Great, thanks everyone for joining.

Today my name’s press 9 month.

I have the distinct honor of introducing our Cancer Center, guest speaker today Doctor Abby Rosenberg.

Doctor Rosenberg is an associate professor of pediatric hematology and oncology at the University of Washington School of Medicine.
Cambia Palliative Care Center of Excellence at University of Washington, director of the pilot of Keran Resilience Laboratory at Seattle Children’s Research Institute and the Director of Survivorship and Outcomes Research at Seattle Children’s Hospital, Cancer and Blood Disorders Centers through her work as Program Co. Director for the University of Washington T32 program in Positive care research. And a lead mentor in the palliative care and Resilience Laboratory. Doctor Rosenberg is very active and training the next generation.
of palliative care and supportive care. Doctor Rosenberg is a palliative care clinician scientist at the postdoctoral and junior faculty levels. She holds multiple national leadership positions, including the chair of the Ethics Committee at the American Society of Clinical Oncology. She is the Co-Chair of the scientific program for the American Academy of Hospice and Palliative Medicine, and the Associate editor in Chief of Palliative Care. Doctor Rosenberg’s NIH funded research focuses on developing programs to support clinicians.
help patients and families with serious illness build resilience, thereby alleviating suffering and improving quality of life.

The title of Doctor Rosenberg’s talk today is promoting resilience in children with serious illness and their families.

I’ll be moderating the discussion afterwards, so please enter your questions into the chat function will take questions after Doctor Rosenberg’s talk. Thank you so much Doctor Rosenberg for speaking with us today.

Thank you for having me.
This is such a pleasure to be here and that was a very kind introduction process that it’s really humbling in a little embarrassing, happy to be here with all is as all of you as you just heard.

I’m going to talk today about promoting resilience in patients and families. I know this is a larger Cancer Center. I’ll be talking about what we’ve learned in our work with adolescents and young adults with cancer,
and by the end of this talk I will be sharing with you how to translate our experiences to older patients with cancer, their caregivers, and ourselves.

As folks who are caring for these patients, I wanted to start with this question about why resilience is important for our patients with cancer. Despite that lovely introduction, that piece of my history that you didn’t hear is that I started my career...
00:03:03.924 --> 00:03:06.111 as a social worker and I will say
NOTE Confidence: 0.87158483
00:03:06.111 --> 00:03:07.815 I was vastly undertrained and under
NOTE Confidence: 0.87158483
00:03:07.815 --> 00:03:10.360 qualified to do the work I was doing,
NOTE Confidence: 0.87158483
00:03:10.360 --> 00:03:12.796 taking care of kids with HIV
NOTE Confidence: 0.87158483
00:03:12.796 --> 00:03:14.859 and their families during the
NOTE Confidence: 0.87158483
00:03:14.859 --> 00:03:16.989 tail end of the HIV epidemic.
NOTE Confidence: 0.87158483
00:03:16.990 --> 00:03:18.992 I burnt out within about a year
NOTE Confidence: 0.87158483
00:03:18.992 --> 00:03:21.209 from that work and the thing that
NOTE Confidence: 0.87158483
00:03:21.209 --> 00:03:23.147 I continued to think about during
NOTE Confidence: 0.87158483
00:03:23.218 --> 00:03:25.384 the year and then thereafter during
NOTE Confidence: 0.87158483
00:03:25.384 --> 00:03:27.452 my training in medical school in
NOTE Confidence: 0.87158483
00:03:27.452 --> 00:03:28.696 pediatric residency and fellowship
NOTE Confidence: 0.87158483
00:03:28.696 --> 00:03:31.019 and ultimately in my experience as an
NOTE Confidence: 0.87158483
00:03:31.019 --> 00:03:32.724 oncologist in palliative care physician,
NOTE Confidence: 0.87158483
00:03:32.730 --> 00:03:35.117 is this why are there some patients
NOTE Confidence: 0.87158483
00:03:35.117 --> 00:03:37.647 and families who seem to figure it out,
if not thrive in the face of adversity, is it cancer? Why are some other people just falling apart? And is there a way that we could teach to the ones who are struggling with the ones who had figured it out? It turns out it's pretty hard to translate this idea of what resilience is into what we do in medicine, and there were definition of resilience.
comes from the material Sciences and physics.

It’s defined as the capacity of a particular material to absorb energy when it’s deformed, and then appan up unloading to have its energy recovered.

So the classic example is a rubber band where you stretch it and it rebounds back to its original shape, and therefore it is resilient.

But what does that mean when we’re talking about patients and families in their own experiences?

And when I started this work over a decade ago, one of my mentors said this to me.
He said, Abby, if you want to change something, you have to be able to measure it. When you say resilient, what are you talking about? What are you measuring? When we started this question was hard to answer because there was a lot of controversy in the world of psychology and social sciences about what resilience is. This is a study done by a psychologist named George Bonanno who studies bereavement and he's...
one of the preeminent scientists in the resilience world.

On the X axis, here’s time and on the Y axis is levels of distress and depression.

And you’ll notice there are three lines of people moving through their lives until a traumatic event happens. In this case, it’s the death of their spouse and following that, every single one of those lines has a normal and expected spike in distress and depression, followed by some new pathway towards wherever folks are going to end up.
And was really interesting to me about this graph. Is that it kind of illustrates the three controversies that at the time were swirling around how we should think and operationalize resilience. There was a school of thought who would look at this graph and say resilience is defined on the left. It is a innate, perhaps immutable characteristic, something like grit, hardiness, optimism, something we either have or we don’t, and whether we have that thing.
or not predisposes us to being resilient in the long run. So sure enough, there's a group that's represented with that line dot line there at the top of these three collections of lines. They are for whatever reason. Less resilient at baseline. They're less protected from this trauma, and sure enough they end up having chronic grief. A second theory on a second debate was that resilience was a process of how we adapt to our adversities, how we change with our new normals, and they would look at this graph.
and they’d say no resilience is defined in the middle. It’s the way that recovery line is able to go from a relatively high level of distress to a relatively low one because they figure it out along the way. And if we wanted to intervene, we could move the needle by helping those folks to cope better. And then a final school of thought was that no, no resilience is defined on the right of this graph. It is only measurable after a particular trauma,
and after a particular amount of time has passed and resilience after the death of a loved one might be different than resilience after a natural disaster or war, and you can only tell that someone is resilient or not based on some dichotomized outcome. So if you have a negative outcome, for example, you must not be resilient, and if the absence of that outcome, like chronic grief, is notable. Then you must be resilient 'cause you’re doing better than we might expect. So for me as a clinician who was relatively early in my career
as a pediatric oncologist, I felt like none of these theories matched to what I saw. And here are some of my questions. Number one is illness. An isolated event? Can you draw a single line on a cancer patients experience and say this is the moment that they have to define their resilience? Or is resilience a series of micro traumas and A series of micro and macro events that can change someone’s whole trajectory? Who’s the unit?
In Pediatrics, we look at patients. We look at their siblings. We look at their families with a look at their social supports in their school communities. Which of those units is the way I need to think about resilience and my defining resilience for the patient or for their family? Is there a difference between getting through adversity or growing from it? A lot of the resilience is an outcomes theory at the time was saying, you know you really have to show some benefit, some growth, some lesson learned,
some idea that you have improved from whatever your adversity is in order to demonstrate resilience, and I will tell you when I was starting this work I was working with a lot of bereaved families and I would ask them what do you think I would ask them what do you think about this idea of resilience? What do you think about this idea that you’re supposed to have grown from it and they would say you know it’s pretty offensive that you think I’m supposed to somehow be better from having my child die from cancer. The fact that I got out of bed today
makes me pretty darn resilient.

Which outcomes matter into poems.

If I’m a pediatric oncologist taking care of a teenager with cancer, I might say that that person is resilient because they’re taking their oral chemotherapy as I prescribe it.

Their mom might say they’re resilient because they’re going to school and maintaining their GPA.

And the patient might say they’re resilient because they’ve maintained their social network.

Who’s right?

How do we integrate individual differences?

Is there a one size fits all in resilience?
Or does my resilience look somewhat different from someone else's?

And finally, how do we integrate cultural differences into these ideas?

This last one is important because this idea of resilience.

This value that we put on it is very very Western.

So here in the United States we say that things like which doesn't kill you makes you stronger.

We have this inherent respect for people who can pull themselves up from their bootstraps and lived this American dream.
But that is really an American ideal, and it doesn’t actually translate around the world. In Southeast Asia, resilience has been equated with the sense of balance. So instead of the stretchiness of a rubber band, it is the lack of stretching. It is the willingness or the ability of a material to stay within its shape. In South American cultures, resilience has been equated with the values. And in Afghanistan, resilience has been equated with mastery in a particular skill set. In Native American cultures,
here in the United States, resilience President has been equated with spirituality and a constant quest for meaning and purpose. And what is fascinating is that in almost no language in the world is there a direct translation for the word resilience. In the places where this does exist, it is either translated back from English into whatever is the native language, or it is purely described as that physical science construct that I started with. So with this sort of swirling set
up debates and this challenge that we were having as a community, figuring out what resilience was in 2013 at the International Society of Traumatic Stress Studies, there was a plenary panel where they got a whole bunch of resilience researchers up on stage, including George Bonanno, whose graph I just showed you. And this is a picture of a cultural anthropologist named Doctor Catherine Pantry brick. She’s speaking here at a different organization, but she was one of the speakers at
NOTE Confidence: 0.83782303
00:11:37.904 --> 00:11:40.140 this plenary and what she does is
NOTE Confidence: 0.83782303
00:11:40.140 --> 00:11:41.480 what’s called ethnographic studies,
NOTE Confidence: 0.83782303
00:11:41.480 --> 00:11:43.976 and she goes around the world and she.
NOTE Confidence: 0.83782303
00:11:43.980 --> 00:11:45.620 Lives in places that are
NOTE Confidence: 0.83782303
00:11:45.620 --> 00:11:46.604 going through adversity,
NOTE Confidence: 0.83782303
00:11:46.610 --> 00:11:47.882 and she bears witness,
NOTE Confidence: 0.83782303
00:11:47.882 --> 00:11:50.143 so that might be going to a
NOTE Confidence: 0.83782303
00:11:50.143 --> 00:11:51.533 place that has just undergone
NOTE Confidence: 0.83782303
00:11:51.533 --> 00:11:53.849 a war or a natural disaster,
NOTE Confidence: 0.83782303
00:11:53.850 --> 00:11:55.908 or folks who are living in poverty
NOTE Confidence: 0.83782303
00:11:55.908 --> 00:11:58.150 and what she’s noticed in all of
NOTE Confidence: 0.83782303
00:11:58.150 --> 00:12:00.094 her work is that consistently across
NOTE Confidence: 0.83782303
00:12:00.158 --> 00:12:02.078 every adversity she has studied.
NOTE Confidence: 0.83782303
00:12:02.080 --> 00:12:03.770 Resilience is a process of
NOTE Confidence: 0.83782303
00:12:03.770 --> 00:12:05.460 harnessing the resources we need
NOTE Confidence: 0.83782303
00:12:05.520 --> 00:12:07.010 to sustain our well being.
NOTE Confidence: 0.85031116
00:12:09.370 --> 00:12:10.522 And more importantly,
NOTE Confidence: 0.85031116
00:12:10.522 --> 00:12:13.210 she says that in every single adversity,
NOTE Confidence: 0.85031116
00:12:13.210 --> 00:12:15.891 how people do that is they harness
NOTE Confidence: 0.85031116
00:12:15.891 --> 00:12:17.816 resilience, resources that always fall
NOTE Confidence: 0.85031116
00:12:17.816 --> 00:12:20.120 into one of these three categories.
NOTE Confidence: 0.85031116
00:12:20.120 --> 00:12:22.040 The first is our external
NOTE Confidence: 0.85031116
00:12:22.040 --> 00:12:22.808 resilience resources.
NOTE Confidence: 0.85031116
00:12:22.810 --> 00:12:25.498 These are things like our social support,
NOTE Confidence: 0.85031116
00:12:25.500 --> 00:12:27.420 our community, who helps us.
NOTE Confidence: 0.85031116
00:12:27.420 --> 00:12:29.340 This second is our internal
NOTE Confidence: 0.85031116
00:12:29.340 --> 00:12:30.108 resilience resources.
NOTE Confidence: 0.85031116
00:12:30.110 --> 00:12:32.156 These are traits like grit and
NOTE Confidence: 0.85031116
00:12:32.156 --> 00:12:34.230 hardiness as well as learn skills
NOTE Confidence: 0.85031116
00:12:34.230 --> 00:12:36.798 like how we adapt and cope and then
NOTE Confidence: 0.85031116
00:12:36.866 --> 00:12:38.939 finally existential resilience.
Resources are things like meaning making, faith, spirituality. These sorts of inherent human questions that we ask when times get tough. Which is why is this happening to me, and what does this mean for my family? I will say that when I was starting to try to figure all of this out and think about what it meant for our patients with cancer, I really struggled with how to translate all of these different and conflicting theories into what we could do at the bedside. And at the same time there was a similar, if not parallel debate happening in the psychology and social Sciences about how
we experience what we see in the world.

And specifically, this is a theory called stress and coping theory, which essentially says that our perceptions influence our outcomes.

So if we go through a stressful event, the first thing we do is we think about it. We appraise it, we say, is this a good or a bad thing for me? Is this catastrophic or is this manageable? And the answer to that appraisal question the veillance we apply to that response translates to how we cope, how we feel and how we function.

And the idea behind this theoretical construct is that if you can change
the balance of that appraisal
from catastrophic to manageable,
for example, you can change your coping,
to be more positive.
So we first tested this idea of do
people’s perceptions of their own resilience translate to outcomes in a cross sectional study of bereaved parents of children with cancer we had about 120 parents in this study and the first thing we noticed is that when you use a validated instrument to measure self perceptions of resilience,
00:14:19.220 --> 00:14:21.523 parents of kids with cancer feel less resilient than the rest of the population.
NOTE Confidence: 0.86361223
00:14:21.523 --> 00:14:23.917 There’s something about having watched your kid go through cancer that makes you believe you are less resilient.
NOTE Confidence: 0.86361223
00:14:23.920 --> 00:14:26.005 And perhaps not more poignantly, parents who reported lower resilience were the ones who had ongoing psychological distress, sleep difficulties, an in abilities to express their hopes, and worries to their medical team.
NOTE Confidence: 0.86361223
00:14:31.110 --> 00:14:33.180 Around the same time in the gerontologist there was an analysis of the US Health and Retirement Study.
NOTE Confidence: 0.86471814
00:14:33.180 --> 00:14:34.568 Most of you know this.
This is a long, ongoing cohort of American adults, ages 50 to 98. In this particular analysis and what they did here was they asked folks to fill out a survey about their self, perceived resilience, and then they monitor them overtime. And let's say you had two gentlemen who were matched in every way except one, believed he was resilient and the other doesn’t, and they both go through their lives and both fall down and break their hips. The gentleman who believed he was less more resilient for whatever reason.
The gentleman who believed he was less resilient again, for whatever reason, is not only going to not go to physical therapy and not return to his activities of daily living, but he’s going to die sooner. His life expectancy is actually shorter. My research partner is a health psychologist and behavioral scientist named Joyce E. Frazier. This is some of her earlier work. She works with patients with diabetes, and on the X axis is changes in diabetes related distress on the Y.
axis is changes in hemoglobin, A1C, or a marker of glycemic control. And here on those two dotted lines that are sort of diagonal, these are folks who believe again for whatever reason that they are less or moderately resilient, and for them changes in A1C level translate directly to changes in distress, meaning that the more swings there are in their distress levels, the harder it is for them to control their diabetes. In contrast, that more flat solid black line
00:16:25.340 --> 00:16:26.703 represents people who believe
NOTE Confidence: 0.8527747
00:16:26.703 --> 00:16:28.059 that they’re more resilient,
NOTE Confidence: 0.8527747
00:16:28.060 --> 00:16:30.046 and for them even wide fluctuations
NOTE Confidence: 0.8527747
00:16:30.046 --> 00:16:31.743 in their distress don’t translate
NOTE Confidence: 0.8527747
00:16:31.743 --> 00:16:33.288 to changes in a onesie.
NOTE Confidence: 0.864682
00:16:35.840 --> 00:16:37.772 As a validation at we did another
NOTE Confidence: 0.864682
00:16:37.772 --> 00:16:39.713 analysis at the Seattle Cancer Care
NOTE Confidence: 0.864682
00:16:39.713 --> 00:16:41.813 Alliance among about 1800 patients who
NOTE Confidence: 0.864682
00:16:41.813 --> 00:16:44.140 had received a bone marrow transplant.
NOTE Confidence: 0.864682
00:16:44.140 --> 00:16:46.528 And here again, those who reported
NOTE Confidence: 0.864682
00:16:46.528 --> 00:16:49.240 low resilience were the ones who went
NOTE Confidence: 0.864682
00:16:49.240 --> 00:16:51.690 on to have more frequent missed work.
NOTE Confidence: 0.864682
00:16:51.690 --> 00:16:52.486 Increased disability,
NOTE Confidence: 0.864682
00:16:52.486 --> 00:16:54.078 lower quality of life,
NOTE Confidence: 0.864682
00:16:54.080 --> 00:16:55.226 higher psychological distress,
NOTE Confidence: 0.864682
00:16:55.226 --> 00:16:57.136 and more frequent medical complications
during their survivorship period. So all of this sounded really interesting to me, and it felt like there was something there, but I still didn’t know how to take these ideas, and these theories and identify him and operationalize resilience in the patients and families. I was working with. And so the next thing we did was what in the rest of the world would be called market research. It’s sort of when you go directly to your stakeholder and say hey, what should we do?
What would you like to do?
What would you use?
What materials would be helpful to you?
And in the Health Sciences we call this qualitative work. So similarly, we went directly to our stakeholders and we said we need to understand this concept from your own perspective. What would be helpful to you? We started with parents. We went back to that cohort of 120 parents that we had and we started to listen to their stories while we surveyed them using validated instruments of their self,
perceived resilience and what they shared with us is that resilience is, for example, who I was, what I learned, how I ended up, and what it all meant. This was apparent who sat next to me looking at that banana graph and saying no. It’s the left, middle and right and the whole thing for me. Or resilience is facilitated by who I am who helps me and what I believe this was a parent who identified those resilience resource categories and said all three of them matter.
What was particularly interesting about this analysis is, as I said, we have these surveys, and we interviewed people at the end of the surveys, we asked folks to fill out a final page that essentially said tell us whatever else you think we need to know and parents wrote pages, pages and pages of stories that they felt like were important for us to understand. And when we got these things in the Mail, we read them and I said to myself, huh? Here’s resilience. There’s resilience in these stories.
And so a social worker, health services, researcher and I all of us read 120 different transcripts blinded to each other, and we graded all 120 as either resilient or not. Did this person seem resilient to us in their words? And what was really interesting to us is that we agreed we, three blinded reviewers, agreed in a person’s categorization of resilience. Our labeling of their resilience 100% of the time. 120 out of 120 times. We agree.
And then when we looked at how our impressions of their resilience aligned with validated patient reported outcomes, we were wrong. Half the time we were as good as a coin toss in predicting somebody else's resilience. When we looked more carefully, we were a little bit better at recognizing someone's distress. Our impressions of their lack of resilience aligned with their measurement of their own distress and what that tells me is 2 things. Number one we in medicine tend to assume someone is not resilient when
they’re having a hard time and #2.  
We in medicine probably shouldn’t assume someone is resilient or not unless we ask them.

The next thing we did was we did this same stakeholder engaged work with adolescent and young adults, or ay ay patients, and here I want to introduce you and here I want to introduce you to a young man named Daniel Maher. He was one of our first key stakeholders, which means that every time I did an interview or every time I was developing an idea, he was one of the people I would sit
down and talk to you about it and say,

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hey, am I getting this right?

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Does this align with your experience?

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Daniel had met a static and

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ultimately progressive Ewing sarcoma,

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and he died from his cancer several

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years after we started working together.

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And towards the end of his life I started

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asking him about his own resilience

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and how I should continue to tell

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his story or how it translated to the

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resilience of other folks with cancer.

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And he said Abby cancer happened

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to me for a reason.

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It’s to help others like me understand

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and to make it easier for them somehow.
And so, with Daniel’s help, we interviewed multiple teens and young adults with cancer from the time they were diagnosed. Three months later, six months after that, a year after that and so forth, to the point that now, of course, without Daniel, we are continuing to interview some of these adolescent and young adult patients 10 years later. And what we hear from them are things like this.
Resilience depends on the person and their experiences. It’s kind of like exercising. You have to gain some muscle before you run a race, personal strength or resilience is how you rebound from something like being able to fight back. It can be taught. It should be taught.

What’s interesting to me about this analysis, which now includes hundreds and hundreds of hours of interviews with teens and young adults, is that at the beginning, many of these young patients don’t
NOTE Confidence: 0.8839102
00:21:38.108 --> 00:21:39.980 know what the word resilience means,
NOTE Confidence: 0.8839102
00:21:39.980 --> 00:21:41.468 or they can’t figure out what
NOTE Confidence: 0.8839102
00:21:41.468 --> 00:21:43.176 it is that they’re doing to
NOTE Confidence: 0.8839102
00:21:43.176 --> 00:21:44.488 get through their experience.
NOTE Confidence: 0.8839102
00:21:44.490 --> 00:21:47.028 But once they do, once they figured out once,
NOTE Confidence: 0.8839102
00:21:47.030 --> 00:21:49.568 they can say, oh, this is what I do.
NOTE Confidence: 0.8839102
00:21:49.570 --> 00:21:51.544 They seem to latch on to that
NOTE Confidence: 0.8839102
00:21:51.544 --> 00:21:53.800 particular resilience resource,
NOTE Confidence: 0.8839102
00:21:53.800 --> 00:21:55.767 and they carry it forward.
NOTE Confidence: 0.8839102
00:21:55.770 --> 00:21:57.180 So even five or ten years later,
NOTE Confidence: 0.8839102
00:21:57.180 --> 00:21:59.718 they’ll say, I don’t know.
NOTE Confidence: 0.8839102
00:21:59.720 --> 00:22:01.130 This is what I do when times get tough.
NOTE Confidence: 0.8839102
00:22:01.130 --> 00:22:02.816 It’s always what I’ve done.
NOTE Confidence: 0.8839102
00:22:02.816 --> 00:22:08.190 This has always been my thing.
NOTE Confidence: 0.83683133
00:22:06.090 --> 00:22:08.190 We distill those hundreds of hours of
NOTE Confidence: 0.83683133
00:22:08.190 --> 00:22:10.128 interviews into this particular idea of
NOTE Confidence: 0.83683133
00:22:10.128 --> 00:22:12.084 what helps somebody contribute to or
NOTE Confidence: 0.83683133
00:22:12.084 --> 00:22:13.869 inhibit their resilience at any given
NOTE Confidence: 0.83683133
00:22:13.869 --> 00:22:15.886 moment and for teens and young adults.
NOTE Confidence: 0.83683133
00:22:15.886 --> 00:22:18.640 It really does feel like a Teeter totter and,
NOTE Confidence: 0.83683133
00:22:18.640 --> 00:22:21.280 at any given moment, the scales can tip
NOTE Confidence: 0.83683133
00:22:21.280 --> 00:22:23.559 towards their feeling resilient or not.
NOTE Confidence: 0.83683133
00:22:23.560 --> 00:22:25.672 The things that contribute to that
NOTE Confidence: 0.83683133
00:22:25.672 --> 00:22:28.297 resilience are the sense of being able to
NOTE Confidence: 0.83683133
00:22:28.297 --> 00:22:30.677 manage their stress and idea of having a
NOTE Confidence: 0.83683133
00:22:30.677 --> 00:22:33.386 sense of purpose or goals to look forward to,
NOTE Confidence: 0.83683133
00:22:33.386 --> 00:22:34.966 being able to stay positive,
NOTE Confidence: 0.83683133
00:22:34.970 --> 00:22:37.189 being able to find meaning from their
NOTE Confidence: 0.83683133
00:22:37.189 --> 00:22:39.298 experience, and maintaining a sense
NOTE Confidence: 0.83683133
NOTE Confidence: 0.83683133
00:22:41.540 --> 00:22:43.310 And when we thought about these
ideas in these constructs, we noticed two things. Number one, these top for stress management goal setting. Staying positive and meaning making. These are all things that we can teach individually to patients. Whereas a social support type of program felt different and all of these things map back onto those resilience resource categories that Catherine Patrick had described so long ago. Which leads us to that, promoting resilience and stress management or PRISM program.
And the first thing we debated when we were thinking about what to do next was where to start on the left. Here you’re looking at one of our parent quiet rooms on the edges of our adolescent and young adult oncology floor. We have these separate spaces for parents to get away and have some time by themselves if they need to leave the patient room and on the right, you’re looking at one of our other key stakeholders. So when we were thinking about this, we first thought about parents and we thought you know parents, particularly kids of parents of cancer.
have poor psychosocial outcomes.

So specifically one in seven appearance of children with cancer will have such high distress that they can’t take care of themselves or the other children in the home. And if you’re a caregiver of a patient with cancer, it’s really hard to access traditional mental health. Supportive care parents don’t want to leave their kids bedside, as all of us know, it’s incredibly difficult to network mental health services in the community.
And we thought, wouldn’t it be great if we could just provide something to parents here within the Children’s Hospital so that we could support them? On the flip side, adolescents and young adults have poor psychosocial outcomes compared to younger pediatric or older adult patients. They have some of the worst psychosocial outcomes that we can find. They have higher rates of poor mental health and survivorship. They’re less likely to get a job or get married. They are less likely to be paid the same
as their otherwise age matched peers. They have higher rates of suicide and other serious mental health, comorbidities, and the idea that we had was maybe we could fix some of those problems if we started now. We also know that teens and young adults also have challenges with traditional methods for mental health support. So, for example, teens with chronic illness, only a third of them will access in hospital available mental
health services and of the ones who do only a third stay in. And when asked why you aren’t using these services that are available to you, most teens and young adults will say either the stigma or the time commitment is too much. But at the end of the day, when we thought about where to start, we felt we remembered that idea that I shared with you about how a lot of the teens and young adults we meet don’t yet know how to be resilient. They haven’t had the life skills yet, or no life opportunity yet to develop those resilience resources.
And our curiosity was maybe we could get in the door and start teaching these skills right away. And if we did that, could we change some of these downstream outcomes? So that leads me to PRISM, which teaches and targets those same four resilience resources that we had heard from teens and young adults were important. The first thing we teach is stress management skills. This includes three mini skills within one session.
The first mini skill is a deep breathing, simple relaxation technique. It helps people quiet their minds so they are receptive to additional learning and the next too many skills are progressive mindfulness exercises. One to help deepen your relaxation and two to become aware of stressors without judgment. The next thing we do is a goal setting module. Here we teach what’s called a smart goal that stands for specific, measurable, actionable, realistic and time dependent goals. We know from this psychology.
and social Sciences that any tiny forward progress towards an achievable and realistic hope is a very positive psychological anchor. And so we help a team. Translate quote.
I just want to get through my cancer to something that is actually actionable and measurable. The next thing we do is what’s called positive re framing or cognitive restructuring. And here we teach 2 mini skills. The first is how do you recognize all of that negative catastrophic
self talk that can keep us up in the middle of the night and the 2nd is how do you change the appraisal?
The valence of that appraisal from catastrophic to manageable.
The complementary knice of mindfulness, for example, recognizing what’s stressing you without judgment and then positive re framing, which is actually judging your thoughts and making them manageable and less catastrophic, is a really important psychological combination for helping people cope with adversity.
And then the final thing,
the anchor of all of this is meaning making,
and here we help teens and young adults with the exercise of identifying benefits,
with gratitude, purpose, legacy.
It’s sort of asking that existential question of why is this happening?
What are you going to be because of this?
What matters to you?
Who do you want to be next week when this is all over?
After all, four of those sessions we have the optional meeting with the family called coming together, and this is essentially designed to
help the patient share with loved ones.

What worked for him or her and to help family members and caregivers reciprocate and reinforce the skills.

And then after all sessions in between them, we offer opportunities to practice with boosters and worksheets.

Prison, like many psychosocial interventions, is what we call Manualized.

That means we have a very reproducible script.

We measure Fidelity to make sure it’s being delivered in the same dose and delivery style,

and we train all of our coaches with at least 8 hours to make sure that they are
certified and fluent in the program.

All of our coaches are college grads. Some of them have PHD’s, but by design we intended this to be coachable by folks who could be lay stuff so that it’s more translatable across different institutions.

The next thing we did having designed this was we tested prisms feasibility amongst adolescents and young adults with either diabetes, cancer or cystic fibrosis, and we notice that enrollment was very high, 83% across the program with high completion rates,
and each of these different groups of patients asked us to do PRISM differently. So for example, patients with diabetes here in Seattle will come from thousands of miles away. In Alaska. Our catchment area includes Alaska all the way to Wyoming, and so folks will come into Seattle for their diabetes. Care for one annual Big long day, and then the rest of their care is delivered via Tele Health. And they said, you know, we can sit with you for a long time on one day,
00:29:16.360 --> 00:29:18.680 or we want to do this through video,
00:29:18.680 --> 00:29:20.710 but we don’t want multiple sessions overtime,
00:29:20.710 --> 00:29:22.455 and so patients with diabetes
00:29:22.455 --> 00:29:25.130 preferred to get it all in one chunk.
00:29:25.130 --> 00:29:25.692 In contrast,
00:29:25.692 --> 00:29:27.097 patients with cancer and cystic
00:29:27.097 --> 00:29:28.869 fibrosis tend to be in the hospital.
00:29:28.870 --> 00:29:30.739 They are often isolated and they said,
00:29:30.740 --> 00:29:33.134 you know, we want you to come visit us.
00:29:33.140 --> 00:29:34.736 Well, we’re here in the hospital.
00:29:34.740 --> 00:29:36.876 We want you to sit at our bedside,
00:29:36.880 --> 00:29:38.749 and we’d rather break up the intervention.
00:29:38.750 --> 00:29:40.220 All those four sessions into
00:29:40.220 --> 00:29:41.396 separate four sessions delivered
00:29:41.396 --> 00:29:42.490 every other week or so.
When we asked all of these young folks what they thought, their qualitative feedback or things like this, this is so helpful. I wish we’d done this sooner. Yeah, I was actually telling my friends about it afterwards and they said they would try it out. I think it’s good techniques to use. Definitely, I’m teaching my little sister. I’m sure it can help her too. Or I used to be in the hospital and think it was a waste of time, not want to be there doing things not like this make you realize you’re here to make yourself feel better.
So the next thing we did was a randomized control trial amongst 92 adolescents and young adults with cancer. These are all of the outcomes we measured in that study. The zero line means there was no difference between patients who received usual care and those who received PRISM. Our center includes an assigned social worker for every single family available, psychology services and a whole host of other embedded psychosocial services. So moving left to right on this graph, you’ll notice that resilience scores...
went up with the intervention.
Distress scores went down with the intervention. Hope went up benefit finding went up and quality of life went up.
Perhaps more importantly to me that D there is a statistically significant effect size and by convention anything greater than .3 is considered clinically significant and in every single way that we could look, there were clinically significant changes in these outcomes of interest. But we weren’t looking for was this six months after the study started.
We looked at the surviving 74 patients who were still available and we looked at their clinical criteria for depression and we notice that 21% of the usual care patients versus 6% of the prison patients met criteria for depression, which translated to a 90% reduction in the odds of developing depression during those first six months of their cancer experience. The next thing we did was we tried to figure out are things getting better or they staying the same like what’s happening when you get prison versus
usual care and so each of these pairs

NOTE Confidence: 0.83446914

of graphs has the usual care group

NOTE Confidence: 0.83446914

on the left and PRISM on the right,

NOTE Confidence: 0.83446914

and you’re looking at clusters

NOTE Confidence: 0.83446914

of resilience scores.

NOTE Confidence: 0.83446914

Hope benefit finding,

NOTE Confidence: 0.83446914

quality of life and distress

NOTE Confidence: 0.83446914

moving left to right.

NOTE Confidence: 0.83446914

In red means that their scores

NOTE Confidence: 0.83446914

deteriorated overtime in pink means

NOTE Confidence: 0.83446914

they started at risk and stayed there.

NOTE Confidence: 0.83446914

Light blue means they were well

NOTE Confidence: 0.83446914

at the beginning and stayed there.

NOTE Confidence: 0.83446914

An blue means they got better

NOTE Confidence: 0.83446914

overtime and the takeaways here

NOTE Confidence: 0.83446914

are that in every single scenario,
folks who got prism improved
and folks who didn’t get prison
were more likely to deteriorate.
Finally, anecdotally, this is one of my favorite findings from this study.
We gave each of the participants in each arm $50 at the end of their participation,
and then we got this in the Mail.
This is a letter that said, Dear Abby,
thank you so much for the $50.00 gift card.
I had a great time doing this study and
learn a lot of great life skills that I
will continue to use for a long time.
So thank you so much for letting me participate.
Like the perfect example of a well mannered teenager.

The other thing we heard from patients was,

Hey, my mom needs this too for my dad needs us too and we heard from parents.

Hey, can you do something like this? For me this seems really helpful and so we went back to that original question we had about.

Well maybe we should have tried that well maybe we should have tried that also and we adapted the program using the same for PRISM skills but with language that was more appropriate for parent experiences and we piloted the program amongst 24 parents.
And again they reported that it was very valuable. Qualitatively, they said this should be part of every parent’s toolbox. These skills help us to take better care of our kids. And before and after the intervention, their resilience went up and their distress scores went down. The challenges, though, that it was really hard for them to get away from their kids bedside. This was exactly our concern.
when we started to do this work, and so we tried to brainstorm what would be an easier way for parents to do this. And maybe it would be a symposium style coaching program where we have a whole lot of parents. Together they sit with us for four hours and we deliver the program that clap. We had about 72 people show up at the door. We had turn folks away and we put them at Round Top tables in a big room and we did group coaching of the PRISM intervention of RFR Hour period. 92% of parents said they gained new insights and skills.
98% said it was easy to understand and 100% felt like the group format was helpful to them. So then we said, OK, well, what’s better group coaching versus usual care or one on one? So we did another randomized trial this time amongst 102 parents or caregivers of children with cancer. And here you’re looking at a forest plot of usual care compared to one on one coaching. And what we found was that the intervention when delivered one on one...
one improved parent resilience and benefit finding compared to usual care. But when we compared group to usual care, we actually couldn’t see any differences, but in outcomes it looked like the group delivery didn’t seem to have an effect on parent resilience or any of our other outcomes of interest. And there’s more to the story than what we could see in those quantifiable data. So I want to share her story with you of a particular parent. This was a father whose daughter died unexpectedly about two weeks after his group PRISM session. And when she died,
we as of study team were trying to figure out you know, how do we re engage this dad? Do we? What would his resilience skills scores look like in the context of this immediate death of his daughter? And so at the end of the day, we decided to reach out to him and express our condolences and our gratitude and say hey, we’re here and he wrote back and he said, I’m actually really happy to hear from you. I talked with my group and
with their permission,

I'm going to share with you.

Email string that we have been

had going around.

He forward this email This is

him writing to his group.

He says, I think of all of you.

He goes on interesting Lee.

I feel better as I type this.

It's literally myself and my wife.
This is the only time I’ve talked about what I’m feeling. Thank you all for reading this and staying in touch and helping each other through this.

My takeaway, by the way from that experience with that Dad is 2 things. One I am not convinced that the group by itself isn’t doing something ’cause clearly it helped this father. I also think that the cumulative shared grief of watching another parent’s child be ill was something we hadn’t anticipated and so that idea of how do we support families needs to include?
How do we examine this shared grief in this shared stress that can come from a group intervention? Which leads me to what’s next for PRISM and where we’re moving forward. We have a whole bunch of different projects in progress, including several multi site trials for adolescents and young adults with advanced cancer or diabetes in the advanced cancer studies. We’re looking both at the integration of Advanced care planning, for example, for teens with incurable cancer. Can Prism help be a platform for integrating larger conversations?
about goals of care,
and how does it influence anxiety, depression,
and other mental health outcomes amongst kids and caregivers who are receiving bone marrow transplant?
We’re doing a dissemination implementation pilot here at Seattle Children’s,
where we’re essentially putting the program Alex to make it publicly available,
and we’re trying to see how different clinical teams use it.
We are adapting their program for adolescents with chronic pain.
The Pi of that study is at the
Children’s Hospital of Philadelphia.

We have an adaptation for patients of adult congenital heart disease. So folks who are transitioning from pediatric to adult care in the setting of congenital heart disease, that pie is here at the University of Washington. We have a different investigator, Doctor Crystal Brown who is using PRISM to help support caregivers who experienced racism in critical care units here in the United States. We have a different investigator, Amoeba O’Donnell, who is studying Prism adaptation for...
health care workers during the pandemic.

We have preliminary data from that study which essentially shows that PRISM compared to usual care for healthcare workers on the front lines, improves their burnout and improve their resilience in significant ways. And then finally, we have an investigator, Kiske Smith, who is translating the program and implementing it here in the Seattle Public Schools for kids. We’re schooling at home. This is for school aged kids who are really struggling with this new
world that we live in and helping them to manifest their own resilience early on in their childhood. Within all of these studies, we have analysis to evaluate cost effectiveness, adherence, for example, to oral chemotherapy caregiver well being, resource utilization, optimal delivery strategies. So is it better to do it all at once, or is it better to do it one on line? How can we integrate digital health? And finally, we’re looking at biomarkers of stress and resilience and. Gene expression profiles to sort of,
NOTE Confidence: 0.8732671
00:39:17.740 --> 00:39:18.148 say,
NOTE Confidence: 0.8732671
00:39:18.148 --> 00:39:21.004 can we change the the way we
NOTE Confidence: 0.8732671
00:39:21.004 --> 00:39:22.767 experience physiologic stress and
NOTE Confidence: 0.8732671
00:39:22.767 --> 00:39:25.389 its downstream effects on our health?
NOTE Confidence: 0.88783324
00:39:28.230 --> 00:39:30.354 Last, the thing that I think about a lot
NOTE Confidence: 0.88783324
00:39:30.354 --> 00:39:32.639 these days is how can we get PRISM into the
NOTE Confidence: 0.88783324
00:39:32.639 --> 00:39:34.819 hands of patients and families who need it.
NOTE Confidence: 0.88783324
00:39:34.820 --> 00:39:37.007 You can see we are studying this a lot.
NOTE Confidence: 0.88783324
00:39:37.010 --> 00:39:39.026 It is this huge platform of my research
NOTE Confidence: 0.88783324
00:39:39.026 --> 00:39:40.974 program and I’m getting to the point where
NOTE Confidence: 0.88783324
00:39:40.974 --> 00:39:43.141 I just want this thing out there and I’m
NOTE Confidence: 0.88783324
00:39:43.141 --> 00:39:45.011 trying to figure out how to do that.
NOTE Confidence: 0.88783324
00:39:45.011 --> 00:39:46.993 This picture is a picture of the original
NOTE Confidence: 0.88783324
00:39:46.993 --> 00:39:49.033 worksheets that we developed for the
NOTE Confidence: 0.88783324
00:39:49.033 --> 00:39:51.297 intervention when we first started doing it.
NOTE Confidence: 0.88783324
These are the ways that people can practice the skills between sessions and when we go to our stakeholders and we asked him about this. They say, you know, hey, this isn’t how we learn anymore. Everything’s on line and be 2:00 o’clock in the morning when we wake up and we’re having those negative thoughts in our heads. I don’t want to go get a worksheet, I want to pick up my smart phone and have prism at my fingertips. And so we listened to our stakeholders and based on their feedback,
we created an app that would help them practice their skills in real time.
I'm just going to share with you the quick introductory module of what the app looks like when a patient opens it on their phone.
This is imagine the first time you're opening it and the orientation to the program.
So once folks of how that introduction and they use the app as a compliment to the in person coaching that we do, or the Tele health coaching that we now do, they can personalize their homepage.
They can upload their goals, they can sync it with their calendar,
so it sets the little reminders for things that they have staged as a way to accomplish that longer goal. They can upload pictures a lot, Instagram and ways to remember particular moments of gratitude and so and they can track their own sense of stress and resilience within the app and see how the different modules help. Alleviate those senses of stress or bolster those senses of resilience in real time.

So before I close, I have a couple of final thoughts about resilience. The first is what we’ve learned during the last year of the pandemic. When we started, I had this
NOTE Confidence: 0.8914943
00:42:07.624 --> 00:42:09.230 idea that resilience was linear.
NOTE Confidence: 0.8914943
00:42:09.230 --> 00:42:11.574 I had this idea of that banana graph
NOTE Confidence: 0.8914943
00:42:11.574 --> 00:42:14.031 that there was a line we would follow
NOTE Confidence: 0.8914943
00:42:14.031 --> 00:42:15.919 as we marched through our lives,
NOTE Confidence: 0.8914943
00:42:15.920 --> 00:42:18.668 and I don’t think that’s true.
NOTE Confidence: 0.8914943
00:42:18.670 --> 00:42:20.160 I think resilience is actually
NOTE Confidence: 0.8914943
00:42:20.160 --> 00:42:22.050 something that exists in phases,
NOTE Confidence: 0.8914943
00:42:22.050 --> 00:42:23.892 and the first phase is what
NOTE Confidence: 0.8914943
00:42:23.892 --> 00:42:25.120 I call getting through.
NOTE Confidence: 0.8914943
00:42:25.120 --> 00:42:27.479 This is where we literally put 1
NOTE Confidence: 0.8914943
00:42:27.479 --> 00:42:30.210 foot in front of the other where we
NOTE Confidence: 0.8914943
00:42:30.210 --> 00:42:32.888 literally say I got out of bed today.
NOTE Confidence: 0.8914943
00:42:32.890 --> 00:42:34.388 It reminds me of that bereaved mom.
NOTE Confidence: 0.8914943
00:42:34.390 --> 00:42:36.102 I told you about at the beginning of
NOTE Confidence: 0.8914943
00:42:36.102 --> 00:42:37.600 this talk, the one who said, yeah,
I did get out of bed today and that makes me pretty darn resilient, because if it were me and my childhood just died, I don’t know if I’d be able to do the same. However, that was ten years ago, and if I might met her and talk to her today and she still said, well, I got into bed today, then I would worry then I would say I don’t know if you’re still resilient in my mind. I think you need to do more. And so the next phase, if you will, of how we move through this
experience of resilience, is when we start to do the work of harnessing our resources. This is where we begin to leverage those individual community and existential resilience resources. We start to actually figure out how do we move forward. In between getting through and harnessing resources, the psychological thing we do is we start to appraise or assess the situation. What have I done before? Who helps me? How am I going to get through this?
We actually start to articulate in our own minds whether we know it or not. What needs to happen for us to move from just simply getting out of bed to starting to thrive?

And then the third phase, if you will. Of this overlapping Venn diagram is when we look back and learn. This is when we finally have the brain space to reflect on what we learned and what it means. Sometimes that can be in a day. Sometimes that can take us years, but ultimately almost all human beings will have this capacity to think about what just happened.
00:44:08.172 --> 00:44:10.449 them and what it means to them.

00:44:10.450 --> 00:44:12.355 In between harnessing those resources

00:44:12.355 --> 00:44:14.260 that active activation of resilience

00:44:14.315 --> 00:44:15.809 and when we start to reflect,

00:44:15.810 --> 00:44:18.986 we build our identity and I and our

00:44:18.986 --> 00:44:21.601 purpose we start to ask ourselves

00:44:21.601 --> 00:44:24.799 the question of who we want to be.

00:44:24.800 --> 00:44:26.105 And in between getting through

00:44:26.105 --> 00:44:27.410 and looking back and learning,

00:44:27.410 --> 00:44:28.976 we are appraising the situation again.

00:44:28.980 --> 00:44:30.540 What does this mean for us?

00:44:33.770 --> 00:44:35.990 Practically. As folks will hear all

00:44:35.990 --> 00:44:38.828 of this and then say to themselves,

00:44:38.830 --> 00:44:40.456 what am I going to do?

00:44:40.460 --> 00:44:42.080 I’m seeing a patient this afternoon.
Here’s some thoughts.

First of all, use your palliative care psychosocial chaplaincy.

Child live any other supportive care team that you have.

This is their bread and butter.

This is what they do in their regular assessments.

Leverage that experience and rely on it as part of your team.

As clinicians, we need to help families identify their resources and strengths and their struggles.

We need to promote the first two and normalize the third.

Just because people are having a hard
00:45:09.499 --> 00:45:11.480 time does not mean they are not resilient.

00:45:11.480 --> 00:45:13.628 That means they’re normal.

00:45:13.630 --> 00:45:15.640 Our job is to help them diversify their portfolios.

00:45:15.640 --> 00:45:16.645 Our job is to help them recognize the things that they already have in their Arsenal or resilience resources so they can go from getting through to starting to harness those resources.

00:45:19.002 --> 00:45:21.494 And how I do that? Is this? I ask about thoughts I’ll say.

00:45:21.494 --> 00:45:23.329 That helps me understand their existential resilience resources.

00:45:23.390 --> 00:45:25.707 I ask about thoughts I’ll say.

00:45:25.707 --> 00:45:28.970 How do you see your experiences?

00:45:28.970 --> 00:45:31.224 That helps me understand their existential resilience resources.

00:45:31.224 --> 00:45:33.156 I ask that actions.

00:45:33.160 --> 00:45:35.086 I ask that actions.
What do you do when things are hard?
NOTE Confidence: 0.8697707
What have you done before?
NOTE Confidence: 0.8697707
When times have gotten tough?
NOTE Confidence: 0.8697707
This helps me identify their individual resilience, resources.
NOTE Confidence: 0.8697707
And finally I ask about supports.
NOTE Confidence: 0.8697707
Who supports you?
NOTE Confidence: 0.8697707
This is me taking a sort of categorization and or an inventory of their social resilience, resources.
NOTE Confidence: 0.8697707
And together I can sort of recognize which of those three buckets is relatively full, or which is relatively empty.
NOTE Confidence: 0.8697707
And I can help them articulate those resources they’ll need.
Last I’m going to close with advice from Daniel Maher. Who said you have to work sometimes to be happy to move past the hard? The sad the scary. We all do it. But maybe you need help sometimes. Maybe you need a little bit of learning or a little bit of strength, or remembering what matters or a little after. Poor little love. Figure out what you need and hold on. But please, whatever you do live the time you have with meaning and purpose.
I want to thank the many members of the palliative care and Resilience Lab, in particular, Joy C. Fraser, who is my research partner and the Co creator of Prism. We have many mentors, advisors and collaborators who have helped us along the way, as well as multiple funders that I'd like to thank and thank you to all of you for being here today.

I'm going to stop sharing my slides so that we can have some time for questions and answers. Appreciate you all.

Thank you.
Abby, thank you so much for such a powerful and inspiring talk. While we're waiting for folks to pop their questions into the chat, I thought maybe we could start out with a couple of my questions. Uhm, what sorts of obstacles early on did you encounter? Or you know where? There are people who were naysayers or disbelievers in this approach? And how did you overcome some of those obstacles or address people’s concerns? Oh gosh, this is such a good
question pressing it, I think.
Philosophically,
I guess I have two answers.
One is, believe in what you're doing.
So I one of the first people I talked
to here in Seattle about this idea is
someone who I really respect and admire.
And she said I don’t think
resilience is changeable.
I just don’t think that that’s
going to be a thing.
I don’t think this is a good idea,
and as a young.
Faculty member I was devastated,
but I felt like my idea still needed some.
I don’t know unpacking so I moved
00:48:20.863 --> 00:48:22.640 around to find mentors who would
support me and I think for early
career faculty that piece of advice
is really necessary that you need
someone who believes in you and
you need people who will also help
you find holes in your project.
Which leads me to the next thing you know.
Science is defined by failures
we learn from those failures.
And that’s maybe one of the
messages of resilience too.
But you need to be around
people who will push you.
Who will help challenge you.
Who will help you think about the ways
that something might or might not work,
and so that same person who
made me question it is somebody
who I now really rely on.
When I have an idea 'cause I know
she's going to be like Nope,
still a bad idea.
Abby and that helps me think
around all of the barriers so that
I can continue to move forward.
The last thing I think though
about all of this is.
Finding meaning and purpose in the work
that we do is critically important.
As clinicians as scientists would
You have to have the passion and the belief that what you were doing matters? And for me this is bad for other people that we can be taking care of a patient or writing a paper or mentoring or teaching. But the thing that we all need to do is to figure out what brings us value in our lives and how can we continue to champion that.

In the meanwhile I of course have so many questions. One thing I was wondering about in terms of scalability.
So what do you say now with this robust intervention that now has a mobile option as well?

What have you said to folks at various institutions who may be interested in bringing a similar intervention to their institution?

Soon.

Two things I want. I want prism out there at like. I just think that it has potential and I would welcome anybody who wants to help me figure out how to do that.

And as folks in this audience will know, doing anything takes resources and money and time,
and so one of the things we have learned in this pilot study that we're doing here in Seattle is, even if we make it available, people don’t use it if they don’t have the human resources to deliver it. So right now, it’s just it’s designed to be an in person coaching program because I think that that matters. I think that human connection is really necessary. But we’re learning that that might be a huge huge barrier, and so the next study where we're
designing right now is in fact trying to ask the question that you just asked how much digital can we get away with? How much can we get away with taking away the in person component? Will that compromise the efficacy of the program? I think the answer is probably yes, but it turns out funders and other organizations need us to prove that, and so that’s what we’re working on now. And I’ll just say, you know, imagine the number of little apps that you have on your phone that are self help or mental health or whatever other programs you have.
And most of us don’t open them at all. And when we do we open them for a few weeks and then we stop and that to me is why prison works better because there is a human interaction you’re engaging with somebody who cares about you who listens to you, who coaches you. And so I worry a little bit about moving things purely to digital health without that degree of human interaction, especially for teens and young adults. Absolutely. How did you adapt during the pandemic? Wait, so we switched to the whole thing.
We used to go as I said to the patient’s bedside and we would sit next to somebody and coach with them. And then we held the program for about six months as many in the world did when we all kind of had to figure out how this new normal would work and when we came back in about a little over a year ago. Last summer, we started delivering the program purely via Tele Health and what was super fascinating is that especially for teens and young adults, maybe because they’re more fluent and savvy and things like FaceTime and digital ways of connecting.
Anyway, they seem to like it better this way. They seem to feel like this is almost a safer way for them to be vulnerable. They can sort of move back from the screen if they need to. They can engage in a way that is. Psychologically, more appropriate for them to my surprise. And so now I think moving forward we will only deliver the health. The program via Tele health. Unless somebody asks us to do otherwise, and we’ll see how it goes. When you were starting out with developing Prism,
00:53:14.090 --> 00:53:16.960 did you start out restricting it
NOTE Confidence: 0.83027625
00:53:16.960 --> 00:53:19.335 primarily to adolescent young adult
NOTE Confidence: 0.83027625
00:53:19.335 --> 00:53:21.280 patients with advanced cancer?
NOTE Confidence: 0.83027625
00:53:21.280 --> 00:53:24.628 Or were would you include patients at
NOTE Confidence: 0.83027625
00:53:24.628 --> 00:53:27.496 any point in their character directory?
NOTE Confidence: 0.85549736
00:53:28.220 --> 00:53:30.901 Yeah, the first program we designed the
NOTE Confidence: 0.85549736
00:53:30.901 --> 00:53:33.490 pilot study the Phase two pilot City
NOTE Confidence: 0.85549736
00:53:33.490 --> 00:53:35.968 that I shared was for either people
NOTE Confidence: 0.85549736
00:53:35.968 --> 00:53:38.453 with brand new cancer or people who
NOTE Confidence: 0.85549736
00:53:38.453 --> 00:53:40.985 had just record and the reason was
NOTE Confidence: 0.85549736
00:53:40.985 --> 00:53:42.800 we believe that resilience coaching
NOTE Confidence: 0.85549736
00:53:42.865 --> 00:53:45.007 is necessary during times of stress.
NOTE Confidence: 0.85549736
00:53:45.010 --> 00:53:47.930 So if the construct is Ono right now,
NOTE Confidence: 0.85549736
00:53:47.930 --> 00:53:50.485 my life feels hard. I need help.
NOTE Confidence: 0.85549736
00:53:50.490 --> 00:53:52.793 We wanted to identify those periods of
NOTE Confidence: 0.85549736
00:53:52.793 --> 00:53:54.580 a patient’s cancer experience where

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they would be receiving chemotherapy and in the hospital and needing some additional support.

And so in that first study of roughly 92 people, 3/4 of them were teens with brand new cancers and then about 1/4 of them worked. Folks who had been well and then had had a recurrence. And when we tried to look at the differences between the groups, we couldn’t find anything that said prison work better or worse. If you were new to cancer or really experienced with your cancer,
the thing that we did notice that was different in the patients with advanced cancer. And then this was replicated amongst teens with CF is hey, Prism just taught me all this stuff about how to identify what matters to me and why. My goals are and now I need help talking to my family about this. And so as I sort of quickly described one of our larger grants right now is building on that for patients specifically with advanced incurable cancer. I’m saying, can we teach these four skills and then
build on that to integrate advanced care planning for teens and young adults? And that’s important because maybe 20% of teens and young adults in the United States actually fill out advance care planning documents. Fewer than that are involved in care decisions about their ongoing medical care and end of life plans and so. The idea was maybe PRISM can be a safer on tray into some of those really hard conversations that are so important at the end of the patient’s life. Absolutely OK. We have a couple of hands race so
I’m going to let Jeffrey Townsend own and go ahead and unmute yourself. Hopefully he can leave.

Alright, well, while we’re waiting for Doctor Townsend, Amanda Gorbaty near you able to unmute.

Renee, I may need your help.

Yeah, I just mark this a webinar so the attendees can send in something via the chat. Thanks, mark.

Alright, so so Amanda and Jeffrey. If you want to put your questions into the chat, will be sure to try to get to them.

Overweighting Abby.
to share how you thought about measuring some of those longer term psychological outcomes, or in terms of outcomes like.

So of those 92 patients that we had in that first pilot trial, a little less than a third have died since then. In the two years that followed that project,
and that is across both advanced cancer and new cancer patients in equal measure. So we’re down to a little over 50 folks who we can still follow, and it’s harder to gauge long term outcomes in a smaller and smaller sample size. That said, what we’re noticing, which is really interesting to me is, and this is like an ongoing work in progress data, so forgive me ’cause it might change when we finally publish it. But the initial analysis that we’re looking at right now suggests. Two really interesting things.
people who responded to PRISM in that beginning six months phase have a long term protection of it. So if you were in the group who got prison, Khalaj Ikle benefit seems to indoor two years later, so that sense of new resilience. Hope for the future and ability to find meaning and benefit those indoor. What is more interesting, in a different way is that while distress immediately improved, and as I showed you, depression risk went way down.
That risk of endurable, non negative psychological outcome doesn’t seem to persist, and so what I mean by that is people were no longer distress during their immediate cancer experience when they got PRISM, but overtime there’s a regression to the mean between usual Karen Prism participants with respect to their overall distress. And the combination of those things tells me two things. Number one, we do want to alleviate negative pathology in the moment.
so we do want to alleviate distress in real time.

But the long term benefit of PRISM might be that positive psychological gain is an inoculation for later well being. And what I mean by that is you want somebody’s hope for the future to be the thing that lasts. I care less that they are not distressed overtime as much as that they maintain that positive outlook, because I believe that when the next stressor comes. That positive psychological
00:59:35.032 --> 00:59:37.396 benefit that they have gained those
NOTE Confidence: 0.8078167
00:59:37.396 --> 00:59:39.066 resilience resources that they have
NOTE Confidence: 0.8078167
00:59:39.066 --> 00:59:40.890 learned will help them deal with
NOTE Confidence: 0.8078167
00:59:40.943 --> 00:59:42.648 whatever is the future stressor,
NOTE Confidence: 0.8078167
00:59:42.650 --> 00:59:45.278 and so this is the long way of saying
NOTE Confidence: 0.8078167
00:59:45.278 --> 00:59:47.937 that I think what prison does is it
NOTE Confidence: 0.8078167
00:59:47.937 --> 00:59:50.389 boosts long term positive psychology,
NOTE Confidence: 0.8078167
00:59:50.390 --> 00:59:52.150 but the protection from negative
NOTE Confidence: 0.8078167
00:59:52.150 --> 00:59:54.347 pathology is more in real time
NOTE Confidence: 0.8078167
00:59:54.347 --> 00:59:56.603 and we probably need measures to
NOTE Confidence: 0.8078167
00:59:56.603 --> 00:59:58.424 address people’s support to Puerto
NOTE Confidence: 0.8078167
00:59:58.424 --> 01:00:00.314 Kearneys right in times of stress
NOTE Confidence: 0.8078167
01:00:00.314 --> 01:00:02.358 and then help them figure out
NOTE Confidence: 0.8078167
01:00:02.358 --> 01:00:04.470 their way as they move forward.
NOTE Confidence: 0.8328513
01:00:05.860 --> 01:00:08.485 Absolutely. So we have one last question.
NOTE Confidence: 0.8328513
01:00:08.490 --> 01:00:10.975 I received this message by text because
it looks like people aren’t able to actually put messages into the chat, so I apologize so this question is from Amanda Garber Teeny. She is a social worker in pediatric oncology. She said she’s traded a few emails with you so she’s focused on adolescents, young adults and currently uses many prism techniques and models with her patients at Yale, so she was wondering if it would be possible to have access to the app or other PRISM resources for her patients.
And thank you for asking it.
The answer is yes and we as I said, we really do want to share this and we have ways to make be able to sustain the program. So we unfortunately right now cannot give it out for free. But please email me and I’m happy to chat with you about how we can provide the program. Cost effective way is we can until we can figure out how to publicly just make it available. Alright, well thank you so much Doctor Rosenberg for being here with us and for sharing your insights.
And thanks to everyone who joined the webinar today.