

[MUSIC PLAYING]

**SPEAKER 1:** So typically the response I get when I say I work in pediatric oncology is a bad one. People think, oh, that must be really, really hard and really, really sad. And a lot of times it is, but really this graphic shows that it's not as bad as you think it is.

This is really a significant success story in modern medicine, that we look back in the '50s at survival rates of childhood cancers being less than 20%. It was a dismal prognosis. And that has gradually increased over time, and now we have more than an 80% cure rate in our childhood cancer patients, so it's really quite tremendous.

One of the biggest changes was that-- back in that green area here that you see things really start to change-- one of the biggest impacts was that they started to add CNS prophylaxis for leukemia patients. And that's where things really started to skyrocket, and they've made vast changes since then. So it does result in a new population. We didn't worry about survivorship before because we just don't have them. So now we have this new and rapidly growing population that you're guaranteed to see in your practices at this point.

It used to be-- it would be really rare that you had a patient who survived a childhood cancer, but now estimates are-- I have one here. One in 500 young adults using ages 20 to 34 will be a childhood cancer survivor. And this actually was from 2010 data I believe, and some sources will say even 1 in 250 young adults living in the US is going to be a childhood cancer survivor. So they're a really significant population.

Sorry, I think my sides went out of order. But cure certainly does not come without its cost, unfortunately. Really, there is no body system that is spared after a cancer treatment. So sometimes there are mild things that don't really carry much impact. Maybe some skin changes, maybe some dental abnormalities, sometimes the roots of the teeth aren't as long as they would normally be, sometimes the enamel thins, or we can have really significant effects. It can be secondary cancers or cognitive deficits that really impair executive functioning. So really, it can run just the whole gamut.

We do differentiate between late effects being something that occurs up to several years after treatment, as opposed to a long term effect, which will occur during treatment, maybe in a avascular necrosis due to steroid treatment. And so that develops during treatment, and you have pain in symptoms, and then it's something that just continues with you lifelong. It usually results in joint replacements, and then these patients are young when this happens, so they end up getting revisions and things later on. So long term is different than late effects, but we do kind of use them interchangeably.

I'd say the majority of patients really seem to come through unscathed through therapy. They can have physical effects, but what we really see the biggest impact in I think is psychosocial affects. So a lot of patients have some ongoing depression or anxiety, some post-traumatic distress symptoms in patients and as well as in the parents. They do tend to have from research that we've seen higher risky health behaviors after therapy.

We see patients that are underemployed or unemployed. A lot of times they just seem to get stuck, they never really get into post-secondary education or a training program. So that's a lot of what we spend time helping patients to work through in our clinic.

So last year there were some standards put out of what survivors should be receiving in regards to psychosocial care because a lot of times, we're just focusing either on the cancer itself and its recurrence or more physical symptoms. So this was about making sure that these patients are being screened every year. We've tried to be much more conscious of doing that in our annual health questionnaires. And then also that patients and their parents are receiving anticipatory guidance at their annual visits.

Some of the research that brought this forward was showing that patients who had worse psychosocial outcomes were ones that were not as well supported during treatment. They didn't have a family member, or friend, or someone who was able to navigate through that system with them. So really pulling a team into their care going forward has been important.

So we do know that these patients have higher risk of chronic health conditions. They're more likely than their siblings to have a problem of any degree. They're eight times more likely than their siblings to have a grade 3 or 4 chronic health condition. They're five times more likely to have two or more chronic health conditions that typically are lifelong. They have a higher rate of early mortality.

This all comes from the childhood cancer survivor study, the CCSS. This was started by St. Jude back in the very early '90s when we were really starting to see a growing number of survivors in the population. And it's a multi-institutional study, it's all done by self-report. So Pittsburgh is a participating institution.

And survivors receive questionnaires that they fill in and send back in. And so this has kind of supported most of the literature that's out there on survivorship in childhood cancers, and it's again kind of always constantly changing. But we know from that as well that about 2/3 of survivors will have at least one late side effect. Again, it can be kind of any grade 1 to 4. But then a third of them are going to have a severe life threatening condition, either a secondary malignancy, or meningioma, or they have congestive heart failure.

The CCSS though was originally done on a cohort of patients that were treated from 1970 to 1986, I believe. So treatment was dramatically different at that time. We were given higher doses of radiation, we were giving more intensive chemotherapy, very traditional chemotherapies.

So they did start a second cohort that is patients treated from '87 to maybe mid-90s, I forget the exact dates. But we'll start to see some of that data come forth and see if we see this incidence of late side effects start to decrease. Because as we started getting really good at curing cancer, then the focus started to turn, can we keep the same cure rates, but get less intensive, less toxic therapy, and have a better quality of life? So I think we'll see that continue to change, but this is where we are right now.

So then it's a question of how do we best serve this population? Who is involved with what, and when? And what should the different roles be? So we've identified kind of three different key players that we have.

The PCP is obviously important up to the point of diagnosis. We try to maintain that relationship during the course of treatment. A lot of times patients think that they have a diagnosis, and then we're their PCP. They want to only come see us for every sore throat that they have during the course of treatment.

But we want to make sure that they're maintaining that relationship, because eventually they get to the point they get to go back to that. We want to have less and less of a role in their care. Even though we hate to give that up sometimes, it is actually the best thing for them.

So we at Children's do five years off therapy is where we consider patients transitioned into survivorship. So we like that number because typically, we'll consider patients to be cured at five years. We're not doing disease surveillance anymore, they stop getting scans for solid tumors, they are getting just an annual blood count for a leukemia patient. As opposed to a lot of institutions will do two years off therapy, but then you're still doing a lot of disease surveillance, and we like the five year model because it's a clean break. We can really focus on health promotion, disease prevention, and really look at moving forward.

So I just kind of said a lot of this, but it is truly a shift of focus. And then we want to not only focus on health promotion, but also transitioning back into kind of a normal world. Maintaining that ongoing care with their primary care provider, we want to make sure that they're comfortable with them. We want to always be educating them about what their treatment was so that they're better able to share that then with providers that they meet in the future, as well as they see new specialists, or anybody else.

So we started our clinic in 2008. I think this is a little bit old now-- to 574 patients. I think we're at about 600 now this year. Our average age is 20.4 years.

So we do have some younger patients who if they were treated at birth or age one or two, they're coming to us at five years, and then we're following them for a really extended period of time. But then we have some outliers as well that come for a one time consult. I think our oldest on record right now is 44. I got a call from a 60-year-old the other day who knows that she had childhood cancer and got some form of chemotherapy, but doesn't know what and was looking for help to track down her record. So you never know what you'll get coming through.

But we're pretty good. Mixed male and females, split about halfway. And about 60% were either leukemia or lymphoma patients, which matches up well with what our most common pediatric diagnoses are.

So like I said, we do see patients beginning five years after the completion of their therapy, and then we typically are doing annual visits. But we will have some that come in more frequently every three or six months maybe. Like iron overload, or patients who have maybe some significant either psychosocial needs, or just other ongoing care that they're just not well-established with getting provided elsewhere. And then we do a one time consult for anyone either who maybe was treated in the Pittsburgh area or specifically at Children's, but we also have people sometimes who move from out of state, who never had survivorship care available from where they came from. And then they come and want to have us kind of piece things together for them, so we're always happy to do that.

So when patients come clinic to see us in survivorship, we do have them complete a very extensive questionnaire. It's always a big shock to them. They're used to coming in and having a one page little thing that their parents always fill out for them. And then they come in, and all of a sudden, it's asking about sex, drugs, and alcohol, and all of a sudden, the parents are ready to hand off the papers now.

But we try to do-- this is where we try to pull in some of that screening with the anxiety and the depression. That's kind of our first look into what's going on with the patient at the time. And then we have a team that they come in and meet with our physician's assistant. We have a project coordinator who does a lot of getting them enrolled in our database. And we sometimes will have a psychologist who is always available for consult, or sometimes she'll sit-in with every visit as well.

And so at that point, they kind of get to start to meet the team and realize that there is a whole new level of support behind them. That it's not just looking at their MRI anymore, or that it's not such a straightforward visit, that we're really trying to look at a more holistic picture for them. So they have a significant period of time, and then they are reviewing their treatment summary. And then Health Links we'll talk about a little bit later, it's patient education that we have. And just really again trying to focus on health promotion and improving quality of life moving forward, and then making any referrals as needed.

They then go for just their typical history and physical with our physician as our program director as well. And then what's also new lot of times to these patients is even though they're maybe 18 during treatment, they're typically always just-- they have the parent in the room or whoever is with them. But we really try to make sure that we get the patient alone and have some one on one time with them, and are oftentimes able to pull out a lot more details than we get otherwise. And then we start talking about transition from the time they come to survivorship to keep reinforcing that they're not going to see us lifelong, that they need lifelong care. We want to make sure they know the best ways to get that, but they don't need oncology care long term.

So the Children's Oncology Group convened several different consortiums back in the '90s. Kind of everyone pulled together and is under one umbrella now as the Children Oncology Group. And they have been able to write our chemotherapy protocols, that now people are want more of a national and even international standard of care. And then they've also gone on to develop survivorship guidelines.

So the COG is a members only site for looking at protocols, but the guidelines are available to anyone. So the link is here, it's on [survivorshipguidelines.org](http://survivorshipguidelines.org), and I think I have a slide on that later. But these are very individualized, risk based, evidence based as best they can be, exposure related guidelines that you can go in and search by what chemotherapy drugs someone had, what site of radiation, what dose, what amount of chemotherapy they had. And then pull together what their potential late side effects would be, who's at risk, who's at highest risk, and then how you should be screening for it.

And there is a lot of other useful information on those as well. So it's really great resources, especially for someone who doesn't really know extensively what their history was, just kind of some general. You can look loosely to get an idea of what things you should be looking for in practice.

So we use the guidelines then to generate the treatment summary. So this is kind of the main focus of at least an initial visit to survivorship, is that they get provided this treatment summary. That was kind of put out as a big recommendation by the Institute of Medicine back in 2005 originally, and so then the guidelines were developed in 2008, and we've been using them since that time.

So there's kind of three main pieces to a treatment summary. That we want them to have their cancer history, which can be very overwhelming for them to look at. I just keep reminding them, you don't need to memorize the details of this, I just want you to know that you had chemotherapy. You don't have to know all the names of the drugs, or all the different names of each drug. You don't need to know the doses that you had, but know that there is a way for you to find it, that you always have this available to you. We put the radiation details, any surgery, and then if they had complications at the time of treatment as well.

And then the next part is their individual testing recommendations. So there's a lot of diagnostic testing that we do as well as lab work. A lot of times it's just baseline, so someone who had-- mercaptopurine is a drug that can be very toxic to the liver, but typically that's going to be an acute thing. We might modify dosing during treatment to deal with that, and then afterwards, it's not something that's ongoing. So we might do baseline liver function testing, but we don't expect that to ever become an issue later on.

So a lot of it is base line, some of it is lifelong. So patients who had cardiotoxic therapy, if they had an adverse cycling drug, they're going to get echocardiograms. Frequency is determined by dosing of the anthracycline, the age they had when they got it, whether or not they received chest radiation as well. So some might be recommended to have yearly echocardiograms, that is what our current guidelines-- how I think that's going to change in the next version that's coming out, that that's not shown to be cost effective, but I think every two years is going to be kind of the most common frequency.

Some only need every five years, but it's going to be lifelong testing. So they might be perfectly fine for 50 years of life, but then come 70 years old, they're going to have this cardiomyopathy because of that history they had a child. So we didn't used to have a lot of information on older survivors, but we're certainly now getting to see them in old age. So we'll start to see-- the original CCSS study, I think the oldest patient was 48. But now in this new cohort, I think they'll start to get to see a lot of older patients and really see what impact this has on older adulthood.

And then the last piece for patients in their treatments summary is education. And again, this can sometimes seem overwhelming. It lists a lot of things, but we don't want patients to experience something or hear something and say, no one ever told me that, or no one ever talked about that with me. And it's easy for us to talk in clinic about the things that we're screaming for. Like if we're doing echoes and DEXA scans, of course we're explaining why you're doing that and why we're doing the testing.

But we don't always necessarily talk about things like a bladder malignancy that can occur much earlier in life from say toxin exposure. It's not something that we're screening for. They don't get regular urinalysis testing, but it's something that's there. So we like to have this that they can at least refer to, and then ask questions if there is something that jumps out at them.

This is an example of the health points I mentioned. This is also published by Children's Oncology Group, so these are on the survivorshipguidelines.org site, but then they are also available to patients through Cure Search-- is kind of our more patient friendly site through Children's Oncology Group as well. So it's just again kind of more details. They can absorb as much or as little information as they want, but we try to give them as much information as we can.

So like I said before, a big part of our survivorship is it's from the beginning of their transition-- is talking about transition back into primary care as well. So we just have kind of some loose guidelines that we want patients to be at least 18. Really, we focus more on like 22 and plus. We like to see them through college age and then see where they are. But at least 18 before we say they-- don't have them come back.

We want them to be at least 10 years off treatment. So if we've treated a patient at age 22 for a Ewing Sarcoma, we're happy to see them until 10 years later still coming to survivorship at age 32 and beyond. We want to make sure that they're well established with a primary care provider as well.

And we have some new tools that have been useful in helping making that transition a little bit more smooth. I think that's coming next, but Passport for Care is mentioned on there, so I'll come back to that. But there are challenges with this population. There are a little bit different groups like sickle cell disease and cystic fibrosis, they've gotten much better at transition, making it a smoother process. Because there are patients that have a disease, and they go from pediatric to adults who know how to treat the same disease, and they're treating them for the same thing, and it's kind of a smoother process.

But with our survivors, they don't necessarily have any problem. They don't need to go see an adult survivorship, or they don't see an adult oncologist. They're just ones that might have a problem later, but they have very unique needs, can be very complicated. And it's trying to find what the best process then is to give them the best care in that move.

So Passport for Care is now available to survivors. It used to be only be available to us as providers. So we're really excited about this. It was developed out of Baylor in conjunction with Children's Oncology Group. And it's kind of an online easy access summary of care. Again, it's a lot of the same information.

[COUGHS] This is what some of the pieces of it may look like. So it used to be that I would enter the same information I put in our electronic medical record for generating a treatment summary. But then I was the only one that could see it, so that wasn't very helpful. It was good for people who didn't have a way of making their own treatment summary for a patient. But they would just print it and give it to them, and kind of that's what we were already doing.

But now they've created a survivor portal. So we get patients enrolled in the Passport for Care. They get a password, it's very secure, all HIPAA compliant, And they can access their own summary. It gives, again, all their treatment details, and then it tells what their potential effects may be, and what they should be doing about it, how often. And this Links again back to all of the Health Links if they want to see that information as well.

And what is really exciting about this is that we've said, what happens if-- so the COG updates their guidelines every five years. We're due for version 5 to come out next year. So if we transition patients away and say, you should have an echocardiogram every year for the rest of your life. But then the next set of guidelines says, no, you don't really need it that often. You only need every two years, or three years.

Or something else that maybe we weren't screening for, but now we're finding to be a problem. We want to make sure patients get that new testing. Passport for Care will automatically update any changes that apply specifically to them. So then whenever they log in, that flags for them, and they're able to see what they should be doing differently.

And another piece then for transition, like Josie mentioned in introducing you, was we participated in the Pitt Innovation Challenge a few years ago. And we were able to receive funding to focus on creating a better model of transition from oncology to primary care for survivors. Like I said before, there's was not really a national model. There isn't anyone saying that they feel like they have the best way of doing this, and everyone's kind of looking for answers moving forward.

So we really want to enhance the collaboration with the primary care world so that they know what resources are available, how to access them, know that we are available if they have survivors in their practice who aren't in our clinic, that they can always reach out to us at any time. And there has been a lot of research done looking at what that partnership may look like, and there's always an interest and willingness of PCPs to partner with us. There just isn't always that communication kind of reaching both ways. So we look to really close the gap.

This was our logo for the study. It was taking the survivor as well as the survivorship team in the PCP and connecting all virtually. So we use something called video technology. It's like a HIPAA secure Skype.

So the survivor would go to the PCP for their regular history and physical, complete all that portion of their visit, and then they would connect with us as the survivorship on the other end. And we could all talk directly rather than making the survivor the middle person-- is what we do a lot times. We say-- we see them in clinic, and we say, here's your information, and you should go and tell your PCP you need this done for the rest of your life. And they don't understand half of what we're telling them, they don't process all of that, the information doesn't get there. So this way, we kind of all talk to each other about what the treatment history was, what the recommendations are going forward, and again, just making sure that everyone is equipped with all those resources.

So it was a really, really great study in theory. Everyone seemed to be very excited about it. Overall, it was positive. The survivors-- you can see 90% of them thought it made it much easier to communicate with their PCP. 88% had increased confidence in PCPs. A lot of these were out in rural communities where they don't have a lot of other resources available, so that was beneficial.

And then some of our main objectives were increasing knowledge and awareness of PCP, so we did meet that objective as well. You can see here that they mostly reported improved ability to care for that group and improved knowledge. The struggle was the equipment. It was really hard to navigate that for each-- we did 21 different telemedicine visits, and half of them weren't able to use the equipment, it was difficult to install, practice managers were spending hours trying to set things up. So it definitely had its hindrances, but really showed that this collaboration can really be a good thing moving forward in transition.

So we have submitted this for publication, waiting to hear on that. And lost my train of thought. I apologize. I had one more comment about [INAUDIBLE].

But overall, it was a really good piece moving forward. I was going to say that we want to-- in the future, I think our next step will be to identify practices that might have multiple survivors already. There was one group that we had two of these visits done within their practice, so we know that they're seeing these patients regularly. So we can identify different groups who might have an interest, and go through the process once of getting them set up with equipment, and then moving forward. We think that might be a better strategy going forward.

And I just wanted to mention our Survivor Connect is kind of linked to our survivorship program. We have a project manager who was hired initially through grant funding from Hyundai Hope On Wheels. And it was to initially develop our website, and then just be finding ways to be more interactive with this group, because we lose a lot of patients to follow up. They are a mobile group, they're young adults, they're going to different schools, they're going to grad school, they're moving away. We don't know where they're going to be, but we want to know they can always be in touch with us.

So that was kind of the initial development of Survivor Connect, and then these are just some of the things we've been able to do with that then. That we still have our website that I think I had listed, and it didn't make it into this version. But where it's [chp.edu/survivorship](http://chp.edu/survivorship) if you want to see anytime kind of what we're up to. We send out quarterly newsletters, so you can feel free to sign up on our email list.

We do have a closed Facebook group now, which has been a battle to get. But now that we have it, it's been great. We're able to connect these survivors that feel isolated otherwise. And some of them have made unexpected friendships and have now traveled together, or done all kinds of things, and it's been really good for them.

We do several different events through the year. We have a celebration at Kennywood for National Cancer Survivors Day, which is always the first Sunday in June. And then we do an education symposium a couple of times a year, and just try to get out there in the community and do different fundraising events.