

06| Pediatric Cancer: The Role of a Neuropsychologist (Part 2) – With Dr. Christine Trask

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Speakers: Christine Trask, Ryan Van Patten, John Bellone



Intro Music 00:00



Ryan Van Patten 00:17

Welcome, everyone, to Navigating Neuropsychology: A voyage into the depths of the brain and behavior. I'm Ryan Van Patten...

John Bellone 00:23



...and I'm John Bellone. Today we're bringing you the rest of our discussion on pediatric cancer with Dr. Christine Trask, a neuropsychologist with both the general and pediatric subspecialty board certifications. We'll talk about neuropsych testing, how best to deliver feedback, and some of the challenges to working with this population among many other topics. Just a reminder that we'll be raffling off another AACN Oxford Workshop Series book at the end of our next episode on November 1. This is a "thank you" to all of you who have left us a review, it really helps. If you happen to win, you get to pick from a lot of great neuropsych books. Although we've gotten a good amount of ratings, not too many people have emailed us to be entered into the raffle. So the odds of winning have been pretty good actually. If you want to be entered, leave us a written review and then email us at feedback@navneuro.com telling us what screen name you left the review under. You can find easy to follow instructions at navneuro.com/itunes. All right, well, let's jump right back into our discussion with Christine.



Transition Music 01:36

John Bellone 01:46



I'm curious, when you schedule testing, I'm sure it's important to avoid the acute cognitive effects of when they're going through the treatment. Do you have any rules or guidelines with respect to how long you wait after different treatments?

Christine Trask 01:58



So it changes a little bit for children with brain tumors versus leukemia. Leukemia is the easier one to address because, again, treatment is a very long process. Many children are in treatment for two to three years and it takes a long time for us to see the effects of the treatments. So I often encourage providers to realize that we have this long window of time to get a baseline before we really expect things to be changing. So we usually recommend that children get through their acute phases of treatment into the last phase, which is called maintenance, where the treatments are a little bit more spread out, they're not quite as intense, and children generally are feeling better at that point in time. That's often an ideal time to get that baseline assessment for them.

For children with brain tumors, it can be different because sometimes, depending on the family, depending on the tumor, depending on the surgeon, there may be a desire to have some assessment done prior to surgery. So, on occasion, I've had a

few children where that has been an issue. Where the family really wanted to have a better understanding of before and after surgery and I've done some baseline testing in the hospital prior to a surgery. But more often than not, I would usually see those children six months to a year after surgery, again, for that baseline so that there's time for that acute healing to have happened and for them to be more stable. There's been one or two interesting studies that have said that the psychologist's nature to be protective is maybe over protective. There have been some studies looking at how well children can tolerate having neuropsych testing done while they're acutely hospitalized for cancer and found that it's not a hardship for them at all. In fact, many of the children reported that they enjoyed it because it broke up their day, gave them something else to do, felt more like typical school for many of them, which felt like what they should be doing. So there's been some argument that we shouldn't shy away from assessment, if there's an indication to do it during that period of time.



Ryan Van Patten 03:55

I wish we heard that in the adult world. [laughs]



Christine Trask 03:59

[laughs]



Ryan Van Patten 03:59

That people were interested and it was a "cool thing to do." [laughs]



Christine Trask 04:02

But I think, again, partly for children, their day-to-day life most of the time is in school doing many of the activities that look like neuropsych testing. So it feels like what they're supposed to be doing on a day-to-day basis.



John Bellone 04:14

I think for neuropsychologists, maybe it's more the fear that you're going to pick up all of these non-organic causes of cognitive impairment.



Christine Trask 04:24

Yes, it certainly makes it much more challenging trying to separate it out. I think you'd see it the most in parent ratings. Trying to get parents to give you information about their child's functioning when they're under acute stress and distress, it's very hard for them to try to step back and look at it in a different way at that point in time.



Ryan Van Patten 04:43

You mentioned the centrality of academics to children. Obviously that's sort of the ebb and flow of their world. How much does the school year progression from one grade to another impact when you might do neurocognitive testing?



Christine Trask 04:58

What we often talk about is when children are younger, their cognitive development is more of a stair step. There are these leaps that happen and then sort of plateaus and then a leap and then a plateau. Then, as they get older, it turns more into a linear uphill climb, which mirrors more of the adult world where it starts to flatten off before it goes down. So, in childhood, one of the challenges is trying to time it so that we can see where they are in those jumps. So when children are young, we sometimes say we need to see them more often because we can have these really big leaps that happen. And if we're just assessing it at various distant points in time, we may miss what's really changing or happening. But we're also looking for those big cognitive change points. So usually when children are about 8, 9 years old, 3rd, 4th grade. If you talk to most parents and most teachers, they'll talk about that 3rd to 4th grade time period as being a big leap in what goes on in the school, how children function in the school, how children think, that corresponds neuropsychologically to a lot of the change in executive functioning really coming on board and that frontal lobe becoming much more involved. So that's one of the time points that we really focus on.



John Bellone 06:10

I see. So it's not really an annual evaluation?



Christine Trask 06:13

When children are very young, we might. And, again, for a more significant cognitive concern noted, we might recommend an annual eval when they're very young. But we start building up practice effects and we don't want that to keep snowballing. So we're going to start pushing it out. So it might be annual until they're about 8 and then we'll start pushing to two years, and then to three years, and pushing out. Usually, then I start talking about school transition points as those markers for when we're trying to do the assessment. So if we see them when they're about 3rd, 4th grade, then we see them when they transition to middle school, we see them when they transition to high school, and if they're going to go on to college, we'll see them at that transition point as well.



Ryan Van Patten 06:55

So how frequently you test them, is it strongly dependent on their response to treatment? Some kids respond better and they're functioning better, others physically are struggling? Or is it more standardized, regardless of response?



Christine Trask 07:08

I wouldn't say it's about response to treatment unless you talk about complications from treatment. So certainly children that have more profound or severe complications from treatment, particularly if they develop seizures or other brain or significant hearing loss in response to their treatment, we might see them more frequently because, again, we're trying to assess another variable or another characteristic in there. Otherwise the issue is less about their response to treatment. It doesn't really matter whether you were a rapid responder or a slow responder, it's more about how you're functioning. So, again, someone that's struggling more in school, we might see more often than someone who really seems to be doing quite well in school.



John Bellone 07:55

Is there anything different about the testing battery for these populations?



Christine Trask 07:59

Each of my testing batteries will vary a little bit. There's a lot of overlap or commonality across any child I would see. But certainly within this group, we're going to have a heavier focus on executive functioning, and memory measures that can really look at executive functioning as well. And a real need to make sure that there's processing speed assessed. Some academic measures don't include aspects of fluency or efficiency in academic work, and that's one of the highlights that we need to look at for these children so we always make sure to include that with this group.



Ryan Van Patten 08:30

There's at least some data showing that processing speed tends to be impacted above and beyond general intellectual functioning. So you might - like the typical WASI, matrix reasoning, vocab - there may be pretty steady. So you might not see if you're using that to estimate overall IQ and might be somewhat stable. But then, more white matter efficiency based measures like processing speed can be impacted.

Christine Trask 08:54



I think that's the difference between some of the pediatric approaches versus adult approaches. Most pediatric people will probably avoid the WASI, to some degree, because you only get a partial picture of a child. The processing speed and working memory components of the full IQ really have such an influence on what we predict for kids year after year. It will start affecting what we see in terms of how those other indices develop. It's true there's a real disconnect. So within the oncology group, I would say the reasoning components are generally better preserved. So verbal reasoning, visual reasoning are generally better preserved. Processing speed tends to be the most vulnerable area that we see impacted first, and then working memory to some degree as well.

John Bellone 09:39



I'd imagine that these kids get fatigued pretty easily. Is it difficult to get them through an evaluation?

Christine Trask 09:44



Well, I think it also depends on when we're really seeing them. So, again, a child who was treated for leukemia and was diagnosed when they're 3, you know, by the time they're 8 years old and I'm doing an evaluation, treatment is long gone. There's no real fatigue issue per se coming up. I mean, there's some cancers that do have more long lasting fatigue issues, but most of those acute effects of treatment are done because treatment is done. So, really, in many ways [they] are going to function more like a typical child in that setting. When you do see them for that first baseline, sometimes we do have to break it up and we do think more carefully about that. But I would say the larger issue, usually when they're closer within treatment, is really being mindful of infection. When they're in active treatment, they're immunocompromised. We have to be really careful about who they are exposed to, who was in the room before them, how things have been cleaned and disinfected, and making sure that it's a really safe environment for them.

John Bellone 10:44



So you wipe down the testing material? [laughs]

Christine Trask 10:47



Yes. [laughs]



John Bellone 10:49

We should all be doing that. [laughs]



Christine Trask 10:50

All those little blocks. [laughs]



Ryan Van Patten 10:53

So we've talked a little bit about cognitive domains. Clearly processing speed tends to be impacted, executive function, memory. I'm curious, specifically with respect to brain tumors, if you have a child with a brain tumor in a particular area, do you look for localized effects? Is it usually the case that it correlates? Like a lesion in the left temporal lobe? Or is it more diffuse or widespread?



Christine Trask 11:20

I think a lot of it comes down to, again, this whole issue of child development and when did this tumor likely develop and how infiltrative was that tumor. So when tumors develop when children are very, very young, we often do not get this beautiful localization. A little bit like epilepsy. When you have a child who develops epilepsy at a very young age, they may not show that same lateralization of a left hemisphere epilepsy resulting in language impairment. They may actually show the reverse, where it seems like visual motor skills are more impacted. So we see that same issue with children [with brain tumors]. The group that I would say that we sometimes see more focal findings is when children are in their adolescent years, craniopharyngioma, more of those midline tumors. I've seen a couple of children with those types of tumors and some of them have much more focal memory deficits associated with those tumors. But by and large pediatric diseases don't have the same signature that adult diseases have because those cognitive areas have not yet been so firmly established and localized.



John Bellone 12:27

This speaks to the power of plasticity, too.



Christine Trask 12:30

Both ways. Both the good and the bad of plasticity. The sense that you can reconfigure something and move it somewhere else. But also, there's more to disrupt because that system hasn't developed yet.



Ryan Van Patten 12:42

The sensitive periods.



Christine Trask 12:44

Right. And that's the belief of why, again, we see this processing speed effect in children that we don't see as much of in adults, because those executive systems or those frontal systems have not yet developed in children. So they're vulnerable to being disrupted. Whereas an adult can have some of those similar treatments, and may not have those same effects.



Ryan Van Patten 13:03

Yeah.



John Bellone 13:04

Do the kids miss a lot of school because of their treatment? And, if so, does that play a role in the cognitive sequelae that we see?



Christine Trask 13:12

We've certainly been working to try to minimize that. And, again, there's been a lot of leaps and bounds in the field. Many children, when they're diagnosed are quite young, 3 and 4 years old. So they're not really going to be missing school time. When children move into the maintenance [phase], especially leukemia on the longer part of treatment, most of those children will attend school on a regular basis. They may have Friday afternoons [when] they have to come to clinic, and so they'll miss a small amount of school on a regular basis. But there have been a lot of attempts to really make sure children stay integrated within the school. Some schools use webcams so kids can log on on those days when they're not there and see their class. Some schools have gone to the point of having something to represent the child in the classroom - a teddy bear or an object to take their place in the classroom. A lot of schools use web pages or other ways, again, to keep the kids really linked in with what's going on in their school.



John Bellone 14:03

I can imagine they might even be more socially connected, because there's so much support that pours in.

Christine Trask 14:09



I think it partly depends on how the family and the school respond. There's a whole group within the hospital here who works on reintegration when kids do go back to school. They offer and will go to the school and do presentations for the other students, the teachers, however the family wants it done, to explain what the child is dealing with and how best to support the child. Some families love that and they want it out there and discussed and talked about. And, for some families, that doesn't fit their style and it's a lot harder to have that spotlight on them. And we respect that and we meet them with where they're at and what's going to work best for them.

Ryan Van Patten 14:46



I can see school as being something that is really helpful, fulfilling, something to take the child's mind off of cancer and give them something to do. So, in that way, they may be more motivated to want to get out and stay in school.

Christine Trask 15:04



I think when children are younger, they're often better able to handle when they look different than their peers. Sometimes the group that has a harder time with it are the adolescents. If they've lost their hair, it can be much more difficult for them to deal with that particular side effect at school than for the younger children.

Ryan Van Patten 15:20



Yeah.

John Bellone 15:22



Why don't we move on to some recommendations that you typically give for these kinds of cases pertaining to academic, educational issues, across the board?

Christine Trask 15:32



So if we think about the main issue being processing speed, or the most common issue being processing speed, a lot of our recommendations are then focused on how to deal with that. We can't slow down the world. So it's how can we adjust to it and manage it. So many times for children, that does mean that they get extra time for their exams, extra time for bigger assignments. Their homework may get modified where they do every other problem versus every problem. We may ask for teachers to try to build in some opportunity for delays - if they're going to pose a question that they do a little brief filler before the child has to respond so they have

a few more minutes to gather their thoughts. Those are the main types of things we talk about for processing speed. A lot of the children also struggle with organizing material as well. So we'll talk about approaches for note taking or study habits that can also build a stronger organizational system, which can help with memory and recall.



John Bellone 16:30

Do they usually get academic accommodations?

Christine Trask 16:32

It's going to depend on their functioning level. So the big distinction is if a child has a deficit in an area where they need a specialist, so their math skills are low enough that they need a math specialist, their reading is low enough they need a reading specialist, they need a physical therapist, they need an occupational therapist, they'll get a service under an IEP usually for those issues. If they don't need a specialist, but they need extra time, they may have a 504 plan to get them accommodations. But it will all come down to this discussion between the family and the school. The letter of the law is: does it significantly impact the child's success or progress and their ability to access the curriculum? And that's a vague definition. So sometimes it's hard to figure out when a child should be getting that and when it is not needed.



John Bellone 17:25

Are you typically involved in that process with the school?

Christine Trask 17:28

For the most part, no, simply because of issues more related to payment. Most health insurance won't pay for issues that they deem school-related or school functioning. So a meeting at the school would fall into that category. There are some institutions that have been able to provide internal support for neuropsychologists and psychologists to participate more actively in those. So there are some folks that do have that role. But by and large, it's more of a handoff, where at the hospital here we try to communicate with the school psychologist or the teacher or someone else within the school who then is going to try to then take that part over within the school setting.



Ryan Van Patten 18:11



In addition to those accommodations, thinking about other forms of interventions, things you might recommend. Is there any good data on cognitive remediation or medications like psychostimulants? I'm thinking about working memory and processing speed.

Christine Trask 18:25



So like a lot of children who take psychostimulants to help for attention and distractibility, there's been some research that shows that it does benefit children who have those same effects from cancer related treatment, but probably not the same degree of success. A lot of people have estimated that for a typical child with ADHD, you get about an 80% benefit, or 80% of them would show some benefit from the psychostimulants. For a child who may be having struggles with attention related to cancer diagnosis, that rate may drop to 50%. So there's still going to be a group of children that are going to benefit from it, but it may not be as robust. Depending on the type of cancer, there may be issues involved in terms of the side effects of psychostimulants when you can disrupt sleep or appetite. Those may be things that are concerning in a particular patient that you'd want to be more sensitive to as well. A lot of folks have been working at cognitive remediation as a treatment avenue. I would say it's similar to a lot of the other research with cognitive remediation. We have definitely seen some improvements on some of the measures that we use, but we're still waiting to see how well it generalizes in the real world.

Ryan Van Patten 19:37



Yeah, that general conclusion I think is present with cognitive remediation across a lot of different populations. With the psychostimulants, in your clinical experience, how common is it for the prescribing physician to consider that? Obviously, we know kids with ADHD frequently get it - it's the go-to thing. Roughly, how frequently are doctors prescribing that?

Christine Trask 20:00



I don't know if I have a good sense of a figure for that. I would say that there's definitely a group of families that I've worked with who would say, "My child's had enough medication. I don't want them to have more." And so there is a group that elect not to pursue that. But there's also a group that definitely are using stimulant medication after cancer treatment. A lot of times it comes down to how severe those symptoms are and what is the nature of the symptoms. For most children, we say that once you have a high level of impulsivity, particularly where it puts a child

at any degree of risk, then we're more strongly advocating considering those psychostimulants.

John Bellone 20:39



I know the National Cancer Institute in the US has some survivorship resources. I was hoping you might be able to talk about some other resources that might be available for these children and their families.

Christine Trask 20:53



I think there are a variety of ones, both at the state level and hospital level. Certainly within the state here, the Leukemia and Lymphoma Society does a lot of charitable work for families. They can help with co-pays for medications they might need or other costs or expenses. The hospital itself here has the Tomorrow Fund, which is another charitable group within the hospital to help families both in treatment as well as after treatment with costs and issues related to that. There's also a number of camps that go on. We have Camp Dotty that happens here at the hospital, which is run for survivors and some of their siblings, that happens in the summertime. They do different events throughout the year, too, for survivors and their families. I think there's a real recognition that it really helps kids to know that they may be the only one at their school who's undergone cancer treatment, but they're not the only one who's undergone cancer treatments. So having that opportunity to help other children who have had a shared experience. Many times many of these camps will incorporate the whole family because the family has really experienced it as well.

Ryan Van Patten 21:56



Yeah.

John Bellone 21:56



So maybe for people just to look at what the resources are in their specific region - that sounds like the best way to go about it.

Christine Trask 22:03



I would say certainly the best place to start for anyone who's been treated for cancer, more often than not, the academic medical centers are where those treatments occur. And they're the ones that are going to be most tied in to the resources that are available.

Ryan Van Patten 22:19



Yeah. So we've talked about most aspects of a clinical neuropsych eval in pediatric oncology. When we're conceptualizing this and putting it together in a report, is there anything specific to this population that might change how you write your report? I'm thinking, considering who's reading and digesting the report, is it often just the oncologist or usually the family? Is there anything else unique to these reports?

Christine Trask 22:48



I would say within any child report, we struggle with having multiple readers for what we're writing. So we're writing for a physician who wants the concise, "What's the big picture? What are the main things I need to know when I'm caring for this child?" We're writing for the parent who says, "I want to know that you know my child as well as I do from top to bottom inside out. And that you get these nuances and these subtle things that I've seen." And then we're getting the teacher who, again, maybe wants a more concise version, but really more at that cognitive level versus the medical treatment level. So trying to keep that balance. In pediatrics in general, I'd say there's a greater need to try to keep jargon to a minimum because of these different audiences that are reading, many of whom don't have background in medical terminology. But the unique thing, I think, for oncology in particular is that many of these children at some point in time are going to have to take over. They'll become adults, and they will take over their survivorship care, which means they will have these reports as adults and be reading about what they were like as children. A lot of other kids treated for ADHD don't look at that report when they were 5 years old and read what they were like when they were 5 years old. So there's another mindset I have when I'm writing those. I'm thinking of, "What is this going to be like when they go back and look at this 10 years later? 12 years later?"

Ryan Van Patten 24:10



Yeah, it's interesting. I hadn't thought about that, that piece of it. So how might that impact your writing? When you're projecting out this 5 year old is going to be 25 and may read this report, what might you do differently? Or how might you write it such that the 25 year old version of this person would get benefits?

Christine Trask 24:28



I often think about it in terms of the behavioral observations is probably the part where I really think carefully about what I'm using as examples and what that will imply. I had one adolescent girl where I made - to me it really was a mistake. I was trying to capture the fact that she was not so aware of her body presence and so

she had let her bra strap slip down her shoulder and her mother kept fixing it for her. And, to me, it was a notable thing that, again, she wasn't that aware of her body presence, and that her mother was immediately taking care of it for her, not waiting for her to recognize it. But she read the report and she was mortified that I talked about her wearing a bra, and that I could see her bra. And it was one of those moments, in retrospect, that I thought I should have handled differently. Maybe there are other ways to describe that same thing that I was trying to capture without being so detailed. That it felt like an invasion of privacy.

Ryan Van Patten 25:26



I can see everything you're saying and how you could look back and see it as a mistake. I would have done what you did [laughs]. I wouldn't think to not include that or to say it differently.

John Bellone 25:36



Any other observations that you make that we should have on our mind?

Christine Trask 25:39



It's that whole thing, again, those details, especially [for] a young child. You know, young children do things that are socially inappropriate, that are rude, that are disrespectful. Do you give the literal example so that everybody knows exactly what they did or do you use a more general term? Like, that there were some "impulsive statements" versus saying that "he said, blank, blank, blank, blank." I do think about that a lot when I write the behavior observations.

Ryan Van Patten 26:09



Yeah, that's a great point. I think that's helpful for everyone listening and thinking about these sorts of evaluations. It's not natural when I often describe behavioral observations. You want to be as descriptive and include as much detail without any problematic identifying information or anything that's unethical, but include as much information as you can. So you have this balancing act of wanting to include as much as you can, but also not anything that could be embarrassing for them later. So the language you use is very much...

Christine Trask 26:37



I think about the report as a therapeutic intervention. Again, the point of the report is not to show "Oh, I'm smart. I was able to see this or recognize this." The point of the report is to help people see what needs to be targeted and move it in a more

positive direction. So if my highlighting something is going to make somebody more defensive about it, that's not going to serve a therapeutic point. I need to think about that in terms of, again, that audience and who's going to read it.



Ryan Van Patten 27:08

Yeah, that's great.



John Bellone 27:09

So let's talk about feedback now. The last part of the evaluation. What do parents need to know about the cognitive findings? How do you talk about likely neurocognitive late effects to a parent whose only concern is, "Is my child going to survive?" How do you talk through those things?



Christine Trask 27:28

So, again, the difference usually is when we see parents. Many times we're seeing kids for these evaluations after treatment is completed. So they do know their child is going to survive. We don't have to deal with that most difficult conversation. But, parents vary in how educated they've become about late effects and how much they know [about] that. I try with all of my feedbacks to do a pretty systematic review of how a child performs, trying to use some visual models to show what we would typically expect for a child at this age and where their skills are falling. Are they generally falling in a unified pattern in a similar place? Or do I see the late effect pattern where reasoning skills, basic language skills are maybe in this unified pattern, and speed of processing is way far out? And then I can talk with them about how this is a typical pattern. If I've seen that child for multiple evaluations, we're tracking those over time. And so I'm showing them how processing speed changes. If each time I'm seeing that child, I'm seeing it look weaker and weaker and weaker, relative to their age, then I'm talking with them very bluntly about this is what the concern is, we need to really mobilize and act on what we can do to support this child. Or if it's inconsistent, one year it's low, one year it's back, one year it's low, then we talk about still being vigilant for signs but we don't see a clear pattern of that emerging.



John Bellone 28:56

That's interesting. I'm not sure if we covered it yet, but sometimes the effects don't come up right away and it's not until maybe school gets a little harder, or their peers develop...



Christine Trask 29:06

The brain is supposed to be developing and hasn't done certain things. Yes.



John Bellone 29:11

Okay. How common is that kind of presentation versus the cognitive effects coming right away?

Christine Trask 29:17

This is something probably much more unique to pediatrics than adults. We rarely see cognitive effects right away. The neurocognitive effects from pediatric cancer, by definition, have been described as emerging at least two years after diagnosis or treatment. So we're talking about something that takes a very long time to emerge.



We really are seeing something that's disrupting future development. So you don't see it taking away a skill. It's becoming a roadblock that keeps something from developing. So you need considerable time to progress to see that that hasn't come on board the way it's supposed to. And again, it's that thing that you have to help parents balance. You don't want to be sitting on the edge of your chair monitoring and being hypervigilant for something that may happen three years from now. But at the same time, we know that if we can get involved sooner, we can help kids before it escalates and becomes more difficult for them to manage.

Ryan Van Patten 30:16



That's really interesting. It's so different from adults. There's an insult to the brain and then we assume medical care, management, they're doing better, that they recover, hopefully, to baseline, maybe not. But those late effects, the delayed effects, make sense in terms of what we know about brain development.

Christine Trask 30:32



And then again, we see those separations occur usually at those points in time where we're expecting big brain development. So when the executive system is really supposed to take over, that's usually where we start seeing separation at that point in time from peers, but it takes a while to see it.

Ryan Van Patten 30:46



So these ideas are complex, and we're talking through them. We've just been over how you might explain it to parents. Earlier, we were talking about how to conduct a clinical interview with a child whether or not to include the child and that was really

helpful. What about with feedback? Is it the same sort of rules about when the child might hear the feedback and how you tailor it to them?

Christine Trask 31:07



It is sort of a general similar rule. I always tell parents there's the option for the child to attend part or all of the feedback session. Again, usually when children are [in] single digit ages, I say it's a lot harder for them to sit and hear that. I'll talk with parents in feedback about what they could share with the child. We might say, "You're doing like most kids your age. And certain things are coming easier to you. But some of the things that maybe sometimes are a little bit harder are getting your work done quickly." Something like that. And we'll try to abbreviate it so parents have a shorthand way to explain it to them. By the time children are in high school, I do encourage them more and more to be involved in that feedback session because they start having to take on the role of being their own advocate at school. The school is less interested in the parent coming forward and saying this is what my child needs, and they want the student to be the one. And again, there's a good reason for that particularly if we think that these students are going to go on to college. At the college level, parents are not going to be able to have that role and the child needs to be comfortable in how to talk about their learning style, what learning supports they need. The more we can do this in a stepwise graduated format in high school, that really helps them get ready for what they need to do later on.

John Bellone 32:21



So we talked about how children become adults, we've talked a little bit about that. But I want to maybe focus a little bit more on it, and how the effects of cancer treatments like chemotherapy, differentially impact adults. Is there a difference between the presentation in adults versus children?

Christine Trask 32:43



There is, and it's a little hard to know exactly all of the causes. I mean, first of all, there are different types of cancers in adults than children. There's different types of treatment for adults than for children. So it's hard to know sometimes is it the cancer that leads to these different effects? Is it the treatment that leads to the different effects? Or is it the developmental nature of the adult versus the child? But by and large, these neurocognitive late effects are not something that's typically seen in adult populations. Rather, if you're going to talk about cognitive effects from cancer treatment in adult populations, it's more of the acute - the chemobrain, when you're in the middle of treatment, this fuzziness, this fogginess that can sometimes

persist but it's usually much more acutely related to treatment and less of this gradual long term build up.



John Bellone 33:32

This might be a little controversial, but I've heard chemobrain is somewhat analogous to post-concussive syndrome, or some people might think that. Where the cognitive effects are due more to the fatigue and sickness and mood changes, sleep deprivation, anxiety, all these things, rather than the actual chemotherapy. I was curious what you think about that?



Christine Trask 33:53

So I think it's interesting because I think adults, in general, try to separate the somatic versus the psychological more discreetly. In pediatrics, we understand how these things really are interwoven and are difficult to separate. But, yes, I think there is this sense of recognition that anybody knows if you don't sleep well, if you're in pain, if you're tired, you don't think clearly. So what is driving the not thinking clearly? Is it this indirect effect through that pathway? Or is it a direct effect, like the neurocognitive effects with children where we see changes in white matter myelination? I think from the adult side, we don't see as many clear markers of a physiological process that they are clear about. So there's more of this belief that it's coming through indirect means. But again, I think anyone that's been acutely ill really recognizes that you take medication and sometimes you don't think clearly and that's not to say that it's all in your head. Like, you can really not think clearly at this point in time.



Ryan Van Patten 35:02

Right.



John Bellone 35:02

Yeah, definitely.



Ryan Van Patten 35:03

I mean, the more we move towards - we understand that psychology, emotions, sleep is all in the brain, right? But there's still this push to say, "What's the neurological piece to this? What's the true organic damage versus these other things?" In a way, that's semantics. And it makes sense to think that way. But I like what you're saying about the more we can in our verbiage, and the way we talk to

patients even, explain that those things really go together. That if you're depressed, it's in your brain.

Christine Trask 35:35



Right. And, you know, the reality is that it does give us multiple avenues to intervene. So maybe we can work on somebody's thinking ability by addressing their sleep. And maybe we can work on somebody's thinking ability by managing their pain in a more effective way. That there's other ways and that gives a greater hope for prognosis in a sense of if we have multiple avenues of how we can work on that issue.

John Bellone 35:59



I think that's probably why most of the adult-focused people try to separate it out for intervention purposes, but it's a little bit of a false dichotomy.

Ryan Van Patten 36:07



Yeah, for sure. So, a question I've thought of multiple times: this idea of chemobrain, which we brought up, the terminology seems fairly common and people are using it a lot. I've often wondered why we don't have a "radiation brain". Obviously, cranial radiation clearly can cause cognitive effects. I don't know if it is just a fad, or it's kind of a catchy term.

Christine Trask 36:30



I think it is a little bit of a catchy term. But again, I think it's that timing. So if you're going to talk about what you see acutely with radiation, you see more often sleepiness. You don't necessarily see the cognitive impact right away. What you will see with radiation as an acute effect is kids that can't stay awake, that are falling asleep all the time. And, they do use similar things of trying to pair that up and make a cute little label out of it. But you don't see those cognitive effects, again, so acutely. So then I think there's that disconnect when the treatment and the effect are well separated in time. It doesn't work so well to put the label together because you don't know yet. You don't know yet where it is and what it's coming from.

Ryan Van Patten 37:14



Makes sense.



John Bellone 37:16

So what should we, adult focused clinicians, know about pediatric cancer? Do we need to ask the same questions to our adults as you usually do during the interview?



Christine Trask 37:27

I think it's something that would be part of an adult evaluation, knowing someone's medical history, if they've been treated. If they have been treated, obviously, the types of treatments they have received. Complications from those treatments are very, very important. And the recognition that, again, children that have gone through those treatments, they may no longer think of that as an important part of their history when it's 40 years in the past, 50 years in the past. And that we only have a limited understanding of how this is going to intersect with aging. Because the mortality rate had been so high in pediatric cancer in the past, we didn't have a large cohort that survived that we really understood that well. We're now developing it and looking at it, but that research is still pretty young. And really knowing, is there an accelerated aging or something else that would happen for long term survivors. We do know that, for many of them in their 40s and 50s, depending on treatments received, they may be at greater risk for cardiac problems. And so, again, if you hear that your adult patient has a history of childhood cancer and they're having cardiac symptoms, that may be something to make sure that they're being followed by a cancer specialist who would be thinking about the potential relationship between those things.



John Bellone 38:38

Yeah, that's a really good point. Do you think it's easy to get the records for children?



Christine Trask 38:44

No. [laughs]



John Bellone 38:45

I'm thinking through how we would even go about that, if it was 50 years ago when they were treated.



Christine Trask 38:49

So if you know the institution where they were treated - the one benefit, I would say, for children that are treated for cancer, which I think is a little different from adults, is

that almost all children treated for cancer are going to be treated in a large academic medical center. Very few practitioners would ever say, "Oh, let me just treat the child for leukemia in my office." They're just not going to do that. So many of those institutions do have records well preserved. Oncology, again, because of the way treatments [have] progressed, have documents that will lay out every exquisite detail of their history of what they call the "roadmap" where they literally write every single treatment that occurred, the day, the dose, and it's summarized in some of these roadmaps that you can see. So you can get a pretty good sense of those records. But that involves the adult remembering where they were treated, the adult being willing to sign off the release form, so that there are other complications to that as well.



John Bellone 39:47

Yeah, they're not going to know if they were 3 years old, really, the regimen that they got.



Christine Trask 39:50

Right, exactly.



John Bellone 39:52

One other question that I thought of is does all this impact vocational attainment? Do you have a sense of that?



Christine Trask 39:59

Certainly when we've been looking at the folks that are, again, in their 40s and 50s at this point in time, who had childhood cancer, we do see that that has impacted vocation and independence. They, as a group, again not everyone, but as a group, they have generally slightly lower vocational attainment. They're a little bit more likely to live at home. And many times, again, this is related to multiple health issues. If they're having ongoing chronic health issues related to their childhood cancer treatment, that often impacts their employability and things of that nature. And from a psychological standpoint, too, for relationships, some kids struggle with how to tell people that they were treated for cancer. How does that impact how they form relationships as they get older as well? There's also been some looking at that. Again, they grow up in a dichotomous world. Part of them are advanced, talking to adults and dealing with these medical issues. And then part of them is delayed, because they've missed out on common childhood experiences. The older group say that they didn't feel like they ever quite fit in with peers, because they had these two different worlds that they were in.



John Bellone 41:09

Any pearls of wisdom for how to help those kids get through that?

Christine Trask 41:14

We're doing a lot better now than we used to do. That's one of the reasons why we try to make such an effort to have groups and have children have experiences with other kids treated for cancer. We also really work to try to keep them more integrated within their schools so that they're not missing as much school time. But, again, part of it may also have to do with some of the cognitive changes. [For] some kids, the visual system is more easily disrupted. And a lot of our social world is built on reading visual cues and responding to visual cues. So some kids do benefit from some of the interventions that might be used for Asperger's and talking about how to read social cues. How do you respond to social cues? Particularly some of the kids with certain brain tumors really will benefit from that type of intervention as well.



John Bellone 41:59

I bet it would also improve vocational attainment.



Christine Trask 42:01

Yes.

Ryan Van Patten 42:03

So we've talked about several different ways children with cancer then go on to become adults. You mentioned the good point that the mortality rate used to be much higher, so we don't have a lot of kids as adults to study or at least we didn't. But now that we are starting to, given better survival rates, are you aware - I'm thinking about longitudinal studies like this. It's a very large undertaking, it's a lot of money, but it can also be really helpful. Do you have a sense as to if those are ongoing? If we have longitudinal studies where we're following children with cancer into adulthood?



Christine Trask 42:39

There's certainly two major avenues of longitudinal studies. The two biggest groups: the Children's Oncology Group, which is the group that has really devised a lot of the treatments, continues to follow children on protocols throughout their lifetime. Periodically, specific research projects will also develop within that group where they may look at cardiac issues in this particular regimen. And another main



group that does this a lot is St. Jude's. So St. Jude's in particular does a lot of surveys of their survivors. And that's where we've seen some of the reports of the impact on vocation, long term relationships, from what the survivors report in their surveys, in their long term follow up. And again, a lot of those children are well attached to the institutions where they were treated, so that we're better able to maintain that long term follow up for them.



Ryan Van Patten 43:28

Yeah, that makes sense.



John Bellone 43:29

We have a few more questions for you, maybe backing up a little bit and taking a more broad approach.



Christine Trask 43:35

Sure.



John Bellone 43:35

So regarding training in pediatric cancer, do you think it's better to get a broad experience with a lot of different cancer types? Or to really specialize in one or two specific populations like leukemia?



Christine Trask 43:50

I think everybody's going to have their preference. I say it's important to always have some breadth behind you. Because you have to not just see the child with cancer, you have to say, "Well, what is the rate of ADHD in general? What is the rate of a learning disorder in general? What do those things look like?" And then how does that get filtered with this additional layer on top of it? And if all you see are children with cancer, it gets hard to know how that fits into the larger world?

That being said, the struggle often then is that there are not that many children with cancer in a given location unless you're in a very specialized thing. So it can be hard to feel like you develop enough expertise within that area. And, again, I think that's the benefit of many of these organizations or groups. When we can pool resources and share experiences, it helps offset that. Maybe I don't see 100 kids with cancer within a given period of time but I have a group that I do see and I can share with these other colleagues that have seen similar amounts and then together we have a shared experience that can give us that in-depth knowledge.



Ryan Van Patten 44:59

Again, from a broad perspective, what do you see as some of the biggest challenges to working in pediatric oncology as a neuropsychologist? I know, it's a big question. We went through a lot, but a few things that jump out [to you].



Christine Trask 45:10

So I think there's a couple of things. One of the ones that we highlighted is, as pediatric neuropsychologists, we like to be involved with the whole child and the whole child's experience. And there's a real tension within our country about separating school from medicine for children and trying to create this artificial divide of what we should be involved with - that we're either involved on the school side, or we're involved on the medical side. And it's hard to combine those two things. That's a real downside in the field and something that does not serve the children well - that we don't cross those lines so easily. There's a lot of layers that go into trying to fix that, but I think that's one of the areas particularly for pediatric neuro-oncology that we do need to address, that we need to have people that can go across both sides of those issues.



John Bellone 46:01

I can imagine this is a very emotionally difficult population to work with. How do you cope with that?



Christine Trask 46:11

I always say that I have the easiest part of it. And I am so lucky. My oncology colleagues do have much more of a struggle because the reality is they're not going to send children to me that they don't expect to survive. If they don't expect them to survive, they have a different focus. They're dealing with preserving quality of life and helping that family through that process. I don't see those families so I don't have to deal with that same level of distress that they do. Instead, I have the group that are their success stories. The ones that they're expecting to survive and go on. I often say that the families that I've worked with from the oncology group have been some of the most inspirational families. They are really families that by and large, for the most part, have pulled together to come through a very difficult traumatic time and are still in the fight. You know, still in there trying to help optimize things for their children. And actually one of the more rewarding parts of my job is to work with those kids and our families.



John Bellone 47:16

Oh, that's good to hear.



Christine Trask 47:17

Yeah.

Ryan Van Patten 47:18



Yeah. So this has been great. Thank you. I know we've thrown a lot at you, Christine. This is the point where I think most interviews would end, but we'd like to ask you a couple more questions, questions that we ask everyone about the bigger picture in terms of neuropsychology and more broadly.



Christine Trask 47:36

Sure.



Ryan Van Patten 47:36

So, to start, if there's one thing [laughs]...



Christine Trask 47:40

One thing. [laughs]

Ryan Van Patten 47:41



One, you only get one. [laughs] If there's one thing about the field of neuropsychology that you would change or an area where we could improve upon, what would it be?

Christine Trask 47:49



I come back to one of my clinical directors in training who told me that one of the dangers in our field is to get a little full of ourselves and see ourselves as having a unique skill that we get very focused on and think that we can do this and only this. The reality is the world around us is constantly going to evolve and change. And if we get so rigid and narrow in our focus, we cannot adapt well and manage well. I think we're struggling with that some as a field now, as healthcare insurance is trying to think about, you know, "Is this worth our money and worth our time?" And everyone says, "Well, of course it is." But neuropsychology hasn't been so good about bringing data to support that. That's something we've overlooked because we were like, "Oh, well, we're important. We know we're important." Well, now we have to show it.



Ryan Van Patten 48:39

Right.

Christine Trask 48:40



I think, as a field, that something we've really lacked in and really haven't been able to step back and say, "So how do we show that? How do we show what we contribute?" And should we do things differently? Just because it's been done this way for the past 20 years, does that mean that's the way it should always be done? Or are there ways that we could change and evolve and really do things in a different way that may be just as helpful as what we're doing?

Ryan Van Patten 49:06



That's a great answer.

John Bellone 49:07



I really love that. I totally agree. I've thought that for a long time. That we do such great work, but we're not great at demonstrating how we add value to hospitals and patients and long term effects from our work. So it's a free dissertation idea for...
[laughs]

Christine Trask 49:24



[laughs]

John Bellone 49:27



The second question we like to ask is, what is one bit of advice, and this might go along with number one but it could be something completely different. One bit of advice you wish someone had told you when you were training that really made a difference. We're looking for just one actionable step that trainees can take that they might not have thought of that could really improve their training and performance.

Christine Trask 49:48



So this is going back to the very beginning of training. My husband and I actually wrote a paper on what we wish we knew before we started graduate school, and it still comes back to haunt us at times. I think, again, many of the people that go into the field are bright people who are used to doing well, who are passionate about what they're doing and want to dive into it. And I think in the process of going to graduate school, for me, one of the things was I was so caught up in, "Well, I have to go. I have to go. I have to find a place to go", that I didn't really step back enough and say, "Okay, so here are my offers. Is that really the best fit for what I want to do?" And really to step back about, "So what is my goal?" My goal is to not just be

getting into graduate school. My goal should be a little bit more thought out than that. And thinking about what program you're entering? What do they do well? Where do their students go? Is that what you want to do? What are the risks when you enter that program? What are the costs involved? What are you going to make? Are you going to be able to offset what you pay to go there? That we all need to step back and take a breath and say, "It's okay, if I don't go."



Ryan Van Patten 51:00

Yeah.



Christine Trask 51:01

You know, it's okay. Will that really get you where you want to go? And if it does, and the risks are worth it, by all means, dive in. But don't go just to go. I think that's a mistake a lot of trainees make.



Ryan Van Patten 51:13

It's a much more empowering stance to take, right? Instead of being forced into "I must do this at all costs, regardless of what my quality of life will be." I like that perspective.



Christine Trask 51:25

I saw it from some of my friends that went through the process. A couple of them when we went through that first round of applying and looking, they stepped back and said, "No. Yes, they made those offers for me, but that's not what I want." And they took time off and did other things and explored other things. Some of them returned and got those offers and got those places, which was the right fit for them. And they were much more in control of their career and their path. Whereas I wandered [laughs]. Because I was like, "Well, the door is open. I have to go through."



Ryan Van Patten 51:56

It's okay to wander a little bit. [laughs]



John Bellone 51:58

Yeah, we all do. Well, this has been amazing.



Ryan Van Patten 52:02

Thank you so much.



John Bellone 52:03

I'm really excited to put this out into the world. And, thanks. Thanks again.



Christine Trask 52:07

You're very welcome. Thanks for having me.



Ryan Van Patten 52:08

Thanks.



John Bellone 52:10

Well, that's all for our discussion on pediatric cancer. You can find the show notes and several resources pertaining to the topic at navneuro.com/06. On November 1st, we'll have a full interview with a neuropsychologist who specializes in assessing and managing driving in older adults with cognitive impairment. As always, thanks so much for listening, and join us next time as we continue to navigate the brain and behavior.



Exit Music 52:39

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