things gave me some relief.

Dr. Maurice Pickard:

The other thing that before we leave, I can't leave without saying how impressed I was by your family and in particular your mother and how little attention is given to what is called caregiver burden and how it's growing in our country, and how Europe for example is recognizing it, and compensating it, and giving respite care. So between the lines this was another message, another deficiency in our system that I think people when they read your book should certainly become cognizant of.

Katy Butler:

Yes. My mother was very impressive, and she did a great job caregiving, but it absolutely broke her. And I believe that once a family member enters this gray zone where there's high disability and life is not so much fun anymore we really need to treat the whole family as the patients and not simply the patient in isolation, because there's no point in simply shifting a burden of suffering from a patient onto the caregiver. And there's a lot of research showing how this can often break the health of the caregiver, and we have more than 28 million caregivers looking after people over the age of 74.

Dr. Maurice Pickard:

I hope the readers of your book and our listeners will think about this and not be crisis-driven as you were but have the important discussions that need to take place long before people are faced with crisis intervention. I want to thank you very much for spending this time with us, and I really recommend your book. So thank you again for joining us today. Knocking on Heaven's Door: The Path to a Better Way of Death.

Katy Butler:

Thank you very much, Dr. Pickard. It's been a pleasure to be with you.

Dr. Maurice Pickard:

This is Dr. Maurice Pickard. Thank you very much for joining us. If you've missed any of this discussion please visit reachmd.com/bookclub to download this podcast and many others in this series. Thank you for listening.