

Childhood Cancer: A Trauma Perspective

Presented By: Ashley Morgan Soukup, MA, LMFT
Summit Emotional Health

Transcription

The art of working with someone with trauma is to be really be able to hold them by the hand and say, "You're sitting in hell and we're going to get through it and we're going to get through it together." You're in school six hours a day. You are their family in the majority of the day. With that being said, you get to hold their hand and you get to walk them through this experience and this journey.

"What is trauma?" Trauma is a disturbing or distressing event that impact you physically, emotionally and psychologically.

There's acute trauma: events that occur at a particular time or place. They might be short-lived. It could be a job loss. It could be the loss of a loved one or even a pet. If you're thinking the school setting, you have teachers you love more than anything and the little guy has to go and say goodbye at the end of the year, that can be a traumatic experience. If they come and the teacher retired or they're in a new hall in middle school and they don't get to see their six or seventh grade teachers anymore; that's a big deal.

Complex trauma: exposure to a repeated trauma over long periods of time. That can be continued sexual abuse, domestic violence, etc. Is childhood cancer an acute or complex trauma? It is a complex trauma. You don't go from one end of the road to the other like Robin explained. There are lots of ups and downs and there are lots of difference points in their experience where they might feel are more traumatic even than others.

For some, we've heard losing their fair might be a big piece, or not being able to go to school when they want to, or losing the opportunity to play college basketball or being able to play sports in general. However, they characterize it, is going to be how it's ultimately defined. As caregivers, teachers, nurturers and nurses, we need to be able to ask them, "What is the piece that might be the most traumatic for you?" when they're struggling.

Exercise:

I want you to get involved in experiencing what people might do through when they have a traumatic event. Take a moment, shut your eyes and consider a time that might have been distressing. What do you see? I want you to look; consider what you are hearing when you're thinking about the time and experience. What are some noises going on around you? What are you smelling from that time and experience? Are there any tastes you are experiencing in this moment? What can you tangibly touch around you in the experience? Now that you're back in the present, is your heart racing? Are you feeling a little sweaty? Are you feeling like you want to cry?

For these kids, that's what happens and could happen at any moment in time during their course of treatment and even for years after. It might be hearing a bell that reminds them of being in the hospital; they might taste something that tastes like awful hospital food, or if they couldn't eat hospital food and they really wanted it and they remembered, "Oh, my gosh. I couldn't eat ice cream!" or "I couldn't eat this without getting sick," and that's what they struggle with. That's trauma.

Any dates, whether it's the date of diagnosis, date of when their treatment was over and they had to say goodbye to the amazing treatment team that they loved and cared about

for multiple years or it could be, the date they lost a good friend; could be the date of their birthday that they weren't being able to be home. Those dates are going to affect them and going to continue to affect them event when they're in school. We don't always know those and that's where the characteristics of loved ones (you are their loved ones when they are at school) that we might not know or be aware of, when they are experiencing characteristics that they might be struggling with like behavioral issues, anxiety, attention issues in class; those are the ones that we want to be mindful that those might be dates or things that are happening and be able to support them through it.

It's a brain. This is important because, who do past experiences continue to affect us? Parents bring their kids in to see me and they say, "Hey, I need you to help my kid get over x. I need you to help my child get over childhood cancer." I had a child come. He was three years' post-treatment and was going really well and successful. The parent said "He just can't get over it. Every time something bad happens. He goes, 'Well, I had cancer.' Help him get over it."

I want you to consider the amygdala. This is the initial fight or flight; so when you thought about the bad thing that happened, your body has a response and a stimulate to when you have a traumatic experience. You shut your eyes; you get scared. "Oh, man, I'm either going to run or I'm either going to fight someone." Based upon early development, the initial reaction that you have when you were younger is likely going to be the one that you continue with for decades unless you get retrained. The amygdala piece when you have trauma, becomes overstimulated so you are much more likely to have increases in cortisol and norepinephrine. This is what elicits stress and creates the fight or flight response.

For these kids, this a more hyperactive area. When you have the smell, touch, hearing, sound, etc., it's going to be more highlighted and you're going to end up having a stronger reaction. This in combination with the prefrontal cortex (frontal lobe part of your brain that's not fully developed until you're 25), helps with impulsivity and helps to make clear, rational thoughts. When you have kids in class, do they tend to have continually clear, rational thoughts? No; they tend to be very impulsive and react wildly.

When my four year-old will throw something as his brother and goes, "Oh my gosh. I'm sorry. I didn't mean to do that." He really didn't mean to do that. That piece struggles with a decrease in being able to focus. We have these kids who struggle with a big deal life thing then we're expecting them to pay attention like typical developmental stages. They can't. It's not already developed and now, it's further stunted and unable to make conscious decisions. This created a perfect storm of not being able to engage and make clear decisions in a traumatic life event or when something is triggered.

Consider the statistics; The Children's Hospital of Philadelphia did a really good study in looking at post-traumatic stress symptoms, so PTSS versus PTSD. When you have trauma, it doesn't always mean you have post-traumatic stress disorder; but, people who have struggled with trauma can still have post-traumatic stress symptoms. More often than not, people would have PTSS across the board if a bad situation happened. The Children's Hospital of Philadelphia was looking at whether they meet criteria or diagnostic criteria for PTSD.

24% of children had PTSS with cancer and we know there could be likelihood of having a transplant down the road that would increase the percentage. Cardiac. These are all the long-term late effects we discussed and they can all have a PTSS reaction. Interestingly, parents and siblings of kids who have childhood cancer, this is a significant increase. Percentage of parents is 35 for cancer and then 39 for transplant issues. 30 to 45 percent of

parents and siblings and 15 to 20 percent of childhood cancer survivors experience traumatic symptoms years after treatment. This is due to pre-existing vulnerabilities. Did they have a previous diagnosis of anxiety, depression, ADHD, emotional behavioral challenges that had become undetected prior to even diagnosis? That's for adults too. Then the prior behavioral emotional concerns, and personal opinions about the event.

That is the piece that makes parents and siblings maybe different than kids that are struggling because when you are in the childhood cancer experience, it's like you're swimming and you look up and you're in the middle of the ocean. You go, "Oh crap, I've got to keep swimming, and then I get to the end." Then they say, "Oh my gosh, that was a really bad thing." That's when they might process. Parents are sitting and they have the sleepless nights when they're not in total survival mode. They're going, "Oh my gosh, what if they do die? Oh my gosh, the doctors are telling me that they might not be able to walk because they have an amputation. Oh my gosh, they're telling me that I'm going to have all these late effects and how I'm going to get them supports and how I'm going to get my kid from here to there. They are all struggling, which increases that traumatic experience more.

How behavioral health professionals assist cancer survivors and families with these post-traumatic stress symptoms and the disorder symptoms is impacted by how they normalize the experience of PTSS and cancer, meaning... it is part of it. You're going to have post-traumatic symptoms, and you're going to have cancer, and how do we navigate that? That's where you all come in with being able to hold their hand and walk them through. This is difficult, but we are going to get through it. I highlighted these two in red because you are going to be the additional supports, and you're also going to be able to explore post-traumatic growth. Being able to say, "I'm going to get through it and this is what I want it to look like."

The gentleman Justin on the video, he said, "There's a difference between plans and goals. Plans can go away, but you need to have goals." As the loved ones and caregivers, how we make meaning about things is ultimately how we're going to establish, help them to establish goals going forward. We say, "Hey, it might be terrible and you might not make it," and that's the end of their story, how devastating is that? Where, "Hey, this is going to stink and we're going to get through it and you can go to college, or you can what you want to be, or you can graduate from EMT school or whatever you want it to look like." That's a huge gift and that's going to ultimately provide them with resilience going forward.

Why are some people more affected by traumatic events than others? The effect of the trauma is dependent on the type and characteristics of the event. It's cumulative; so if you have that easy road, that Robin showed and depicted, you might be more less likely to struggle with a traumatic event than if you're going wonky and you had the transplant and the cardiac piece.

Developmental processes, so where you are in stages development. One is being able to make meaning of death to be able to have more successful outcome with a traumatic experience. What does death look like? When you're about 10, 11, you start asking questions about "What is death? People die. I can't believe they're going to pass away and I'm never going to see them again." Being able to have comfortable open conversations with kids about that is important. One of the things I've heard often is they don't want to talk to their parents about the thought of dying because they want to protect them and keep them safe. If they can't talk to their parents, who do they talk to? They're going to talk to you guys. They might have the big deal conversation in the nurse's office say, "Hey, I might die." You got to be ready. So what do you say? I'm going to ask you guys, what do you say? Everyone dies.

I would even say, "Hey, you're going to die. What do you think is going to happen to you after that?" I know there's a difference between you're in school, so you might not be able to have conversations, but you're asking a question. You're not giving them the information. You're not feeding information about religion. You're not feeding information about spirituality. What happens to you after you die? Where do you go? They're going to make their own meaning of that, and you say, "Okay." You buy in. You agree. You go, "You're going to be safe. You're going to be okay. You're going to be happy. Guess what? Your family's going to be okay and they're going to be safe and they're going to be happy, and they're going to be able to move forward too. It's okay." They need safe people to be able to have those conversations with. It helps them to make meaning going forward.

I want to ask you guys another question and give an opportunity for conversation. How do we as support persons make a meaning of childhood cancer? I brought up the rollercoaster of feelings today. When you think about it, is it devastating and totally sad? Or is it everybody's going to die? Or is it like Dr. Dunsmore said, where, "Oh my gosh, there's over 80% of people survive it. Over 80% of people, kids with cancer, they overcome it and they do better and they thrive."

One of the bigger questions we hear from the patient and parent is why? There's not really an answer for the question so helping them process what's they why meaning behind that in their own experience. I think using that as an opportunity. "We don't know how strong you are, but adversity comes with challenges Through adversity you find strength. We are going to figure out how strong you're going to be through this, which is awesome."

I think one thing also about the why question is just to reassure whoever's asking the why question that it's nothing they did and... you may not have the answer for why, but you can at least help them understand that it's not something that your mom did or your dad did or you did that made you have cancer, because I think that people, parents blame themselves, and kids sometimes blame themselves for their diagnosis. That is a negative start to the whole adventure. I think kids want to know that adults don't have all the answers sometimes. It's okay to say, "I don't know why this happened, but I am going to tell you it's really unfair, and you didn't deserve it, but we're going to now get you through it."

The protective factors to trauma, the psychological resources. You need the adaptive resources of coping mechanisms and strategies. What are your coping mechanisms? These are coping cards. My argument about trauma is, when we all shut our eyes, everybody has those moments of they can pinpoint in their life that have been particularly traumatic. Does it mean that you have PTSD? Absolutely not. Does it mean that it affects you on a daily basis? Likely no.

But you've experienced trauma, and how many kids are typically in a class? 20, 25, maybe 30. They all are going through something and they're all struggling. If you as a teacher or the nurse or the school counselor are struggling, the kids in the class are struggling, why not create a culture in the school where everybody has coping mechanisms and strategies they can deal with and struggle? They just have to have their card. They can keep it in their desk, keep it in their pocket, keep it in your office. They can say, "Okay, I want to listen to music for five minutes. I need to get a drink of water when I'm having a hard time. I need to be able to play with my squishy ball when I'm having a hard time. I want to write a note to the teacher and be able to put it on her desk. I don't even need to talk to her. Or I need to go talk to the school nurse and talk to the school counselor." What are they? They can be quick tangible things that they can do that they know they can call in when they're having a hard time.

My best advice for this would be, you can laminate them, you can put little straps around them, hang them around your neck. In that first week of school, everybody does them. Everybody wears them. They see as teachers you have your coping card and coping strategies, or as nurses, or as school principals. Everybody has their coping card mechanism, and guess what? They do too. It creates a dynamic of normalcy for them. It creates a dynamic of ultimately normalcy in the entire school. They need to have a sense of competency and mastery, meaning that they are capable. Again, Juanita, I'm going to use you because you were the poster child for presenting. You are capable, and I can do it, and it's really hard but I'm going to get through it. You're capable, and they see things where they have been successful. That is where all the strategies that come in. I'm going to say mom come discuss, "Let's give them five versus ten math problems, show that they're successful at the five and not make them strive to have to do the ten. They have the mastery." They have a stable sense of self. They know who they are. They might not have the answer to the why question, but they know who they are and they know what they're good at.

I often say when kids come into my office when they are struggling with the trauma piece, "You are not your trauma. You are not your illness. You are not the death that happened. You are not your trauma. You're not the kid with no leg. You are you, and you are great, and you happen to have this." That is very different, being, "I have cancer and that's my identity," versus "I am so-and-so and I am brave. I am courageous. I'm smart. I'm funny. I'm kind. I'm good to my family. I have great relationships with friends. I happen to have this really crappy thing called cancer, and it affects me but it doesn't shape me." They know who they are. A lot of that stuff is being able to feed it. You want to praise them for breathing. That's often with kids. You praise them for breathing. "Oh my gosh, you're so nice. Oh my gosh, you're so smart. I can't believe you did that. That was so great." The more that we do that as adults for kids, the better off that they feel in the long-run.

Again, back to the realistic concept of death. They know that everybody dies, and everybody's going to go, and we can't determine when it's going to happen. We can't always keep people safe, but we can love them while they're here.

You're in good physical health, which ultimately puts kids with cancer at a disadvantage. Why, we might see then that post-traumatic symptoms in kids with cancer tend to be higher. Physical resources, the other piece being intelligence. We know with the cognitive late effects, they tend to not feel as intelligent as maybe they once did, which is ultimately going to serve as a barrier. Then the environmental resources as protective factors. You have an availability of a supportive nurturing family environment. You have a consistent social network. That's you guys. You have stable friendships. What can we do at school to provide the stable friendship piece? What are we doing at school to provide consistent social network for them? That comes with you guys as a whole, whether they're coming into your office to create a ritual every morning, going to school nurses or going to school counselors. It's that piece that's going to be really important.

Physical, emotional, and psychological symptoms across elementary school ages. These are in your binder, so I'm not going to go through them wholeheartedly. I will tell you more often than not, I want to point out the traumatic play piece, particular with little guys, they don't always have the word language. When you're in your brain, and your brain files away things almost like those old school viewfinders where you click it? That's how your brain files away memories. There's going to be the visual cue and then there's going to be the auditory processing. When you're little, you don't really start forming those as a cohort until you're around six or seven. If they were diagnosed really young, they might have the visual depictions of what happened, but they don't have the auditory piece to be able to go

with it, so they act it out in terms of play. You might see if they're little guys, kindergarten, first, second grade, they might react in terms of saying their stomach hurts, or playing doctor in the class with whatever tools you have, or trying to form relationships with kids with playing doctor, that kind of thing, because that's what they know. That's what makes them feel safe, and they're acting out their trauma.

The other one... anger and aggression, this is going to be across the board: mood and irritability. Nine times out of ten, if I'm seeing kiddos that have mood, irritability, aggression issues, and there's not a strong behavioral diagnosis going on, I always say to the families, "What happened?" Particularly if it's onset pretty quickly. You've seen the kid come and it's like two weeks, three weeks, and all of a sudden they're acting out poorly. What's happened around here, what's going on? That's when I always want to go back to the date. Even three, four, five, six years ago, and that date of diagnosis is coming up, the date of discharge, the date of a major transplant, the date of a loss of a family member or loved one. That is the big deal because they very well might be acting out in response to that. Remember, they file things away based in their viewfinder. They might not be able to tell you what's happening, but if you know those things and you start asking them, you go, "Oh, they're just acting out because they're having a hard time and it's a trauma reaction, not necessarily because they're being a bad kid or anything else that's going on in the classroom." Then you provide them extra nurturing and support around that time and it should resolve itself.

Hyperactivity. I want to discuss this one, I think Alma discussed this in her session that when we see hyperactivity we often say, "Are you ADHD?" And more often than not, if kids are having ADHD, and I want to reiterate exactly what she said and she's on medication, if you're truly ADHD and you get on medication and it works, you're likely ADHD. If you get on ADHD medication and it doesn't work, you're not being hyperactive because you have an ADHD brain. We need to be mindful of that. I think just when they're having a hard time and they're hyperactive, I would say let's decrease the environment and the stimuli and provide more nurturing before we put in place things such as medication or counseling or interventions. What can we do in the classroom, or what can we do in the school?

Providing additional supports. This is the piece that we're going to start doing a little bit more experiential stuff, provide additional supports to those with cancer related PTSD. One in five students are diagnosed with mental health concerns, meaning anxiety, depression, ADHD. One in four in the state of Virginia. One in four of that 25% are actually receiving treatment, so only 25% of people who are diagnosed with a mental health condition actually go to counseling.

If you look in your classrooms or look in your school, how many kids are actually having a mental health issue, and then combine that with people who have childhood cancer, those numbers, it's dramatic about how many kids that are struggling. If we create a culture in an environment where we foster a sense of normalcy, we're then going to be able to help everybody have a stronger emotional wellness. With that being said, creating a ritual for trauma is one of the best things.

Exercise:

Mary Jo, if you don't mind, I'm going to send these... this way. I want you to pick a crayon. What Mary Jo is passing out is, it's a mandala. It's a circle. Mandala is Sanskrit and tribal for wholeness and oneness. If you think about the sun, you think about the moon, you think about the earth. Everything is round, right? It celebrates wholeness, togetherness, oneness, and collectivity. You want, in your schools, to create a sense and a culture of being whole and one and collective. One of the best ways to do that is providing almost ritualizations in the classroom because the more people know that things are happening consistently in the class or even in your offices, they're going to decrease in terms of anxiety,

worry, hyper arousal. They're going to ultimately calm themselves and feel more grounded and safe. You can pass it back and forth between you and a child, or you can just say, "Hey, I want you to come in and I want you to spend two minutes redrawing on your mandala." What looks less intimidating, giving them a circle, or giving them a blank piece of paper? A circle.

They go, "Oh man, I can make something out of that," versus you give someone a blank sheet of paper, "Oh man, I'm not creative. I'm not gifted. What am I going to do with that?" Everybody has a crayon? I'm going to set a timer for 30 seconds. I want you to use your one colored crayon for the entire duration and go ahead and put your initials on the top of your page. You have 30 seconds, and I want you to free-draw on your circle. When I say stop, stop. Ready, go. Now I want you to not pass your crayon, but pass your paper to someone else in the room. Now, I want you to pass it somebody else, not back to the person that had it originally. I want you to pass it one more time, and make sure it's not going to somebody who already had it. Now send your paper, this might need a little bit of work in terms of finding initials, but I want it to go back to its rightful owner. Does everybody have theirs back? What was it like to be able to leave with a paper that didn't look like something and come back with something that's entirely different.

Could you imagine if you are having a kid and you're having a really hard day. You come in and every day, could have had a really awful night the night before. You come in and you know that you're going to be able to do a little bit of two minute free-drawing, or you can share an opportunity to engage with your friends. It's not only going to increase opportunities for social network with peers. It's going to increase social networking time with you as a caregiver, a support person. It's ultimately going to de-escalate anxiety and start a really cool consistency to the day. Whatever's happening at home, whatever's happening at the hospital, whatever's going on, they know they're going to come to school and this is an opportunity to really just be present in the moment and create a safe space. Another piece and I want to be mindful of time too. I could talk about trauma stuff all day long, but I know you guys want to go home eventually.

Sandra Bloom, I just want to give a tidbit of this because this is another opportunity to create a ritual in your class. She's a psychiatrist, and she created a lot of work called the sanctuary model in residential treatment center. Kids who have really had really bad traumatic histories in past and they couldn't live at home due to emotional behavioral concerns, they would go to a residential treatment experience. This technique what I'm going to tell you guys about is proven to decrease anxiety, decrease depression, decrease irritability and aggression dramatically. It's an awesome opportunity to have your school create a culture where we're fostering social support. You have three questions. What are you feeling today? They give one or two feelings. What's your goal for today? Who can help you with that?

If you were doing that whether it's in your classes, or say, you're their first line of defense because they're scared to go to school is to go into the school nurse's office because you are their point person or going to the school counselor's office because you are the person that keeps them safe. Every morning they come in and they say, "Hey, I'm feeling x. What's your goal for today, and who can help you?" They are identifying a person that's going to keep them safe and protect them. Whether it's in a classroom, which I would say ideally would be the best option, right? Because they're again fostering that opportunity for social relationships with their peers. Ultimately, if it's happening if it's happening with somebody, they're always going to have that safe place to go. When their amygdala starts firing and their prefrontal cortex is shutting down, right? They're then going, "Oh my gosh, I have that opportunity to have a grounded safe space." That's just another option.

I'm going to give you one, the best thing you can do for kids to keep them in the classroom is to create anxiety or self-soothing toolkit. This is the best gift, and they're so cheap. It's model magic. Have you guys heard of model magic? I'm going to pull some of these out, and you guys can pass them around. It's better than any squish ball you can get, because it doesn't go bad. You just give them a Ziploc. They can keep it in their bag. It doesn't stain anything. It's light. It serves as a great resource to de-escalate and anxiety and stress if you're having a hard time. I keep using that word with anxiety. I know we're talking about trauma. Really, that's what anxiety is. When you're having that adrenaline reaction, that's the stress. That's the anxiety piece. That's what happens when you have a traumatic response. That's a great one for a self-soothing toolkit. You can get this box and it's got... I think six of these for like four bucks at Target. You can get a big one for twelve dollars. As long as you keep it in a Ziploc bag, it stays wet forever. Bubbles is a good one too, whether you have them in your office or in the back of a classroom. They're relatively maintenance free. It's the act of being able to take a deep breath and blow and... blow out and watch it. It creates an opportunity for mindfulness.

These, I love too. They're Velcro dots. If you keep them on the end of your desk, it creates sensory stimulation. If they're having a hard time concentrating, or they're focusing on their scans and they said, "I can't concentrate." If they rub their dot, it's going to ground them back to the moment that they're in the classroom, and be able to provide them with an opportunity to pay attention. Just a different opportunity for sensory stimulation, if you guys want to check those out. People will often say, "I don't want that on my desk, because that makes me weird." Well, if you give everybody a dot, again they're cheap, then everybody has a dot, they don't have to worry about it. They can rub under the table. They can put it under the desk.

If it helps, they can keep in their pockets. They can have hearts or circles, counselor's office. For school nurses and school counselors, maybe you are their point person and they have to go back to class, you can give them a transitional object. It could be a key chain. It could be a pencil. It can be anything. It's not about the object, it's about who gave it to them. Say, "I'm with you whenever you're having a hard time. Even when you're back in class, keep me in your pocket and if you rub me, you know I'm always there and you know I'm thinking about you."

The final thing I just want to leave you guys with, and you have this power point, is vicarious trauma. It's a real thing. We spend a lot of time and these ladies spend a lot of time working with kids with childhood cancer on a regular basis. I spend a lot of time in my office dealing with trauma in general. You guys have your kids, and you have hundreds of kids in the classes that you're dealing with and working with that have had really big deal life things. Vicarious trauma is not when you've experienced a trauma directly, but by virtue of working with it, it can create a lot of negative side effects in you. Just be mindful with it. It's secondary post-traumatic stress reaction. These are some of the symptoms, whether it's social withdrawal, emotional ability, aggression, somatic complaints, sleep disturbances. You all need to practice some self-care and get your anxiety soothing kits too.