

Discussion of Cancer Care, Clinical Ethics, Preimplantation Genetic Diagnosis

Jennifer Cohen & Anne Zimmerman

TRANSCRIPT

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Jennifer Cohen 0:00

Welcome to the voices in bioethics podcast. My name is Jennifer Cohen. And it's my pleasure to speak with Anne Zimmerman today about the experiences which led her into the field of bioethics. And you're the editor in chief of Columbia's online journal voices in bioethics. You're an attorney, you're a student finishing up the master's program in bioethics here at Columbia University. And you are also an incredibly successful and passionate fundraiser for cancer care and research and a fierce patient advocate. And that is because you are the parent of a wonderful young woman who is a four time cancer survivor. Let's start by discussing the multifaceted role of a parent when faced with such a serious illness in a child. Do you were you were aware that your daughter faced an increased risk of cancer even before she was born? Correct?

Anne Zimmerman 0:51

Yes, we were we my husband had retinoblastoma as a baby. And he we knew that the genetic chances the chances of carrying the gene were 50%. And then we had an amnio late in the pregnancy to see whether she would or wouldn't sort of need to undergo the more serious eye exams upon birth. So we knew around 36 weeks of pregnancy or 35 weeks that she did carry the retinoblastoma gene.

Jennifer Cohen 1:19

Okay, so yeah, I want I definitely want us to get into genetic screening. But first, let me ask you about the role of a parent in a child's treatment while the child is in a clinical setting. My experience is any parent of a child with a rare illness or really any kind of serious illness quickly become medical experts in that area? How did you navigate the experience of working with the clinical team.

Anne Zimmerman 1:45

It was a really eye opening experience because it began before she was born. We had a really good relationship with an ophthalmologist who deals with retinoblastoma quite a lot. And so we knew what to expect there basically as a retinoblastoma clinic where children are given given exams under anesthesia. And then when the first tumors are found, our daughter progressed through a series of laser surgeries. I think the

much more complicated clinical care and clinical issues came up when our daughter was diagnosed with a brain tumor at the age of two, which makes it trilateral retinoblastoma, it's a very rare condition to have both eyes and the brain all have the cancer. And she had penneo blastoma was quite a large tumor. And it's really that aspect of care when you get into the point of needing very high dose chemotherapy. And your odds of success are, you know, moderate to low. In our particular case, there were no survivors at all of trilateral retinoblastoma with a tumor greater than one and a half centimeters. And our daughter's tumor was almost four centimeters. So we really kind of had the choice to treat or not because her condition was so deadly at that time. And so navigating that clinical care, I would say was incredibly complicated. We happen to come from kind of an ophthalmology family. My father in law was a really renowned ophthalmologist, and we consulted with people around the world. And we were deciding between Sloan Kettering here in New York and the Hospital for Sick Kids in Toronto, they had a sort of more aggressive treatment. And we really wanted to stay home and be in New York. So we right away, we're faced with certain issues based on how to treat and how to incorporate one aspect of that Canadian care into our care. So we did you know, during toward the beginning of the brain tumor treatment, we had to initiate ourselves in really figure out how to petition the board of Sloan Kettering for an unusual intrathecal chemotherapy that they wouldn't otherwise have offered.

Jennifer Cohen 4:10

That's fascinating that were they not offering it because it was so risky, or they didn't have the training in it. What was the reason?

Anne Zimmerman 4:18

No, it is really interesting. There is a high dose chemotherapy protocol for a bunch of brain tumors that was developed at Sloan Kettering by a team of doctors, some of whom I think have switched to NYU in the meantime. So there was a high dose protocol. We felt that the Canadian protocol which actually was a different high dose, chemo protocol was more aggressive, but it had some more risks. So we ended up not wanting that protocol, and we wanted something much more like the typical Sloan Kettering thing, and then some coloring was familiar with intrathecal chemotherapy, but they weren't didn't use it regularly. And they didn't use it on this kind of tumor. But they it was something they knew how to do. It's just something they were rarely doing. So we really kind of pushed them to the limit to get that. And they felt, you know, in the end that maybe that was the outcome determinative thing. It was a very, you know, it was mixed into the regular high dose chemotherapy protocol, which is incredibly harsh as it is. So it's hard to say, you know, in the end, you don't know exactly which thing worked. So I would say it was the type of thing that Sloan Kettering was familiar with, they just didn't have it as part of a basic approach to children's brain tumors.

Jennifer Cohen 5:40

Okay, so an example of patient advocacy, really making the difference in the way they were treating your daughter and presumably others who came afterwards.

Anne Zimmerman 5:53

Yeah, they use intrathecal. A little more than they did before. Even on other things, you know, cancers unrelated to retinoblastoma. I think they have been, I think, since our time they started using intrathecal in more children's brain tumors.

Jennifer Cohen 6:07

Okay, now, these first two cycles were when your daughter was quite young. But let's talk about the concepts of patient autonomy when the patient is a minor. How did you navigate the process of ascent? What kind of standard did you use? Did you use her the best interest standards? And would that be the best interest of your daughter or your whole family? How did you balance risks and benefits? How did that process of ascent work?

Anne Zimmerman 6:34

It's interesting, because ascent, you know, is more of a bioethics term. And when our daughter her second two cancers, one was at age 11, and one was at age 18. When she was 11. For one thing, she was incredibly mature, 11 year old. So I always have these issues with when a mature minor doctrine should, should kick in and things like that. I see how cancer patients are mature before their time, they've lived in this system of doctors and nurses and been surrounded by adults for a lot of their youth. So I would say in some ways, a scent wasn't relevant in that we agreed with her when she was 11. And it was a third cancer. It was a basic osteosarcoma. It was quite large, it was staged to be and it took up but the vast majority of her thigh her femur was cancer. But she agreed with us that we would want to treat it and she had certain goals in mind. So as an 11 year old, she would say she definitely wants to save her leg. And then if that couldn't be done, she'd still wants to save her life. And so they she sort of had a hierarchy of saving her life saving her leg and then just wanting to have the best possible treatment. She understood that osteosarcoma has a sort of a noted protocol that everyone kind of goes through the same thing and then they have an approach to a relapse that is similar where it's 12 rounds of a different set of chemo. So luckily, we never needed the relapse situation or the recurrence but she she knew what she was getting into and some of the drugs were a little bit altered for her because of how much chemotherapy she'd had as a two year old. Then when she was 18, and had a completely different osteosarcoma in her shoulder. All of the osteosarcoma I should mention is related to genetic retinoblastoma and 5% of osteo sarcoma patients have had retinal blastoma and a lot of retinoblastoma patients get osteosarcoma as a secondary cancer. When she was 18 you know it's kind of similar we wouldn't have considered not treating it and I don't think she would either. So she we all had buy in together in deciding what to do. She definitely wanted to treat it and again it was like the treatment very because she was cancelled out from you know, she kind of was getting toward the maximum lifetime dose of some of the important drugs like doxorubicin and when she was 11. She had developed seizures from i phospho mide. But we really had to use it again at 18 or there just wouldn't be there wasn't a different drug combination that would work so well. When she was 11 She also had quite a lot of methotrexate so because of that we didn't use methotrexate at all when she was 18 so it was a completely different protocol. Just because of what she was maxed out on so to speak. You know there's there's a heart protective medicine you give before doxorubicin. But you don't you that's not foolproof, you wouldn't do it forever. So you basically check your heart In between each dose, we did have the doctor petition for a couple more doses beyond that typical lifetime dose, but she couldn't have as many cycles as she otherwise would.

Jennifer Cohen 10:12

Now, once Perry left, your daughter left the hospital when she was a young girl, after the first three tumors were discovered and treated. How did the experience of being a caregiver in the home inform your understanding of how healthcare delivery works in the US?

Anne Zimmerman 10:31

Yeah.

Anne Zimmerman 10:33

I think people when these treatments go on a long time, right, so we're talking about a matter of months. So in her case, it's a matter of years, it was when she was two, she was sick for about seven months of chemo plus a stem cell transplant and then took just after that, it's a massive long time of recovery during which you need physical therapy, occupational therapy and a lot of other things. And then same with you know, after every cancer, there is a long recuperation period, I think the more important time that that maybe you're referring to is just coming home from the hospital. During chemotherapy, it's it's very interesting how much care a parent is expected to give. And when we would bring her home during this most recent cancer, we would bring her home from the hospital on four pumps stuffed into one or two of the hospital backpacks, so lines attached to her poured. And she was having trouble. You know, having had a huge sole shoulder surgery kind of in the middle of the protocol, it was very hard for her to maneuver and get around. So she would have

been bringing all her schoolbooks and things to the hospital as a day patient and staying in the day hospital, there's a ton of care that you're doing at home, when she was 11, for example, on methotrexate, you're checking all through the night, you're checking urine for alkalinity and seeing if she's too acidic and giving sodium bicarb throughout the night, if something were to not be right. So parents are expected to really deliver quite a significant amount of health care themselves. I think some people do for various reasons, seek out either an at home nurse or some other kinds of caregiver. And I think in certain circumstances, while that isn't something generally paid for covered by health insurance, I think that, that there are organizations that try to help people provide that care. But we had two parents living at home and for various reasons, we were so familiar with how to deal with everything to do with pumps, or giving her other things like IV antibiotics at home, a lot of wound care was done at home. So we were really literally stuffing in beta dine tape very deep into wounds and sort of pulling it out and changing it. There's just there's a lot of at home care that we were giving ourselves, I think one of our biggest, you know, our country has a big problem with how much care a parent may or may not be able to give and how to deal with the parents who, who don't have the wherewithal at home or who simply aren't home for all that time because I both my husband and I throughout these cancers spent quite a lot of time with Perry and with our other three children. So it's very time consuming to take care of your own cancer patient through these high dose chemotherapy protocols.

Jennifer Cohen 13:39

So mentioning your other three children, let's turn to the other part of this amazing story, your family's decision to screen for the genetic mutation, your daughter inherited, a process known as pre implantation genetic diagnosis, which is actually different from pre implantation genetic screening, correct.

Anne Zimmerman 13:59

Sort of, yes, our pre implantation genetic diagnosis is sort of it's sort of a bigger deal than your more typical screening. And that is, we were looking for a gene, a genetic mutation that my husband had, and looking for an exact match. So basically, you pull a cell from that sort of pre embryo and search for that. So it's a little different from searching for the type of genetic anomaly that anybody might have more like a trisomy 21, or things, other genetic problems where the gene looks the same in the whole general population where the retinoblastoma gene is individualized to the person right

Jennifer Cohen 14:39

now, can you describe the decision making process you went through to conduct pre implantation genetic diagnosis?

Anne Zimmerman 14:46

Yeah, I think, you know, it's a big process partly, my husband and I are both from pretty big families. And I think that made us think we wouldn't expect to have just one child or an only child. And then having been through just the initial part of retinoblastoma with our daughter, Perry, she did have quite a few tumors in both eyes. And you did notice just the risks of everything, the risk to eyesight, the danger of the condition, and we knew the risk of secondary cancers. So, so we did, we had asked our doctor about whether there was any opportunity to do that type of diagnosis, we wouldn't have even known to call it pre implantation genetic diagnosis. And at the time, around the time, we were getting pregnant with Perry, they're really wasn't anything like that, although they always felt they were on the brink of it. So then, we were more in touch with the hospital having been there probably every week through her retinoblastoma journey. And because of that, we were very much on their radar screen. So I think the doctor kind of approached us when we were saying, we want to have another child to say we think that the hospital can do this. So our daughter, Lizzie was the first person really the first person in the world to have a pre implantation genetic diagnosis for genetic cancer at all. Yeah, it had been done more for things like sickle cell anemia, and I think cystic fibrosis where those genes are very common. So everyone has the same gene, rather than just looking for Larry's Zimmerman's retinoblastoma gene was really a different thing that they hadn't conquered yet.

Jennifer Cohen 16:30

And what level of certainty were they able to give you that the PGD they did would in fact, pick up this RB one mutation?

Anne Zimmerman 16:39

Quite a lot of certainty. It's interesting, because they didn't want to claim certainty to the point that we would not examine the child's eyes when she was born. But they really when she was born, they took blood. We did do the first few eye exams. And I just I think there was a level of confidence that they didn't know how to put a number on, but they really did, you know, test her blood and see no sign of that retinoblastoma mutation. So it really turned out to be a sure thing.

Jennifer Cohen 17:14

Terrific.

So your family has been a huge part of fundraising for cancer. Your family won the 2019 game changer award given by Memorial Sloan Kettering for your work raising more than \$4 million in their cycle for survival program, what is cycle for survival? And how did you decide to focus your efforts on fundraising?

Anne Zimmerman 17:36

I think a combination of things cycle for survival is this really wonderful event? It is it's an indoor cycling event, and it is all focused on rare cancers. And I think that's the most important aspect of it. There are certain cancers that really get a lot of funding, federal funding and a lot of labs devoted toward things like breast cancer and prostate cancer. So rare cancers are left behind, but when rare cancers are put together, they are about half of all cancers are a little over half of all cancers are rare cancers. So we were really excited to really further retinoblastoma research at the time and brain tumor research. And retinoblastoma research has come such a long way that that intra arterial chemotherapy has become a standard of care. And that was something that didn't really exist before some of this fundraising was done and money was put toward the retinoblastoma team. And so we were just really interested in rare cancer research in general in rare genetic cancers. And cycle for survival just kind of gave us a platform for that. And it was really great at the time. I loved cycling, I still do love cycling, so I was going to maybe between seven and 10 spin classes in New York a week anyway. So this event kind of fell in our lap. But when we went to it the first year, I signed up and started our team and I wrote for two hours and my husband and another friend wrote for an hour each. And we just had the best time ever it is it's they have about 200 bikes in the room, the gym is completely cleared out. So the bikes are all on the main floor. And they've just provided such a great platform for fundraising where you can invite friends and have fun and have as many people ride as you want. So we ended up becoming a team of closer to 80 to 100 people and we ended up in eight different cities throughout the US. And it's just mostly it's been a really fun event for our family. So it's just it's a combination of things that make cycle really special to us.

Jennifer Cohen 19:53

And Seth Meyers he's the celebrity spokesman sort of for the for the cycle for survival program and he in the clips Where he is talking about the ride he you can see he has a real bond with your daughter. How did that come about? That's so much fun.

Anne Zimmerman 20:10

I think it's just a crazy thing. I think that Seth Meyers went to college with a couple of the cycle people cycle was founded by Jennifer Goodman Lynn and her husband Dave Lynn is very is sort of still the still in charge of cycle along with the people at the at Sloan Kettering. So Seth Meyers kind of took on this cause one year to challenge Perry in sort of a fundraising competition. And, and that did, I think it brought out the best in Perry in a certain way that she, she just really hit it off with him. And he has been a great support, and it really shines

a light on cycle for survival, and especially on our team cycle for survival does have a lot of celebrities who have who speak at the events every year. cycle has become huge, and is at the point where it's, it's raising around \$40 million, I think might have been its highest year, but we saw it. The first year we joined cycle, it was only earning a couple hundred thousand dollars altogether. So it's really changed and blossomed.

Jennifer Cohen 21:20

Wonderful. So let me finish up our last area of questioning about your own decision to enter the program and become a bioethicist. In what ways do you think this profound experience with with Perry and other patients, how is that informed your studies in bioethics?

Anne Zimmerman 21:37

It it, I came to the bioethics program, because I had major conflicts with doctors that I feel would hurt my autonomy or not respect my parental authority. And, and it was really a problem, I feel paternalism in medicine is alive and well and is a real problem for families wanting to sort of direct care for their own child. And there was an especially upsetting time period, our daughter, our daughter got epilepsy from taking from I phosphide, which is a chemotherapy infusion that she had needed when she was 11. And again, when she was 18. And we had major conflicts with doctors about how to treat that. And it was not part of her cancer care at all that it was due to a medicine. But they were very my way or the highway about using mainstream epilepsy medicines, when we very strongly felt you could avoid epilepsy medicines by some other techniques, one of which was the keto diet, a ketogenic diet, and we had so many disagreements with them. And it was just very interesting. But when Perry was 11, and to end on I fosse, amide, she two times had seizures. After that, she went seven years without a seizure. And the day we took her to the hospital with that seizure, seven years later, they said, I told you, so she should have been on a seizure medicine. And I was so offended by that, that that there are doctors that would medicate someone 24 hours a day for seven years when she really didn't have a seizure that whole time, seemed absurd. And then the seizure fights continued, where we switch to a doctor at NYU, who had similar feelings that she needed a mainstream medicine, having had maybe a couple seizures. And basically, as as it turned out, she had no seizures at all on the keto diet. Then when she started college and went off the keto diet, we found another doctor at Weill Cornell, who very much supports the keto diet, but who also put her on a much different, completely different category of medicine that has controlled her seizures well without some of the side effects that we didn't want. From the medicines that both NYU and Sloan Kettering had been recommending at first. But the fight just brought me to the brink of just this inability to understand why doctors would think they have so much power other over these medical things that weren't even in their genre that a cancer hospital could have so much say in epilepsy that they almost didn't want to treat the cancer unless we agreed to something which came up at one point and I thought it was a real, a real lapse. And then I felt very, I just felt taken aback over the whole thing. And I remember calling other institutions like I called Johns Hopkins and said, You have all this information on the keto diet and our daughters on that and they said oh, it's fine, just have someone check her liver numbers, they didn't seem to care at all. So it was amazing to me that between Sloan Kettering and NYU, I had felt worried that they would call Child Services on me for not wanting some very dangerous drugs that have very, you know, that all come with a blackbox warning about mental health and suicide risk. And they have major risks of a syndrome that sort of acts like an incredibly bad pharmaceutical allergy that can be deadly. There was a set of side effects that we simply didn't think was worth it for this little bit of epilepsy that was infrequent and not really considered. So life threatening 5 million Americans live with epilepsy, they seem for the most part perfectly fine. People who are on more epilepsy drugs are more at risk for sudden death in epilepsy sudep, which is sort of its own category of problem. So there were just certain risks that were a type of risk we were not willing to take, and doctors were so not understanding. And that is a big, big part of what compelled me to look into bioethics programs and to enroll at Columbia,

Jennifer Cohen 26:14

were you able to avail yourselves of the ethics console process when these challenges arose with the clinical

staff,

Anne Zimmerman 26:21

I didn't even know there was an ethics council or an ethics anything.

And we had doctors who literally would stand in between our son or daughter so that their back was completely to me. So I could not be part of the conversation to try to get her to disagree with us. And I didn't really know there was such a thing or that I had another avenue. I didn't know there was someone at the hospital, I could call. And it's interesting, because I knew quite a lot about patients rights. And I'm a parent who has forced hospital admissions when they maybe tried to send us home, but I knew it was too dangerous. And I have forced hospital discharges when I knew we're ready to go. And they were keeping us over sort of a technicality. And I think being a lawyer and knowing those patients rights, I still didn't really know that there was an ethics committee. I didn't I didn't know how to harness that process or that such a thing existed.

Jennifer Cohen 27:16

Do you feel that bioethics has wandered a bit from its Patient Centered focus? Has it become to align with the clinical side of medicine?

Anne Zimmerman 27:24

Yes, yes. I think that I think the bioethics program is teaching me that paternalism is alive and well, which I already knew from the hospital. And I think I joined the program thinking that bioethics would be a huge check on how professionals behave. And I think some of what I'm learning is that bioethics is kind of it's a self it's institutionally run. So a lot of doctors are making rules for themselves. And it's not the patient focus that I had hoped it would have.

Jennifer Cohen 27:57

And my last question, and how was Perry doing today?

Anne Zimmerman 28:00

Oh, she's doing really well. She's her college is online. So she's living with three friends. She has a job. She has full time classes online. She definitely has major, major long term side effects of chemotherapy. And she definitely has a concern that cancer number five could be on its way. But I think she's a really happy young person and she really wants to be a regular college student and she is having a good time.

Jennifer Cohen 28:28

Thank you, Anne Zimmerman for sharing your incredible story with us.

Anne Zimmerman 28:32

Thanks a lot. Thank you, Jennifer.

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