WEBVTT

NOTE duration:"01:01:21.7710000"

NOTE language:en-us

NOTE Confidence: 0.8496061

00:00:00.000 --> 00:00:02.105 Great, thanks everyone for joining

NOTE Confidence: 0.8496061

00:00:02.105 --> 00:00:04.122 our Cancer Center grand rounds.

NOTE Confidence: 0.8496061

00:00:04.122 --> 00:00:06.540 Today my name's press 9 month.

NOTE Confidence: 0.8496061

00:00:06.540 --> 00:00:08.958 I'm a faculty member in the

NOTE Confidence: 0.8496061

00:00:08.958 --> 00:00:10.167 Department of Pediatrics.

NOTE Confidence: 0.8496061

00:00:10.170 --> 00:00:12.588 I have the distinct honor of

NOTE Confidence: 0.8496061

00:00:12.588 --> 00:00:14.200 introducing our Cancer Center,

NOTE Confidence: 0.8496061

00:00:14.200 --> 00:00:15.220 grand rounds,

NOTE Confidence: 0.8496061

00:00:15.220 --> 00:00:18.280 guest speaker today Doctor Abby Rosenberg.

NOTE Confidence: 0.8496061

00:00:18.280 --> 00:00:20.340 Doctor Rosenberg is an associate

NOTE Confidence: 0.8496061

00:00:20.340 --> 00:00:21.988 professor of pediatric hematology

NOTE Confidence: 0.8496061

00:00:21.988 --> 00:00:24.423 and oncology at the University of

NOTE Confidence: 0.8496061

00:00:24.423 --> 00:00:26.050 Washington School of Medicine.

NOTE Confidence: 0.8496061

00:00:26.050 --> 00:00:28.384 The director of Pediatrics at the

NOTE Confidence: 0.8496061

00:00:28.384 --> 00:00:30.437 Cambia Palliative Care Center of

NOTE Confidence: 0.8496061

00:00:30.437 --> 00:00:32.597 Excellence at University of Washington,

NOTE Confidence: 0.8496061

00:00:32.600 --> 00:00:35.099 director of the pilot of Keran Resilience

NOTE Confidence: 0.8496061

00:00:35.099 --> 00:00:36.659 Laboratory at Seattle Children's

NOTE Confidence: 0.8496061

00:00:36.659 --> 00:00:38.784 Research Institute and the Director

NOTE Confidence: 0.8496061

00:00:38.784 --> 00:00:41.003 of Survivorship and Outcomes Research

NOTE Confidence: 0.8496061

00:00:41.003 --> 00:00:42.819 at Seattle Children's Hospital,

NOTE Confidence: 0.8496061

00:00:42.820 --> 00:00:44.930 Cancer and Blood Disorders Centers

NOTE Confidence: 0.8496061

00:00:44.930 --> 00:00:47.320 through her work as Program Co.

NOTE Confidence: 0.8496061

00:00:47.320 --> 00:00:49.744 Director for the University of Washington

NOTE Confidence: 0.8496061

00:00:49.744 --> 00:00:52.300 T32 program in Positive care research.

NOTE Confidence: 0.8496061

00:00:52.300 --> 00:00:54.757 And a lead mentor in the palliative

NOTE Confidence: 0.8496061

00:00:54.757 --> 00:00:56.290 care and Resilience Laboratory

NOTE Confidence: 0.8496061

00:00:56.290 --> 00:00:58.335 Doctor Rosenberg is very active

NOTE Confidence: 0.8496061

00:00:58.335 --> 00:01:00.529 and training the next generation

NOTE Confidence: 0.8496061

00:01:00.529 --> 00:01:02.989 of palliative care and supportive

NOTE Confidence: 0.8496061

00:01:02.989 --> 00:01:05.511 oncology clinician scientists at the

NOTE Confidence: 0.8496061

00:01:05.511 --> 00:01:08.266 postdoctoral and junior faculty levels.

NOTE Confidence: 0.8496061

00:01:08.270 --> 00:01:09.770 Doctor Rosenberg Additionally holds

NOTE Confidence: 0.8496061

00:01:09.770 --> 00:01:11.270 multiple national leadership positions.

NOTE Confidence: 0.8496061

00:01:11.270 --> 00:01:14.272 She's the chair of the Ethics Committee at

NOTE Confidence: 0.8496061

00:01:14.272 --> 00:01:16.516 the American Society of Clinical Oncology.

NOTE Confidence: 0.8496061

00:01:16.520 --> 00:01:17.178 The Co.

NOTE Confidence: 0.8496061

00:01:17.178 --> 00:01:19.152 Chair of the scientific program for

NOTE Confidence: 0.8496061

00:01:19.152 --> 00:01:21.530 the Annual Assembly of the American

NOTE Confidence: 0.8496061

00:01:21.530 --> 00:01:24.014 Academy of Hospice and Palliative Medicine,

NOTE Confidence: 0.8496061

00:01:24.020 --> 00:01:26.270 and the Associate editor in Chief

NOTE Confidence: 0.8496061

00:01:26.270 --> 00:01:27.395 of Palliative Care.

NOTE Confidence: 0.8496061

00:01:27.400 --> 00:01:29.665 Fast article summaries for clinicians.

NOTE Confidence: 0.8496061

00:01:29.665 --> 00:01:32.222 Doctor Rosenberg's NIH funded research

NOTE Confidence: 0.8496061

00:01:32.222 --> 00:01:34.462 focuses on developing programs to

NOTE Confidence: 0.8496061

00:01:34.462 --> 00:01:36.903 help patients and families with

NOTE Confidence: 0.8496061

00:01:36.903 --> 00:01:38.823 serious illness build resilience,

NOTE Confidence: 0.8496061

00:01:38.830 --> 00:01:40.615 thereby alleviating suffering

NOTE Confidence: 0.8496061

00:01:40.615 --> 00:01:43.590 an improving quality of life.

NOTE Confidence: 0.8496061

00:01:43.590 --> 00:01:45.329 The title of Doctor Rosenberg's

NOTE Confidence: 0.8496061

00:01:45.329 --> 00:01:47.074 talk today is promoting resilience

NOTE Confidence: 0.8496061

00:01:47.074 --> 00:01:48.854 in children with serious illness

NOTE Confidence: 0.8496061

00:01:48.854 --> 00:01:49.850 and their families.

NOTE Confidence: 0.8496061

00:01:49.850 --> 00:01:51.938 I'll be moderating the discussion afterwards,

NOTE Confidence: 0.8496061

00:01:51.940 --> 00:01:53.800 so please enter your questions into

NOTE Confidence: 0.8496061

00:01:53.800 --> 00:01:55.902 the chat function will take questions

NOTE Confidence: 0.8496061

00:01:55.902 --> 00:01:57.506 after Doctor Rosenberg's talk.

NOTE Confidence: 0.8496061

00:01:57.510 --> 00:01:59.544 Thank you so much Doctor Rosenberg

NOTE Confidence: 0.8496061

00:01:59.544 --> 00:02:01.340 for speaking with us today.

NOTE Confidence: 0.856936

00:02:02.560 --> 00:02:04.010 Thank you for having me.

NOTE Confidence: 0.856936

00:02:04.010 --> 00:02:05.826 This is such a pleasure to be here

NOTE Confidence: 0.856936

00:02:05.826 --> 00:02:07.873 and that was a very very kind

NOTE Confidence: 0.856936

00:02:07.873 --> 00:02:09.408 introduction process that it's really

NOTE Confidence: 0.856936

00:02:09.461 --> 00:02:11.256 humbling in a little embarrassing,

NOTE Confidence: 0.856936

00:02:11.260 --> 00:02:13.428 happy to be here with all is as

NOTE Confidence: 0.856936

00:02:13.428 --> 00:02:15.606 all of you as you just heard,

NOTE Confidence: 0.856936

00:02:15.610 --> 00:02:17.759 I'm going to talk today about promoting

NOTE Confidence: 0.856936

00:02:17.759 --> 00:02:19.464 resilience in patients and families

NOTE Confidence: 0.856936

00:02:19.464 --> 00:02:20.920 with serious pediatric illness.

NOTE Confidence: 0.856936

00:02:20.920 --> 00:02:22.840 And by way of a disclaimer,

NOTE Confidence: 0.856936

00:02:22.840 --> 00:02:25.400 I know this is a larger Cancer Center.

NOTE Confidence: 0.856936

00:02:25.400 --> 00:02:26.040 Grand rounds.

NOTE Confidence: 0.856936

00:02:26.040 --> 00:02:27.000 As a pediatrician,

NOTE Confidence: 0.856936

00:02:27.000 --> 00:02:28.710 I'll be talking about what we've

NOTE Confidence: 0.856936

00:02:28.710 --> 00:02:30.634 learned in our work with adolescents

NOTE Confidence: 0.856936

00:02:30.634 --> 00:02:32.439 and young adults with cancer,

00:02:32.440 --> 00:02:34.640 and by the end of this talk I will be

00:02:34.707 --> 00:02:37.101 sharing with you how translate abalar

00:02:37.101 --> 00:02:39.480 experiences to older patients with cancer,

00:02:39.480 --> 00:02:40.086 their caregivers,

00:02:40.086 --> 00:02:40.692 and ourselves.

00:02:40.692 --> 00:02:43.320 As folks who are caring for these patients.

00:02:47.750 --> 00:02:49.689 So I wanted to start with this

00:02:49.689 --> 00:02:51.200 question about why resilience.

00:02:51.200 --> 00:02:53.084 Why are we talking about this

00:02:53.084 --> 00:02:54.026 particular construct today?

00:02:54.030 --> 00:02:55.944 Why does it matter for our

00:02:55.944 --> 00:02:57.480 patients with cancer for me,

00:02:57.480 --> 00:02:59.020 Despite that lovely introduction,

00:02:59.020 --> 00:03:01.676 that piece of my history that you

00:03:01.676 --> 00:03:03.924 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,

NOTE Confidence: 0.87158483

00:03:37.650 --> 00:03:40.274 if not thrive in the face of adversity,

NOTE Confidence: 0.87158483

00:03:40.280 --> 00:03:41.237 is like cancer?

NOTE Confidence: 0.87158483

00:03:41.237 --> 00:03:43.890 Why are some other people just falling apart?

NOTE Confidence: 0.87158483

00:03:43.890 --> 00:03:46.234 And is there a way that we could

NOTE Confidence: 0.87158483

00:03:46.234 --> 00:03:48.643 teach to the ones who are struggling

NOTE Confidence: 0.87158483

00:03:48.643 --> 00:03:51.539 with the ones who had figured it out?

NOTE Confidence: 0.87158483

00:03:51.540 --> 00:03:53.430 Seem to have learned on their own.

NOTE Confidence: 0.87158483

00:03:53.430 --> 00:03:54.778 If we did that,

NOTE Confidence: 0.87158483

00:03:54.778 --> 00:03:56.800 would we be improving the quality

NOTE Confidence: 0.87158483

00:03:56.871 --> 00:03:59.205 of life of patients with cancer

NOTE Confidence: 0.87158483

00:03:59.205 --> 00:04:00.372 and their families?

NOTE Confidence: 0.87158483

00:04:00.380 --> 00:04:02.914 It turns out it's pretty hard to

NOTE Confidence: 0.87158483

00:04:02.914 --> 00:04:05.119 translate this idea of what resilience

NOTE Confidence: 0.87158483

00:04:05.119 --> 00:04:07.555 is into what we do in medicine,

NOTE Confidence: 0.87158483

00:04:07.560 --> 00:04:09.636 and there were definition of resilience

NOTE Confidence: 0.87158483

00:04:09.636 --> 00:04:12.228 comes from the material Sciences and physics.

NOTE Confidence: 0.87158483

00:04:12.230 --> 00:04:14.234 It's defined as the capacity of

NOTE Confidence: 0.87158483

00:04:14.234 --> 00:04:16.031 a particular material to absorb

NOTE Confidence: 0.87158483

00:04:16.031 --> 00:04:17.607 energy when it's deformed,

NOTE Confidence: 0.87158483

00:04:17.610 --> 00:04:19.764 and then appan up unloading to

NOTE Confidence: 0.87158483

00:04:19.764 --> 00:04:21.200 have its energy recovered.

NOTE Confidence: 0.87158483

00:04:21.200 --> 00:04:23.587 So the classic example is a rubber

NOTE Confidence: 0.87158483

00:04:23.587 --> 00:04:26.161 band where you stretch it an IT

NOTE Confidence: 0.87158483

00:04:26.161 --> 00:04:28.375 rebounds back to its original shape,

NOTE Confidence: 0.87158483

00:04:28.380 --> 00:04:30.960 and therefore it is resilient.

NOTE Confidence: 0.87158483

00:04:30.960 --> 00:04:32.244 But what does that mean when

NOTE Confidence: 0.87158483

00:04:32.244 --> 00:04:33.385 we're talking about patients and

NOTE Confidence: 0.87158483

00:04:33.385 --> 00:04:34.575 families in their own experiences?

NOTE Confidence: 0.87158483

00:04:34.580 --> 00:04:35.936 And when I started this work

NOTE Confidence: 0.87158483

00:04:35.936 --> 00:04:36.840 over a decade ago,

NOTE Confidence: 0.87158483

00:04:36.840 --> 00:04:38.640 one of my mentors said this to me.

NOTE Confidence: 0.87158483

00:04:38.640 --> 00:04:39.318 He said, Abby,

NOTE Confidence: 0.87158483

00:04:39.318 --> 00:04:40.674 if you want to change something,

NOTE Confidence: 0.87158483

00:04:40.680 --> 00:04:43.128 you have to be able to measure it.

NOTE Confidence: 0.87158483

00:04:43.130 --> 00:04:44.494 When you say resilient,

NOTE Confidence: 0.87158483

00:04:44.494 --> 00:04:46.199 what are you talking about?

NOTE Confidence: 0.87158483

00:04:46.200 --> 00:04:48.056 What are you measuring?

NOTE Confidence: 0.87158483

00:04:48.056 --> 00:04:50.376 What are you actually changing?

NOTE Confidence: 0.87158483

00:04:50.380 --> 00:04:52.270 When we started this question was

NOTE Confidence: 0.87158483

00:04:52.270 --> 00:04:54.223 hard to answer to because there

NOTE Confidence: 0.87158483

00:04:54.223 --> 00:04:56.428 was a lot of controversy in the

NOTE Confidence: 0.87158483

00:04:56.428 --> 00:04:58.425 world of psychology and social

NOTE Confidence: 0.87158483

00:04:58.425 --> 00:05:00.450 Sciences about what resilience is.

NOTE Confidence: 0.87158483

00:05:00.450 --> 00:05:02.277 This is a study done by a

NOTE Confidence: 0.87158483

00:05:02.277 --> 00:05:03.429 psychologist named George Bonanno

NOTE Confidence: 0.87158483

00:05:03.429 --> 00:05:05.014 who studies bereavement and he's

NOTE Confidence: 0.87158483

00:05:05.014 --> 00:05:06.696 one of the preeminent scientists

NOTE Confidence: 0.87158483

00:05:06.696 --> 00:05:08.128 in the resilience world.

NOTE Confidence: 0.87158483

00:05:08.130 --> 00:05:09.246 On the X axis,

NOTE Confidence: 0.87158483

00:05:09.246 --> 00:05:11.858 here's time and on the Y axis is

NOTE Confidence: 0.87158483

00:05:11.858 --> 00:05:14.008 levels of distress and depression.

NOTE Confidence: 0.87158483

00:05:14.010 --> 00:05:15.846 And you'll notice there are three

NOTE Confidence: 0.87158483

00:05:15.846 --> 00:05:17.837 lines of people moving through their

NOTE Confidence: 0.87158483

00:05:17.837 --> 00:05:19.967 lives until a traumatic event happens.

NOTE Confidence: 0.87158483

00:05:19.970 --> 00:05:20.861 In this case,

NOTE Confidence: 0.87158483

00:05:20.861 --> 00:05:22.643 it's the death of their spouse

NOTE Confidence: 0.87158483

00:05:22.643 --> 00:05:23.940 and following that,

NOTE Confidence: 0.87158483

00:05:23.940 --> 00:05:25.614 every single one of those lines

NOTE Confidence: 0.87158483

00:05:25.614 --> 00:05:27.608 has a normal and expected spike

NOTE Confidence: 0.87158483

00:05:27.608 --> 00:05:29.236 in distress and depression,

NOTE Confidence: 0.87158483

00:05:29.240 --> 00:05:31.772 followed by some new pathway towards

NOTE Confidence: 0.87158483

00:05:31.772 --> 00:05:34.230 wherever folks are going to end up.

NOTE Confidence: 0.8592382

00:05:34.230 --> 00:05:35.494 And was really interesting

NOTE Confidence: 0.8592382

00:05:35.494 --> 00:05:37.074 to me about this graph.

NOTE Confidence: 0.8592382

00:05:37.080 --> 00:05:39.792 Is that it kind of illustrates the three

NOTE Confidence: 0.8592382

00:05:39.792 --> 00:05:41.727 controversies that at the time were

NOTE Confidence: 0.8592382

00:05:41.727 --> 00:05:43.521 swirling around how we should think

NOTE Confidence: 0.8592382

00:05:43.579 --> 00:05:45.647 about and operationalize resilience.

NOTE Confidence: 0.8592382

00:05:45.650 --> 00:05:47.995 There was a school of thought who

NOTE Confidence: 0.8592382

00:05:47.995 --> 00:05:50.580 would look at this graph and say

NOTE Confidence: 0.8592382

00:05:50.580 --> 00:05:52.842 resilience is defined on the left.

NOTE Confidence: 0.8592382

00:05:52.850 --> 00:05:54.290 It is a innate,

NOTE Confidence: 0.8592382

00:05:54.290 --> 00:05:55.370 perhaps immutable characteristic,

NOTE Confidence: 0.8592382

00:05:55.370 --> 00:05:56.450 something like grit,

NOTE Confidence: 0.8592382

00:05:56.450 --> 00:05:57.170 hardiness, optimism,

NOTE Confidence: 0.8592382

00:05:57.170 --> 00:05:59.690 something we either have or we don't,

NOTE Confidence: 0.8592382

00:05:59.690 --> 00:06:01.856 and whether we have that thing

NOTE Confidence: 0.8592382

12

00:06:01.856 --> 00:06:04.070 or not predisposes us to being

NOTE Confidence: 0.8592382

00:06:04.070 --> 00:06:05.805 resilient in the long run.

NOTE Confidence: 0.8592382

00:06:05.810 --> 00:06:06.974 So sure enough,

NOTE Confidence: 0.8592382

00:06:06.974 --> 00:06:09.302 there's a group that's represented with

NOTE Confidence: 0.8592382

00:06:09.302 --> 00:06:11.793 that line dot line there at the top

NOTE Confidence: 0.8592382

00:06:11.793 --> 00:06:14.088 of these three collections of lines.

NOTE Confidence: 0.8592382

00:06:14.090 --> 00:06:15.970 They are for whatever reason.

NOTE Confidence: 0.8592382

00:06:15.970 --> 00:06:17.298 Less resilient at baseline.

NOTE Confidence: 0.8592382

00:06:17.298 --> 00:06:19.290 They're less protected from this trauma,

NOTE Confidence: 0.8592382

00:06:19.290 --> 00:06:21.630 and sure enough they end

NOTE Confidence: 0.8592382

00:06:21.630 --> 00:06:23.502 up having chronic grief.

NOTE Confidence: 0.8592382

00:06:23.510 --> 00:06:25.666 A second theory on a second debate

NOTE Confidence: 0.8592382

00:06:25.666 --> 00:06:27.488 was that resilience was a process

NOTE Confidence: 0.8592382

00:06:27.488 --> 00:06:29.441 of how we adapt to our adversities,

NOTE Confidence: 0.8592382

00:06:29.450 --> 00:06:31.529 how we change with our new normals,

NOTE Confidence: 0.8592382

00:06:31.530 --> 00:06:33.455 and they would look at this graph

NOTE Confidence: 0.8592382

00:06:33.455 --> 00:06:34.980 and they'd say no resilience

NOTE Confidence: 0.8592382

00:06:34.980 --> 00:06:36.575 is defined in the middle.

NOTE Confidence: 0.8592382

00:06:36.580 --> 00:06:38.421 It's the way that recovery line is

NOTE Confidence: 0.8592382

00:06:38.421 --> 00:06:40.588 able to go from a relatively high

NOTE Confidence: 0.8592382

00:06:40.588 --> 00:06:42.905 level of distress to a relatively low

NOTE Confidence: 0.8592382

00:06:42.905 --> 00:06:45.488 one because they figure it out along the way.

NOTE Confidence: 0.8592382

00:06:45.490 --> 00:06:47.266 And if we wanted to intervene,

NOTE Confidence: 0.8592382

00:06:47.270 --> 00:06:49.394 we could move the needle by

NOTE Confidence: 0.8592382

00:06:49.394 --> 00:06:51.730 helping those folks to cope better.

NOTE Confidence: 0.8592382

00:06:51.730 --> 00:06:53.949 And then a final school of thought

NOTE Confidence: 0.8592382

00:06:53.949 --> 00:06:54.900 was that no,

NOTE Confidence: 0.8592382

00:06:54.900 --> 00:06:56.802 no resilience is defined on the

NOTE Confidence: 0.8592382

00:06:56.802 --> 00:06:58.070 right of this graph.

NOTE Confidence: 0.8592382

00:06:58.070 --> 00:06:59.655 It is only measurable after

NOTE Confidence: 0.8592382

00:06:59.655 --> 00:07:00.606 a particular trauma,

NOTE Confidence: 0.8592382

00:07:00.610 --> 00:07:02.380 and after a particular amount of

NOTE Confidence: 0.8592382

00:07:02.380 --> 00:07:03.900 time has passed and resilience

NOTE Confidence: 0.8592382

00:07:03.900 --> 00:07:05.881 after the death of a loved one

NOTE Confidence: 0.8592382

00:07:05.881 --> 00:07:07.605 might be different than resilience

NOTE Confidence: 0.8592382

00:07:07.605 --> 00:07:09.795 after a natural disaster or war,

NOTE Confidence: 0.8592382

00:07:09.800 --> 00:07:11.486 and you can only tell that

NOTE Confidence: 0.8592382

00:07:11.486 --> 00:07:13.405 someone is resilient or not based

NOTE Confidence: 0.8592382

00:07:13.405 --> 00:07:14.869 on some dichotomized outcome.

NOTE Confidence: 0.8592382

00:07:14.870 --> 00:07:17.089 So if you have a negative outcome,

NOTE Confidence: 0.8592382

00:07:17.090 --> 00:07:19.309 for example, you must not be resilient,

NOTE Confidence: 0.8592382

00:07:19.310 --> 00:07:21.529 and if the absence of that outcome,

NOTE Confidence: 0.8592382

00:07:21.530 --> 00:07:23.190 like chronic grief, is notable.

NOTE Confidence: 0.8592382

00:07:23.190 --> 00:07:24.898 Then you must be resilient 'cause you're

NOTE Confidence: 0.8592382

00:07:24.898 --> 00:07:26.348 doing better than we might expect.

NOTE Confidence: 0.8455567

00:07:28.420 --> 00:07:31.068 So for me as a clinician who was

NOTE Confidence: 0.8455567

00:07:31.068 --> 00:07:32.930 relatively early in my career

NOTE Confidence: 0.8455567

00:07:32.930 --> 00:07:34.434 as a pediatric oncologist,

NOTE Confidence: 0.8455567

00:07:34.440 --> 00:07:37.284 I felt like none of these

NOTE Confidence: 0.8455567

00:07:37.284 --> 00:07:39.849 theories matched to what I saw.

NOTE Confidence: 0.8455567

00:07:39.850 --> 00:07:42.125 And here are some of my questions.

NOTE Confidence: 0.8455567

00:07:42.130 --> 00:07:43.482 Number one is illness.

NOTE Confidence: 0.8455567

00:07:43.482 --> 00:07:44.496 An isolated event?

NOTE Confidence: 0.8455567

00:07:44.500 --> 00:07:47.108 Can you draw a single line on a

NOTE Confidence: 0.8455567

00:07:47.108 --> 00:07:48.556 cancer patients experience and

NOTE Confidence: 0.8455567

00:07:48.556 --> 00:07:51.083 say this is the moment that they

NOTE Confidence: 0.8455567

00:07:51.083 --> 00:07:53.387 have to define their resilience?

NOTE Confidence: 0.8455567

00:07:53.390 --> 00:07:55.798 Or is resilience a series or illness?

NOTE Confidence: 0.8455567

00:07:55.800 --> 00:07:58.134 A series of micro traumas and

NOTE Confidence: 0.8455567

00:07:58.134 --> 00:08:00.841 micro and macro events that can

NOTE Confidence: 0.8455567

00:08:00.841 --> 00:08:02.985 change someone's whole trajectory?

NOTE Confidence: 0.8455567

00:08:02.990 --> 00:08:04.166 Who's the unit?

NOTE Confidence: 0.8455567

00:08:04.166 --> 00:08:05.878 In Pediatrics, we look at patients.

NOTE Confidence: 0.8455567

00:08:05.878 --> 00:08:07.038 We look at their siblings.

NOTE Confidence: 0.8455567

00:08:07.040 --> 00:08:08.354 We look at their families with

NOTE Confidence: 0.8455567

00:08:08.354 --> 00:08:09.980 a look at their social supports

NOTE Confidence: 0.8455567

00:08:09.980 --> 00:08:11.376 in their school communities.

NOTE Confidence: 0.8455567

00:08:11.380 --> 00:08:12.843 Which of those units is the way

NOTE Confidence: 0.8455567

00:08:12.843 --> 00:08:14.525 I need to think about resilience

NOTE Confidence: 0.8455567

00:08:14.525 --> 00:08:16.185 and my defining resilience for

NOTE Confidence: 0.8455567

00:08:16.185 --> 00:08:17.927 the patient or for their family?

NOTE Confidence: 0.87048066

00:08:19.980 --> 00:08:21.876 Is there a difference between getting

NOTE Confidence: 0.87048066

00:08:21.876 --> 00:08:23.580 through adversity or growing from it?

NOTE Confidence: 0.87048066

00:08:23.580 --> 00:08:25.916 A lot of the resilience is an outcomes

NOTE Confidence: 0.87048066

00:08:25.916 --> 00:08:27.779 theory at the time was saying,

NOTE Confidence: 0.87048066

00:08:27.780 --> 00:08:29.580 you know you really have to

NOTE Confidence: 0.87048066

00:08:29.580 --> 00:08:31.080 show some benefit, some growth,

NOTE Confidence: 0.87048066

00:08:31.080 --> 00:08:31.980 some lesson learned,

NOTE Confidence: 0.87048066

00:08:31.980 --> 00:08:33.884 some some idea that you have improved

NOTE Confidence: 0.87048066

00:08:33.884 --> 00:08:35.748 from whatever your adversity is in

NOTE Confidence: 0.87048066

00:08:35.748 --> 00:08:37.080 order to demonstrate resilience,

NOTE Confidence: 0.87048066

00:08:37.080 --> 00:08:39.352 and I will tell you when I was

NOTE Confidence: 0.87048066

00:08:39.352 --> 00:08:41.286 starting this work I was working

NOTE Confidence: 0.87048066

00:08:41.286 --> 00:08:43.574 with a lot of bereaved families an

NOTE Confidence: 0.87048066

00:08:43.574 --> 00:08:45.798 I would ask them what do you think

NOTE Confidence: 0.87048066

00:08:45.798 --> 00:08:47.132 about this idea of resilience?

NOTE Confidence: 0.87048066

00:08:47.132 --> 00:08:49.020 What do you think about this idea

NOTE Confidence: 0.87048066

00:08:49.020 --> 00:08:50.538 that you're supposed to have grown

NOTE Confidence: 0.87048066

00:08:50.538 --> 00:08:52.694 from it and they would say you know

NOTE Confidence: 0.87048066

00:08:52.694 --> 00:08:54.267 it's pretty offensive that you think

NOTE Confidence: 0.87048066

00:08:54.267 --> 00:08:55.629 I'm supposed to somehow be better

NOTE Confidence: 0.87048066

00:08:55.629 --> 00:08:57.289 from having my child die from cancer.

NOTE Confidence: 0.87048066

00:08:57.290 --> 00:08:59.090 The fact that I got out of bed today

NOTE Confidence: 0.87048066

18

00:08:59.090 --> 00:09:00.537 makes me pretty darn resilient.

NOTE Confidence: 0.76211596

00:09:04.800 --> 00:09:07.640 Which outcomes matter into poems.

NOTE Confidence: 0.76211596

00:09:07.640 --> 00:09:09.314 If I'm a pediatric oncologist taking

NOTE Confidence: 0.76211596

00:09:09.314 --> 00:09:11.099 care of a teenager with cancer,

NOTE Confidence: 0.76211596

00:09:11.100 --> 00:09:13.284 I might say that that person is

NOTE Confidence: 0.76211596

00:09:13.284 --> 00:09:14.946 resilient because they're taking their

NOTE Confidence: 0.76211596

00:09:14.946 --> 00:09:16.956 oral chemotherapy as I prescribe it.

NOTE Confidence: 0.76211596

00:09:16.960 --> 00:09:18.630 Their mom might say they're

NOTE Confidence: 0.76211596

00:09:18.630 --> 00:09:20.300 resilient because they're going to

NOTE Confidence: 0.76211596

00:09:20.359 --> 00:09:22.139 school and maintaining their GPA.

NOTE Confidence: 0.76211596

00:09:22.140 --> 00:09:24.336 And the patient might say they're

NOTE Confidence: 0.76211596

00:09:24.336 --> 00:09:25.434 resilient because they've

NOTE Confidence: 0.76211596

00:09:25.434 --> 00:09:26.950 maintained their social network.

NOTE Confidence: 0.76211596

00:09:26.950 --> 00:09:27.690 Who's right?

NOTE Confidence: 0.86011916

00:09:30.280 --> 00:09:32.080 How do we integrate individual differences?

NOTE Confidence: 0.86011916

00:09:32.080 --> 00:09:34.780 Is there a one size fits all in resilience?

19

NOTE Confidence: 0.86011916

00:09:34.780 --> 00:09:37.636 Or does my resilience look somewhat

NOTE Confidence: 0.86011916

00:09:37.636 --> 00:09:39.540 different from someone elses?

NOTE Confidence: 0.86011916

00:09:39.540 --> 00:09:42.594 And finally, how do we integrate

NOTE Confidence: 0.86011916

00:09:42.594 --> 00:09:45.190 cultural differences into these ideas?

NOTE Confidence: 0.86011916

00:09:45.190 --> 00:09:46.735 This last one is important

NOTE Confidence: 0.86011916

00:09:46.735 --> 00:09:48.280 because this idea of resilience.

NOTE Confidence: 0.86011916

00:09:48.280 --> 00:09:49.948 This value that we put on

NOTE Confidence: 0.86011916

00:09:49.948 --> 00:09:51.680 it is very very Western.

NOTE Confidence: 0.86011916

00:09:51.680 --> 00:09:53.605 So here in the United States we

NOTE Confidence: 0.86011916

00:09:53.605 --> 00:09:55.515 say that things like that which

NOTE Confidence: 0.86011916

00:09:55.515 --> 00:09:57.549 doesn't kill you makes you stronger.

NOTE Confidence: 0.86011916

00:09:57.550 --> 00:09:58.774 No pain, no gain.

NOTE Confidence: 0.86011916

00:09:58.774 --> 00:10:01.028 We have this inherent respect for people

NOTE Confidence: 0.86011916

00:10:01.028 --> 00:10:03.506 who can pull themselves up from their

NOTE Confidence: 0.86011916

00:10:03.506 --> 00:10:05.838 bootstraps and lived this American dream.

NOTE Confidence: 0.86011916

00:10:05.840 --> 00:10:08.346 But that is really an American ideal,

NOTE Confidence: 0.86011916

00:10:08.350 --> 00:10:10.130 and it doesn't actually

NOTE Confidence: 0.86011916

00:10:10.130 --> 00:10:11.910 translate around the world.

NOTE Confidence: 0.86011916

00:10:11.910 --> 00:10:13.620 In Southeast Asia, resilience has been

NOTE Confidence: 0.86011916

00:10:13.620 --> 00:10:15.329 equated with the sense of balance.

NOTE Confidence: 0.86011916

00:10:15.330 --> 00:10:17.325 So instead of the stretchiness of a

NOTE Confidence: 0.86011916

00:10:17.325 --> 00:10:19.610 rubber band, it is the lack of stretching.

NOTE Confidence: 0.86011916

00:10:19.610 --> 00:10:22.682 It is the willingness or the ability of

NOTE Confidence: 0.86011916

00:10:22.682 --> 00:10:25.456 a material to stay within its shape.

NOTE Confidence: 0.86011916

00:10:25.460 --> 00:10:27.352 In South American cultures,

NOTE Confidence: 0.86011916

00:10:27.352 --> 00:10:29.717 resilience has been equated with

NOTE Confidence: 0.86011916

00:10:29.717 --> 00:10:31.818 and upholding the values.

NOTE Confidence: 0.86011916

00:10:31.820 --> 00:10:32.790 In Afghanistan,

NOTE Confidence: 0.86011916

00:10:32.790 --> 00:10:35.215 resilience has been equated with

NOTE Confidence: 0.86011916

00:10:35.215 --> 00:10:38.429 mastery in a particular skill set.

NOTE Confidence: 0.86011916

00:10:38.430 --> 00:10:39.734 In Native American cultures

NOTE Confidence: 0.86011916

00:10:39.734 --> 00:10:41.364 here in the United States,

NOTE Confidence: 0.86011916

00:10:41.370 --> 00:10:43.675 resilience President has been equated

NOTE Confidence: 0.86011916

00:10:43.675 --> 00:10:45.980 with spirituality and a constant

NOTE Confidence: 0.86011916

00:10:46.052 --> 00:10:48.027 quest for meaning and purpose.

NOTE Confidence: 0.86011916

00:10:48.030 --> 00:10:50.040 And what is fascinating is that

NOTE Confidence: 0.86011916

00:10:50.040 --> 00:10:52.392 in almost no language in the world

NOTE Confidence: 0.86011916

00:10:52.392 --> 00:10:53.972 is there a direct translation

NOTE Confidence: 0.86011916

00:10:53.972 --> 00:10:55.680 for the word resilience.

NOTE Confidence: 0.86011916

00:10:55.680 --> 00:10:58.025 In the places where this does exist,

NOTE Confidence: 0.86011916

00:10:58.030 --> 00:11:00.270 it is either translated back from English

NOTE Confidence: 0.86011916

00:11:00.270 --> 00:11:02.398 into whatever is the native language,

NOTE Confidence: 0.86011916

00:11:02.400 --> 00:11:04.745 based on an Americanization of their culture,

NOTE Confidence: 0.86011916

00:11:04.750 --> 00:11:07.534 or it is purely described as that physical

NOTE Confidence: 0.86011916

00:11:07.534 --> 00:11:09.457 science construct that I started with.

NOTE Confidence: 0.83782303

00:11:11.980 --> 00:11:13.884 So with this sort of swirling set

NOTE Confidence: 0.83782303

00:11:13.884 --> 00:11:15.699 up debates and this challenge that

NOTE Confidence: 0.83782303

00:11:15.699 --> 00:11:17.583 we were having as a community,

NOTE Confidence: 0.83782303

00:11:17.590 --> 00:11:19.240 figuring out what resilience was in

NOTE Confidence: 0.83782303

00:11:19.240 --> 00:11:20.710 2013 at the International Society

NOTE Confidence: 0.83782303

00:11:20.710 --> 00:11:22.006 of Traumatic Stress Studies,

NOTE Confidence: 0.83782303

00:11:22.010 --> 00:11:23.823 there was a plenary panel where they

NOTE Confidence: 0.83782303

00:11:23.823 --> 00:11:25.672 got a whole bunch of resilience

NOTE Confidence: 0.83782303

00:11:25.672 --> 00:11:27.028 researchers up on stage,

NOTE Confidence: 0.83782303

00:11:27.030 --> 00:11:27.912 including George Bonanno,

NOTE Confidence: 0.83782303

00:11:27.912 --> 00:11:29.676 whose graph I just showed you.

NOTE Confidence: 0.83782303

00:11:29.680 --> 00:11:31.535 And this is a picture of a

NOTE Confidence: 0.83782303

00:11:31.535 --> 00:11:32.330 cultural anthropologist named

NOTE Confidence: 0.83782303

00:11:32.386 --> 00:11:33.810 Doctor Catherine Pantry brick.

NOTE Confidence: 0.83782303

00:11:33.810 --> 00:11:35.285 She's speaking here at a

NOTE Confidence: 0.83782303

00:11:35.285 --> 00:11:35.875 different organization,

NOTE Confidence: 0.83782303

00:11:35.880 --> 00:11:37.904 but she was one of the speakers at

00:11:37.904 --> 00:11:40.140 this plenary and what she does is

00:11:40.140 --> 00:11:41.480 what's called ethnographic studies,

00:11:41.480 --> 00:11:43.976 and she goes around the world and she.

00:11:43.980 --> 00:11:45.620 Lives in places that are

00:11:45.620 --> 00:11:46.604 going through adversity,

00:11:46.610 --> 00:11:47.882 and she bears witness,

00:11:47.882 --> 00:11:50.143 so that might be going to a

00:11:50.143 --> 00:11:51.533 place that has just undergone

00:11:51.533 --> 00:11:53.849 a war or a natural disaster,

00:11:53.850 --> 00:11:55.908 or folks who are living in poverty

00:11:55.908 --> 00:11:58.150 and what she's noticed in all of

00:11:58.150 --> 00:12:00.094 her work is that consistently across

00:12:00.158 --> 00:12:02.078 every adversity she has studied.

00:12:02.080 --> 00:12:03.770 Resilience is a process of

00:12:03.770 --> 00:12:05.460 harnessing the resources we need

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.

NOTE Confidence: 0.85031116

00:12:38.940 --> 00:12:41.238 Resources are things like meaning making,

NOTE Confidence: 0.85031116

00:12:41.240 --> 00:12:41.840 faith, spirituality.

NOTE Confidence: 0.85031116

00:12:41.840 --> 00:12:43.640 These sorts of inherent human questions

NOTE Confidence: 0.85031116

00:12:43.640 --> 00:12:45.386 that we ask when times get tough.

NOTE Confidence: 0.85031116

00:12:45.390 --> 00:12:47.286 Which is why is this happening to me,

NOTE Confidence: 0.85031116

00:12:47.290 --> 00:12:49.178 and what does this mean for my family?

NOTE Confidence: 0.893015439999999

00:12:52.750 --> 00:12:55.090 I will say that when I was starting to try

NOTE Confidence: 0.893015439999999

00:12:55.145 --> 00:12:57.449 to figure all of this out and think about

NOTE Confidence: 0.893015439999999

00:12:57.449 --> 00:12:59.877 what it meant for our patients with cancer,

NOTE Confidence: 0.893015439999999

00:12:59.880 --> 00:13:02.032 I really struggled with how to translate all

NOTE Confidence: 0.893015439999999

00:13:02.032 --> 00:13:03.827 of these different and conflicting theories

NOTE Confidence: 0.893015439999999

00:13:03.827 --> 00:13:06.290 into what we could do at the bedside.

NOTE Confidence: 0.893015439999999

00:13:06.290 --> 00:13:09.512 And at the same time there was a similar,

NOTE Confidence: 0.893015439999999

00:13:09.520 --> 00:13:12.460 if not parallel debate happening in the

NOTE Confidence: 0.893015439999999

00:13:12.460 --> 00:13:14.846 psychology and social Sciences about how

NOTE Confidence: 0.893015439999999

00:13:14.846 --> 00:13:17.790 we experience what we see in the world.

NOTE Confidence: 0.893015439999999

00:13:17.790 --> 00:13:19.566 And specifically, this is a theory

NOTE Confidence: 0.893015439999999

00:13:19.566 --> 00:13:21.160 called stress and coping theory,

NOTE Confidence: 0.893015439999999

00:13:21.160 --> 00:13:22.685 which essentially says that our

NOTE Confidence: 0.893015439999999

00:13:22.685 --> 00:13:23.905 perceptions influence our outcomes.

NOTE Confidence: 0.893015439999999

00:13:23.910 --> 00:13:26.358 So if we go through a stressful event,

NOTE Confidence: 0.893015439999999

00:13:26.360 --> 00:13:29.420 the first thing we do is we think about it.

NOTE Confidence: 0.893015439999999

00:13:29.420 --> 00:13:30.950 We appraise it, we say,

NOTE Confidence: 0.893015439999999

00:13:30.950 --> 00:13:34.010 is this a good or a bad thing for me?

NOTE Confidence: 0.893015439999999

00:13:34.010 --> 00:13:36.145 Is this catastrophic or is this manageable?

NOTE Confidence: 0.893015439999999

00:13:36.150 --> 00:13:38.264 And the answer to that appraisal question

NOTE Confidence: 0.893015439999999

00:13:38.264 --> 00:13:40.430 the veillance we apply to that response,

NOTE Confidence: 0.893015439999999

00:13:40.430 --> 00:13:41.960 translates to how we cope,

NOTE Confidence: 0.893015439999999

00:13:41.960 --> 00:13:44.788 how we feel and how we function.

NOTE Confidence: 0.893015439999999

00:13:44.790 --> 00:13:46.578 And the idea behind this theoretical

NOTE Confidence: 0.893015439999999

00:13:46.578 --> 00:13:48.795 construct is that if you can change

NOTE Confidence: 0.893015439999999

00:13:48.795 --> 00:13:50.415 the balance of that appraisal

NOTE Confidence: 0.893015439999999

00:13:50.415 --> 00:13:51.850 from catastrophic to manageable,

NOTE Confidence: 0.893015439999999

00:13:51.850 --> 00:13:54.097 for example, you can change your coping,

NOTE Confidence: 0.893015439999999

00:13:54.100 --> 00:13:55.384 emotional and functional outcomes

NOTE Confidence: 0.893015439999999

00:13:55.384 --> 00:13:56.668 to be more positive.

NOTE Confidence: 0.86361223

00:13:59.060 --> 00:14:01.580 So we first tested this idea of do

NOTE Confidence: 0.86361223

00:14:01.580 --> 00:14:03.227 people's perceptions of their own

NOTE Confidence: 0.86361223

00:14:03.227 --> 00:14:04.827 resilience translate to outcomes in

NOTE Confidence: 0.86361223

00:14:04.827 --> 00:14:06.972 a cross sectional study of bereaved

NOTE Confidence: 0.86361223

00:14:06.972 --> 00:14:09.132 and non grooved parents of children

NOTE Confidence: 0.86361223

00:14:09.140 --> 00:14:11.240 with cancer we had about 120 parents

NOTE Confidence: 0.86361223

00:14:11.240 --> 00:14:13.328 in this study and the first thing

NOTE Confidence: 0.86361223

00:14:13.328 --> 00:14:15.908 we noticed is that when you use a

NOTE Confidence: 0.86361223

00:14:15.908 --> 00:14:17.564 validated instrument to measure

NOTE Confidence: 0.86361223

00:14:17.564 --> 00:14:19.220 self perceptions of resilience,

NOTE Confidence: 0.86361223

00:14:19.220 --> 00:14:21.523 parents of kids with cancer feel less

NOTE Confidence: 0.86361223

00:14:21.523 --> 00:14:23.917 resilient than the rest of the population.

NOTE Confidence: 0.86361223

00:14:23.920 --> 00:14:26.005 There's something about having watched

NOTE Confidence: 0.86361223

00:14:26.005 --> 00:14:28.895 your kid go through cancer that makes

NOTE Confidence: 0.86361223

00:14:28.895 --> 00:14:31.109 you believe you are less resilient.

NOTE Confidence: 0.86361223

00:14:31.110 --> 00:14:33.180 And perhaps not more poignantly,

NOTE Confidence: 0.86361223

00:14:33.180 --> 00:14:34.568 parents who reported lower

NOTE Confidence: 0.86361223

00:14:34.568 --> 00:14:36.650 resilience were the ones who had

NOTE Confidence: 0.86361223

00:14:36.714 --> 00:14:38.538 ongoing psychological distress,

NOTE Confidence: 0.86361223

00:14:38.540 --> 00:14:39.366 sleep difficulties,

NOTE Confidence: 0.86361223

00:14:39.366 --> 00:14:42.257 an in abilities to express their hopes,

NOTE Confidence: 0.86361223

00:14:42.260 --> 00:14:44.738 and worries to their medical team.

NOTE Confidence: 0.86471814

00:14:47.410 --> 00:14:49.144 Around the same time in the

NOTE Confidence: 0.86471814

00:14:49.144 --> 00:14:50.675 gerontologist there was an analysis

NOTE Confidence: 0.86471814

00:14:50.675 --> 00:14:52.880 of the US Health and Retirement Study.

NOTE Confidence: 0.86471814

00:14:52.880 --> 00:14:54.400 Most of you know this.

NOTE Confidence: 0.86471814

00:14:54.400 --> 00:14:56.528 This is a long, ongoing cohort of

NOTE Confidence: 0.86471814

00:14:56.528 --> 00:14:58.380 American adults, ages 50 to 98.

NOTE Confidence: 0.86471814

00:14:58.380 --> 00:15:00.240 In this particular analysis and what

NOTE Confidence: 0.86471814

00:15:00.302 --> 00:15:02.534 they did here was they asked folks to

NOTE Confidence: 0.86471814

00:15:02.534 --> 00:15:04.739 fill out a survey about their self,

NOTE Confidence: 0.86471814

00:15:04.740 --> 00:15:05.534 perceived resilience,

NOTE Confidence: 0.86471814

00:15:05.534 --> 00:15:07.916 and then they monitor them overtime.

NOTE Confidence: 0.86471814

00:15:07.920 --> 00:15:09.928 And let's say you had two gentlemen who

NOTE Confidence: 0.86471814

00:15:09.928 --> 00:15:11.636 were matched in every way except one,

NOTE Confidence: 0.86471814

00:15:11.640 --> 00:15:12.875 believed he was resilient and

NOTE Confidence: 0.86471814

00:15:12.875 --> 00:15:13.616 the other doesn't,

NOTE Confidence: 0.86471814

00:15:13.620 --> 00:15:16.052 and they both go through their lives and

NOTE Confidence: 0.86471814

00:15:16.052 --> 00:15:18.620 they both fall down and break their hips.

NOTE Confidence: 0.86471814

00:15:18.620 --> 00:15:20.587 The gentleman who believed he was less

NOTE Confidence: 0.86471814

00:15:20.587 --> 00:15:22.269 more resilient for whatever reason,

NOTE Confidence: 0.86471814

00:15:22.270 --> 00:15:24.574 is going to get back up and return

NOTE Confidence: 0.86471814

00:15:24.574 --> 00:15:27.118 to his activities of daily living.

NOTE Confidence: 0.86471814

00:15:27.120 --> 00:15:28.635 The gentleman who believed he

NOTE Confidence: 0.86471814

00:15:28.635 --> 00:15:29.847 was less resilient again,

NOTE Confidence: 0.86471814

00:15:29.850 --> 00:15:30.660 for whatever reason,

NOTE Confidence: 0.86471814

00:15:30.660 --> 00:15:32.926 is not only going to not go to

NOTE Confidence: 0.86471814

00:15:32.926 --> 00:15:34.786 physical therapy and not return to

NOTE Confidence: 0.86471814

00:15:34.786 --> 00:15:36.510 his activities of daily living,

NOTE Confidence: 0.86471814

00:15:36.510 --> 00:15:38.328 but he's going to die sooner.

NOTE Confidence: 0.86471814

00:15:38.330 --> 00:15:40.148 His life expectancy is actually shorter.

NOTE Confidence: 0.8527747

00:15:43.150 --> 00:15:45.719 My research partner is a health psychologist

NOTE Confidence: 0.8527747

00:15:45.719 --> 00:15:47.619 and behavioral scientist named Joyce E.

NOTE Confidence: 0.8527747

00:15:47.620 --> 00:15:50.364 Frazier. This is some of her earlier work.

NOTE Confidence: 0.8527747

00:15:50.370 --> 00:15:52.440 She works with patients with diabetes,

NOTE Confidence: 0.8527747

00:15:52.440 --> 00:15:55.167 and here on the X axis is changes in

NOTE Confidence: 0.8527747

00:15:55.167 --> 00:15:57.428 diabetes related distress on the Y

NOTE Confidence: 0.8527747

00:15:57.428 --> 00:15:59.781 axis is changes in hemoglobin, A1C,

NOTE Confidence: 0.8527747

00:15:59.781 --> 00:16:02.547 or a marker of glycemic control.

NOTE Confidence: 0.8527747

00:16:02.550 --> 00:16:04.398 And here on those two dotted

NOTE Confidence: 0.8527747

00:16:04.398 --> 00:16:06.469 lines that are sort of diagonal,

NOTE Confidence: 0.8527747

00:16:06.470 --> 00:16:08.348 these are folks who believe again

NOTE Confidence: 0.8527747

00:16:08.348 --> 00:16:10.341 for whatever reason that they are

NOTE Confidence: 0.8527747

00:16:10.341 --> 00:16:11.709 less or moderately resilient,

NOTE Confidence: 0.8527747

00:16:11.710 --> 00:16:13.859 and for them changes in A1C level

NOTE Confidence: 0.8527747

00:16:13.859 --> 00:16:15.958 translate directly to changes in distress,

NOTE Confidence: 0.8527747

00:16:15.960 --> 00:16:17.844 meaning that the more swings there

NOTE Confidence: 0.8527747

00:16:17.844 --> 00:16:19.550 are in their distress levels,

NOTE Confidence: 0.8527747

00:16:19.550 --> 00:16:21.839 the harder it is for them to

NOTE Confidence: 0.8527747

00:16:21.839 --> 00:16:22.820 control their diabetes.

NOTE Confidence: 0.8527747

00:16:22.820 --> 00:16:23.450 In contrast,

NOTE Confidence: 0.8527747

00:16:23.450 --> 00:16:25.340 that more flat solid black line

NOTE Confidence: 0.8527747

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

NOTE Confidence: 0.864682

00:16:57.136 --> 00:16:58.869 during their survivorship period.

NOTE Confidence: 0.88003993

00:17:02.160 --> 00:17:03.888 So all of this sounded really

NOTE Confidence: 0.88003993

00:17:03.888 --> 00:17:05.912 interesting to me, and it felt like

NOTE Confidence: 0.88003993

00:17:05.912 --> 00:17:07.937 there was something there, but I still

NOTE Confidence: 0.88003993

00:17:07.937 --> 00:17:09.960 didn't know how to take these ideas,

NOTE Confidence: 0.88003993

00:17:09.960 --> 00:17:11.405 and these theories and identify

NOTE Confidence: 0.88003993

00:17:11.405 --> 00:17:12.561 him and operationalize resilience

NOTE Confidence: 0.88003993

00:17:12.561 --> 00:17:14.010 in the patients and families.

NOTE Confidence: 0.88003993

00:17:14.010 --> 00:17:15.062 I was working with.

NOTE Confidence: 0.88003993

00:17:15.062 --> 00:17:17.220 And so the next thing we did was

NOTE Confidence: 0.88003993

00:17:17.220 --> 00:17:19.019 what in the rest of the world

NOTE Confidence: 0.88003993

00:17:19.019 --> 00:17:20.898 would be called market research.

NOTE Confidence: 0.88003993

00:17:20.900 --> 00:17:22.980 It's sort of when you go directly to

NOTE Confidence: 0.88003993

00:17:22.980 --> 00:17:24.338 your stakeholder and you say hey,

NOTE Confidence: 0.88003993

00:17:24.340 --> 00:17:25.324 what should we do?

NOTE Confidence: 0.88003993

00:17:25.324 --> 00:17:26.800 What would you like to do?

NOTE Confidence: 0.88003993

00:17:26.800 --> 00:17:27.792 What would you use?

NOTE Confidence: 0.88003993

00:17:27.792 --> 00:17:29.510 What materials would be helpful to you?

NOTE Confidence: 0.88003993

00:17:29.510 --> 00:17:30.986 And in the Health Sciences we

NOTE Confidence: 0.88003993

00:17:30.986 --> 00:17:31.970 call this qualitative work.

NOTE Confidence: 0.88003993

00:17:31.970 --> 00:17:32.444 So similarly,

NOTE Confidence: 0.88003993

00:17:32.444 --> 00:17:33.866 we went directly to our stakeholders

NOTE Confidence: 0.88003993

00:17:33.866 --> 00:17:35.714 and we said we need to understand this

NOTE Confidence: 0.88003993

00:17:35.714 --> 00:17:37.140 concept from your own perspective.

NOTE Confidence: 0.88003993

00:17:37.140 --> 00:17:40.266 What would be helpful to you?

NOTE Confidence: 0.88003993

00:17:40.270 --> 00:17:41.446 We started with parents.

NOTE Confidence: 0.88003993

00:17:41.446 --> 00:17:43.520 We went back to that cohort of

NOTE Confidence: 0.88003993

00:17:43.520 --> 00:17:45.263 120 parents that we had and we

NOTE Confidence: 0.88003993

00:17:45.263 --> 00:17:47.223 started to listen to their stories

NOTE Confidence: 0.88003993

00:17:47.223 --> 00:17:48.978 while we surveyed them using

NOTE Confidence: 0.88003993

00:17:48.978 --> 00:17:50.654 validated instruments of their self,

NOTE Confidence: 0.88003993

00:17:50.654 --> 00:17:52.309 perceived resilience and what they

NOTE Confidence: 0.88003993

00:17:52.309 --> 00:17:54.160 shared with us is that resilience is,

NOTE Confidence: 0.88003993

00:17:54.160 --> 00:17:55.670 for example, who I was,

NOTE Confidence: 0.88003993

00:17:55.670 --> 00:17:57.784 what I learned, how I ended up,

NOTE Confidence: 0.88003993

00:17:57.790 --> 00:18:00.000 and what it all meant.

NOTE Confidence: 0.88003993

00:18:00.000 --> 00:18:01.617 This was apparent who sat next to

NOTE Confidence: 0.88003993

00:18:01.617 --> 00:18:03.095 me looking at that banana graph

NOTE Confidence: 0.88003993

00:18:03.095 --> 00:18:04.075 and saying no no.

NOTE Confidence: 0.88003993

00:18:04.080 --> 00:18:04.824 It's the left,

NOTE Confidence: 0.88003993

00:18:04.824 --> 00:18:06.960 middle and right and the whole thing for me.

NOTE Confidence: 0.8553326

00:18:09.060 --> 00:18:10.794 Or resilience is facilitated by who

NOTE Confidence: 0.8553326

00:18:10.794 --> 00:18:13.248 I am who helps me and what I believe

NOTE Confidence: 0.8553326

00:18:13.248 --> 00:18:14.949 this was a parent who identified

NOTE Confidence: 0.8553326

00:18:14.949 --> 00:18:16.541 those resilience resource categories

NOTE Confidence: 0.8553326

00:18:16.541 --> 00:18:19.170 and said all three of them matter.

NOTE Confidence: 0.8631404

00:18:21.450 --> 00:18:22.678 What was particularly interesting

NOTE Confidence: 0.8631404

00:18:22.678 --> 00:18:23.906 about this analysis is,

NOTE Confidence: 0.8631404

00:18:23.910 --> 00:18:26.059 as I said, we have these surveys,

NOTE Confidence: 0.8631404

00:18:26.060 --> 00:18:27.288 and we interviewed people

NOTE Confidence: 0.8631404

00:18:27.288 --> 00:18:29.130 at the end of the surveys,

NOTE Confidence: 0.8631404

00:18:29.130 --> 00:18:31.226 we asked folks to fill out a final

NOTE Confidence: 0.8631404

00:18:31.226 --> 00:18:32.809 page that essentially said tell

NOTE Confidence: 0.8631404

00:18:32.809 --> 00:18:35.140 us whatever else you think we need

NOTE Confidence: 0.8631404

00:18:35.204 --> 00:18:37.106 to know and parents wrote pages,

NOTE Confidence: 0.8631404

00:18:37.110 --> 00:18:39.090 pages and pages and pages of

NOTE Confidence: 0.8631404

00:18:39.090 --> 00:18:41.240 stories that they felt like were

NOTE Confidence: 0.8631404

00:18:41.240 --> 00:18:43.135 important for us to understand.

NOTE Confidence: 0.8631404

00:18:43.140 --> 00:18:46.236 And when we got these things in the Mail,

NOTE Confidence: 0.8631404

00:18:46.240 --> 00:18:49.333 we read them and I said to myself, huh?

NOTE Confidence: 0.8631404

00:18:49.333 --> 00:18:50.019 Here's resilience.

NOTE Confidence: 0.8631404

00:18:50.019 --> 00:18:51.734 There's resilience in these stories.

NOTE Confidence: 0.8631404

00:18:51.740 --> 00:18:54.048 And so a social worker, health services,

NOTE Confidence: 0.8631404

00:18:54.048 --> 00:18:56.400 researcher and I all of us read 120

NOTE Confidence: 0.8631404

00:18:56.465 --> 00:18:58.955 different transcripts blinded to each other,

NOTE Confidence: 0.8631404

00:18:58.960 --> 00:19:01.024 and we graded all 120 as

NOTE Confidence: 0.8631404

00:19:01.024 --> 00:19:02.400 either resilient or not.

NOTE Confidence: 0.8631404

00:19:02.400 --> 00:19:04.475 Did this person seem resilient

NOTE Confidence: 0.8631404

00:19:04.475 --> 00:19:06.550 to us in their words?

NOTE Confidence: 0.8631404

00:19:06.550 --> 00:19:08.225 And what was really interesting

NOTE Confidence: 0.8631404

00:19:08.225 --> 00:19:10.670 to us is that we agreed we,

NOTE Confidence: 0.8631404

00:19:10.670 --> 00:19:12.728 three blinded reviewers, agreed in a

NOTE Confidence: 0.8631404

00:19:12.728 --> 00:19:14.100 person's categorization of resilience.

NOTE Confidence: 0.8631404

00:19:14.100 --> 00:19:15.805 Our labeling of their resilience

NOTE Confidence: 0.8631404

00:19:15.805 --> 00:19:17.179 100% of the time.

NOTE Confidence: 0.8631404

00:19:17.179 --> 00:19:18.894 120 out of 120 times.

NOTE Confidence: 0.8631404

00:19:18.900 --> 00:19:20.590 We agree.

NOTE Confidence: 0.8631404

00:19:20.590 --> 00:19:22.638 And then when we looked at how our

NOTE Confidence: 0.8631404

00:19:22.638 --> 00:19:24.507 impressions of their resilience aligned

NOTE Confidence: 0.8631404

00:19:24.507 --> 00:19:26.667 with validated patient reported outcomes,

NOTE Confidence: 0.8631404

00:19:26.670 --> 00:19:27.624 we were wrong.

NOTE Confidence: 0.8631404

00:19:27.624 --> 00:19:29.850 Half the time we were as good

NOTE Confidence: 0.8631404

00:19:29.931 --> 00:19:32.637 as a coin toss in predicting

NOTE Confidence: 0.8631404

00:19:32.637 --> 00:19:33.990 somebody else's resilience.

NOTE Confidence: 0.8631404

00:19:33.990 --> 00:19:35.730 When we looked more carefully,

NOTE Confidence: 0.8631404

00:19:35.730 --> 00:19:38.159 we were a little bit better at

NOTE Confidence: 0.8631404

00:19:38.159 --> 00:19:39.200 recognizing someones distress.

NOTE Confidence: 0.8631404

00:19:39.200 --> 00:19:41.070 Our impressions of their lack

NOTE Confidence: 0.8631404

00:19:41.070 --> 00:19:42.940 of resilience aligned with their

NOTE Confidence: 0.8631404

00:19:43.009 --> 00:19:44.699 measurement of their own distress

NOTE Confidence: 0.8631404

00:19:44.699 --> 00:19:47.178 and what that tells me is 2 things.

NOTE Confidence: 0.8631404

00:19:47.180 --> 00:19:49.539 Number one we in medicine tend to

NOTE Confidence: 0.8631404

00:19:49.539 --> 00:19:51.667 assume someone is not resilient when

NOTE Confidence: 0.8631404

00:19:51.667 --> 00:19:54.117 they're having a hard time and #2.

NOTE Confidence: 0.8631404

00:19:54.120 --> 00:19:56.010 We in medicine probably shouldn't

NOTE Confidence: 0.8631404

00:19:56.010 --> 00:19:57.522 assume someone is resilient

NOTE Confidence: 0.8631404

00:19:57.522 --> 00:19:59.316 or not unless we ask them.

NOTE Confidence: 0.857691

00:20:02.450 --> 00:20:04.066 The next thing we did was we did

NOTE Confidence: 0.857691

00:20:04.066 --> 00:20:05.563 this same stakeholder engaged work

NOTE Confidence: 0.857691

00:20:05.563 --> 00:20:07.303 with adolescent and young adults,

NOTE Confidence: 0.857691

00:20:07.310 --> 00:20:08.370 or ay ay patients,

NOTE Confidence: 0.857691

00:20:08.370 --> 00:20:10.291 and here I want to introduce you

NOTE Confidence: 0.857691

00:20:10.291 --> 00:20:12.167 to a young man named Daniel Maher.

NOTE Confidence: 0.857691

00:20:12.170 --> 00:20:14.330 He was one of our first key stakeholders,

NOTE Confidence: 0.857691

00:20:14.330 --> 00:20:15.635 which means that every time

NOTE Confidence: 0.857691

00:20:15.635 --> 00:20:17.273 I did an interview or every

NOTE Confidence: 0.857691

00:20:17.273 --> 00:20:18.917 time I was developing an idea,

NOTE Confidence: 0.857691

00:20:18.920 --> 00:20:21.305 he was one of the people I would sit

NOTE Confidence: 0.857691

00:20:21.305 --> 00:20:23.778 down and talk to you about it and say,

NOTE Confidence: 0.857691

00:20:23.780 --> 00:20:25.400 hey, am I getting this right?

NOTE Confidence: 0.857691

00:20:25.400 --> 00:20:27.020 Does this align with your experience?

NOTE Confidence: 0.857691

00:20:27.020 --> 00:20:28.640 Daniel had met a static and

NOTE Confidence: 0.857691

00:20:28.640 --> 00:20:29.720 ultimately progressive Ewing sarcoma,

NOTE Confidence: 0.857691

00:20:29.720 --> 00:20:31.484 and he died from his cancer several

NOTE Confidence: 0.857691

00:20:31.484 --> 00:20:33.550 years after we started working together.

NOTE Confidence: 0.857691

00:20:33.550 --> 00:20:35.845 And towards the end of his life I started

NOTE Confidence: 0.857691

00:20:35.845 --> 00:20:37.590 asking him about his own resilience

NOTE Confidence: 0.857691

00:20:37.590 --> 00:20:39.556 and how I should continue to tell

NOTE Confidence: 0.857691

00:20:39.556 --> 00:20:41.468 his story or how it translated to the

NOTE Confidence: 0.857691

00:20:41.470 --> 00:20:43.048 resilience of other folks with cancer.

NOTE Confidence: 0.857691

00:20:43.050 --> 00:20:44.526 And he said Abby cancer happened

NOTE Confidence: 0.857691

00:20:44.526 --> 00:20:45.960 to me for a reason.

NOTE Confidence: 0.857691

00:20:45.960 --> 00:20:48.564 It's to help others like me understand

NOTE Confidence: 0.857691

00:20:48.564 --> 00:20:51.769 and to make it easier for them somehow.

NOTE Confidence: 0.857691

00:20:51.770 --> 00:20:53.230 And so, with Daniel's help,

NOTE Confidence: 0.857691

00:20:53.230 --> 00:20:54.705 we interviewed multiple teens and

NOTE Confidence: 0.857691

00:20:54.705 --> 00:20:56.180 young adults with cancer from

NOTE Confidence: 0.857691

00:20:56.230 --> 00:20:57.590 the time they were diagnosed.

NOTE Confidence: 0.857691

00:20:57.590 --> 00:20:58.463 Three months later,

NOTE Confidence: 0.857691

00:20:58.463 --> 00:20:59.627 six months after that,

NOTE Confidence: 0.857691

00:20:59.630 --> 00:21:01.660 a year after that and so forth,

NOTE Confidence: 0.857691

00:21:01.660 --> 00:21:03.120 to the point that now,

NOTE Confidence: 0.857691

00:21:03.120 --> 00:21:03.786 of course,

NOTE Confidence: 0.857691

00:21:03.786 --> 00:21:04.452 without Daniel,

NOTE Confidence: 0.857691

00:21:04.452 --> 00:21:06.117 we are continuing to interview

NOTE Confidence: 0.857691

00:21:06.117 --> 00:21:08.116 some of these adolescent and young

NOTE Confidence: 0.857691

00:21:08.116 --> 00:21:09.726 adult patients 10 years later.

NOTE Confidence: 0.857691

00:21:09.730 --> 00:21:11.404 And what we hear from them

NOTE Confidence: 0.857691

00:21:11.404 --> 00:21:12.520 are things like this.

NOTE Confidence: 0.857691

00:21:12.520 --> 00:21:13.632 Resilience depends on the

NOTE Confidence: 0.857691

00:21:13.632 --> 00:21:14.744 person and their experiences.

NOTE Confidence: 0.857691

00:21:14.750 --> 00:21:16.150 It's kind of like exercising.

NOTE Confidence: 0.857691

00:21:16.150 --> 00:21:17.770 You have to gain some muscle

NOTE Confidence: 0.857691

00:21:17.770 --> 00:21:19.220 before you run a race,

NOTE Confidence: 0.857691

00:21:19.220 --> 00:21:20.428 personal strength or resilience

NOTE Confidence: 0.857691

00:21:20.428 --> 00:21:22.240 is how you rebound from something

NOTE Confidence: 0.857691

00:21:22.286 --> 00:21:23.678 like being able to fight back.

NOTE Confidence: 0.857691

00:21:23.680 --> 00:21:24.792 It can be taught.

NOTE Confidence: 0.857691

00:21:24.792 --> 00:21:25.904 It should be taught.

NOTE Confidence: 0.8839102

00:21:28.980 --> 00:21:30.947 What's interesting to me about this analysis,

NOTE Confidence: 0.8839102

00:21:30.950 --> 00:21:32.395 which now includes hundreds and

NOTE Confidence: 0.8839102

00:21:32.395 --> 00:21:33.840 hundreds of hours of interviews

NOTE Confidence: 0.8839102

00:21:33.893 --> 00:21:35.178 with teens and young adults,

NOTE Confidence: 0.8839102

00:21:35.180 --> 00:21:36.590 is that at the beginning,

NOTE Confidence: 0.8839102

00:21:36.590 --> 00:21:38.108 many of these young patients don't

43

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 --> 00:21:52.390 particular resilience resource,

NOTE Confidence: 0.8839102

00:21:52.390 --> 00:21:53.800 and they carry it forward.

NOTE Confidence: 0.8839102

00:21:53.800 --> 00:21:55.767 So even five or ten years later,

NOTE Confidence: 0.8839102

00:21:55.770 --> 00:21:57.180 they'll say, I don't know.

NOTE Confidence: 0.8839102

00:21:57.180 --> 00:21:59.718 This is what I do when times get tough.

NOTE Confidence: 0.8839102

00:21:59.720 --> 00:22:01.130 It's always what I've done.

NOTE Confidence: 0.8839102

00:22:01.130 --> 00:22:02.816 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

00:22:39.298 --> 00:22:41.533 of connection and social normalcy.

NOTE Confidence: 0.83683133

00:22:41.540 --> 00:22:43.310 And when we thought about these

NOTE Confidence: 0.83683133

00:22:43.310 --> 00:22:44.490 ideas in these constructs,

NOTE Confidence: 0.83683133

00:22:44.490 --> 00:22:46.150 we noticed two things.

NOTE Confidence: 0.83683133

00:22:46.150 --> 00:22:46.980 Number one,

NOTE Confidence: 0.83683133

00:22:46.980 --> 00:22:49.444 these top for stress management goal setting.

NOTE Confidence: 0.83683133

00:22:49.450 --> 00:22:51.210 Staying positive and meaning making.

NOTE Confidence: 0.83683133

00:22:51.210 --> 00:22:53.492 These are all things that we can

NOTE Confidence: 0.83683133

00:22:53.492 --> 00:22:55.080 teach individually to patients.

NOTE Confidence: 0.83683133

00:22:55.080 --> 00:22:57.460 Whereas a social support type of program

NOTE Confidence: 0.83683133

00:22:57.460 --> 00:22:59.762 felt different and #2 all of these

NOTE Confidence: 0.83683133

00:22:59.762 --> 00:23:01.592 things map back onto those resilience

NOTE Confidence: 0.83683133

00:23:01.658 --> 00:23:03.250 resource categories that Catherine

NOTE Confidence: 0.83683133

00:23:03.250 --> 00:23:05.638 Patrick had described so long ago.

NOTE Confidence: 0.830387

00:23:07.880 --> 00:23:09.440 Which leads us to that,

NOTE Confidence: 0.830387

00:23:09.440 --> 00:23:11.168 promoting resilience and stress

NOTE Confidence: 0.830387

00:23:11.168 --> 00:23:12.896 management or PRISM program.

NOTE Confidence: 0.830387

00:23:12.900 --> 00:23:14.825 And the first thing we debated when

NOTE Confidence: 0.830387

00:23:14.825 --> 00:23:16.613 we were thinking about what to do

NOTE Confidence: 0.830387

00:23:16.613 --> 00:23:18.510 next was where to start on the left.

NOTE Confidence: 0.830387

00:23:18.510 --> 00:23:20.204 Here you're looking at one of our

NOTE Confidence: 0.830387

00:23:20.204 --> 00:23:22.260 parent quiet rooms on the edges of our

NOTE Confidence: 0.830387

00:23:22.260 --> 00:23:23.870 adolescent and young adult oncology floor.

NOTE Confidence: 0.830387

00:23:23.870 --> 00:23:25.454 We have these separate spaces for

NOTE Confidence: 0.830387

00:23:25.454 --> 00:23:27.522 parents to get away and have some time

NOTE Confidence: 0.830387

00:23:27.522 --> 00:23:29.262 by themselves if they need to leave

NOTE Confidence: 0.830387

00:23:29.262 --> 00:23:31.005 the patient room and on the right,

NOTE Confidence: 0.830387

00:23:31.010 --> 00:23:33.230 you're looking at one of our

NOTE Confidence: 0.830387

00:23:33.230 --> 00:23:34.340 other key stakeholders.

NOTE Confidence: 0.830387

00:23:34.340 --> 00:23:36.426 So when we were thinking about this,

NOTE Confidence: 0.830387

00:23:36.430 --> 00:23:37.840 we first thought about parents

NOTE Confidence: 0.830387

00:23:37.840 --> 00:23:39.720 and we thought you know parents,

NOTE Confidence: 0.830387

00:23:39.720 --> 00:23:41.514 particularly kids of parents of cancer

47

NOTE Confidence: 0.830387

00:23:41.514 --> 00:23:42.710 have poor psychosocial outcomes.

NOTE Confidence: 0.830387

00:23:42.710 --> 00:23:44.345 So specifically one in seven

NOTE Confidence: 0.830387

00:23:44.345 --> 00:23:45.980 appearance of children with cancer

NOTE Confidence: 0.830387

00:23:46.033 --> 00:23:47.713 will have such high distress that

NOTE Confidence: 0.830387

00:23:47.713 --> 00:23:49.440 they can't take care of themselves

NOTE Confidence: 0.830387

00:23:49.440 --> 00:23:51.372 or the other children in the home.

NOTE Confidence: 0.830387

00:23:51.380 --> 00:23:53.174 And if you're a caregiver of

NOTE Confidence: 0.830387

00:23:53.174 --> 00:23:54.370 a patient with cancer,

NOTE Confidence: 0.830387

00:23:54.370 --> 00:23:55.870 it's really hard to access

NOTE Confidence: 0.830387

00:23:55.870 --> 00:23:56.770 traditional mental health.

NOTE Confidence: 0.830387

00:23:56.770 --> 00:23:57.966 Supportive care parents don't

NOTE Confidence: 0.830387

00:23:57.966 --> 00:23:59.760 want to leave their kids bedside,

NOTE Confidence: 0.830387

00:23:59.760 --> 00:24:01.250 as all of us know,

NOTE Confidence: 0.830387

00:24:01.250 --> 00:24:02.765 it's incredibly difficult to network

NOTE Confidence: 0.830387

00:24:02.765 --> 00:24:04.790 mental health services in the community.

NOTE Confidence: 0.830387

00:24:04.790 --> 00:24:05.585 And we thought,

NOTE Confidence: 0.830387

00:24:05.585 --> 00:24:07.440 wouldn't it be great if we could

NOTE Confidence: 0.830387

00:24:07.497 --> 00:24:09.402 just provide something to parents

NOTE Confidence: 0.830387

00:24:09.402 --> 00:24:11.307 here within the Children's Hospital

NOTE Confidence: 0.830387

00:24:11.363 --> 00:24:13.019 so that we could support them?

NOTE Confidence: 0.830387

00:24:13.020 --> 00:24:14.004 On the flip side,

NOTE Confidence: 0.830387

00:24:14.004 --> 00:24:15.480 adolescents and young adults have poor

NOTE Confidence: 0.830387

00:24:15.531 --> 00:24:16.867 psychosocial outcomes compared to

NOTE Confidence: 0.830387

00:24:16.867 --> 00:24:18.871 younger pediatric or older adult patients.

NOTE Confidence: 0.830387

00:24:18.880 --> 00:24:20.674 They have some of the worst

NOTE Confidence: 0.830387

00:24:20.674 --> 00:24:22.399 psychosocial outcomes that we can find.

NOTE Confidence: 0.830387

00:24:22.400 --> 00:24:24.158 They have higher rates of poor

NOTE Confidence: 0.830387

00:24:24.158 --> 00:24:25.330 mental health and survivorship.

NOTE Confidence: 0.830387

00:24:25.330 --> 00:24:27.088 They're less likely to get a

NOTE Confidence: 0.830387

00:24:27.088 --> 00:24:28.260 job or get married.

NOTE Confidence: 0.830387

00:24:28.260 --> 00:24:30.438 They are less likely to be paid the same

NOTE Confidence: 0.830387

00:24:30.438 --> 00:24:32.646 as their otherwise age matched peers.

NOTE Confidence: 0.830387

00:24:32.650 --> 00:24:34.348 They have higher rates of suicide

NOTE Confidence: 0.830387

00:24:34.348 --> 00:24:35.870 and other serious mental health,

NOTE Confidence: 0.830387

00:24:35.870 --> 00:24:36.204 comorbidities,

NOTE Confidence: 0.830387

00:24:36.204 --> 00:24:38.542 and the idea that we had was

NOTE Confidence: 0.830387

00:24:38.542 --> 00:24:40.919 maybe we could fix some of those

NOTE Confidence: 0.830387

00:24:40.919 --> 00:24:42.559 problems if we started now.

NOTE Confidence: 0.830387

00:24:42.560 --> 00:24:44.480 We also know that teens and young adults

NOTE Confidence: 0.830387

00:24:44.480 --> 00:24:46.134 also have challenges with traditional

NOTE Confidence: 0.830387

00:24:46.134 --> 00:24:47.999 methods for mental health support.

NOTE Confidence: 0.830387

00:24:48.000 --> 00:24:48.301 So,

NOTE Confidence: 0.830387

00:24:48.301 --> 00:24:48.903 for example,

NOTE Confidence: 0.830387

00:24:48.903 --> 00:24:50.107 teens with chronic illness,

NOTE Confidence: 0.830387

00:24:50.110 --> 00:24:52.350 only a third of them will access

NOTE Confidence: 0.830387

00:24:52.350 --> 00:24:53.675 in hospital available mental

NOTE Confidence: 0.830387

00:24:53.675 --> 00:24:55.457 health services and of the ones

NOTE Confidence: 0.830387

00:24:55.457 --> 00:24:57.357 who do only a third stay in.

NOTE Confidence: 0.830387

00:24:57.360 --> 00:24:59.474 And when asked why you aren't using

NOTE Confidence: 0.830387

00:24:59.474 --> 00:25:01.588 these services that are available to you,

NOTE Confidence: 0.830387

00:25:01.590 --> 00:25:04.152 most teens and young adults will

NOTE Confidence: 0.830387

00:25:04.152 --> 00:25:06.731 say either the stigma or the

NOTE Confidence: 0.830387

00:25:06.731 --> 00:25:08.706 time commitment is too much.

NOTE Confidence: 0.830387

00:25:08.710 --> 00:25:10.565 But at the end of the day,

NOTE Confidence: 0.830387

00:25:10.570 --> 00:25:12.425 when we thought about where to start,

NOTE Confidence: 0.830387

00:25:12.430 --> 00:25:14.369 we felt we remembered that idea that

NOTE Confidence: 0.830387

00:25:14.369 --> 00:25:16.648 I shared with you about how a lot of

NOTE Confidence: 0.830387

00:25:16.648 --> 00:25:18.470 the teens and young adults we meet

NOTE Confidence: 0.830387

00:25:18.470 --> 00:25:20.409 don't yet know how to be resilient.

NOTE Confidence: 0.830387

00:25:20.410 --> 00:25:22.279 They haven't had the life skills yet,

NOTE Confidence: 0.830387

00:25:22.280 --> 00:25:23.876 or no life opportunity yet to

NOTE Confidence: 0.830387

00:25:23.876 --> 00:25:24.940 develop those resilience resources.

NOTE Confidence: 0.830387

00:25:24.940 --> 00:25:26.344 And our curiosity was maybe we

NOTE Confidence: 0.830387

00:25:26.344 --> 00:25:28.224 could get in the door and start

NOTE Confidence: 0.830387

00:25:28.224 --> 00:25:29.714 teaching these skills right away.

NOTE Confidence: 0.830387

00:25:29.720 --> 00:25:31.050 And if we did that,

NOTE Confidence: 0.830387

00:25:31.050 --> 00:25:33.435 could we change some of

NOTE Confidence: 0.830387

00:25:33.435 --> 00:25:34.866 these downstream outcomes?

NOTE Confidence: 0.830387

00:25:34.870 --> 00:25:36.706 So that leads me to PRISM,

NOTE Confidence: 0.830387

00:25:36.710 --> 00:25:38.525 which teaches and targets those

NOTE Confidence: 0.830387

00:25:38.525 --> 00:25:40.340 same four resilience resources that

NOTE Confidence: 0.8484677

00:25:40.401 --> 00:25:42.219 we had heard from teens and

NOTE Confidence: 0.8484677

00:25:42.219 --> 00:25:43.431 young adults were important.

NOTE Confidence: 0.8484677

00:25:43.440 --> 00:25:45.642 The first thing we teach is

NOTE Confidence: 0.8484677

00:25:45.642 --> 00:25:46.743 stress management skills.

NOTE Confidence: 0.8484677

00:25:46.750 --> 00:25:48.222 This includes three mini

NOTE Confidence: 0.8484677

00:25:48.222 --> 00:25:49.694 skills within one session.

NOTE Confidence: 0.8484677

52

00:25:49.700 --> 00:25:52.636 The first mini skill is a deep breathing,

NOTE Confidence: 0.8484677

00:25:52.640 --> 00:25:53.714 simple relaxation technique.

NOTE Confidence: 0.8484677

00:25:53.714 --> 00:25:56.610 It helps people quiet their minds so they

NOTE Confidence: 0.8484677

00:25:56.610 --> 00:25:58.235 are receptive to additional learning

NOTE Confidence: 0.8484677

00:25:58.235 --> 00:26:01.302 and then the next too many skills are

NOTE Confidence: 0.8484677

00:26:01.302 --> 00:26:02.580 progressive mindfulness exercises.

NOTE Confidence: 0.8484677

00:26:02.580 --> 00:26:04.956 One to help deepen your relaxation

NOTE Confidence: 0.8484677

00:26:04.956 --> 00:26:07.714 and two to become aware of

NOTE Confidence: 0.8484677

00:26:07.714 --> 00:26:09.358 stressors without judgment.

NOTE Confidence: 0.8484677

00:26:09.360 --> 00:26:11.352 The next thing we do is

NOTE Confidence: 0.8484677

00:26:11.352 --> 00:26:12.680 a goal setting module.

NOTE Confidence: 0.8484677

00:26:12.680 --> 00:26:14.871 Here we teach what's called a smart

NOTE Confidence: 0.8484677

00:26:14.871 --> 00:26:16.660 goal that stands for specific,

NOTE Confidence: 0.8484677

00:26:16.660 --> 00:26:17.324 measurable, actionable,

NOTE Confidence: 0.8484677

00:26:17.324 --> 00:26:18.984 realistic and time dependent goals.

NOTE Confidence: 0.8484677

00:26:18.990 --> 00:26:20.455 We know from this psychology

NOTE Confidence: 0.8484677

00:26:20.455 --> 00:26:21.920 and social Sciences that any

NOTE Confidence: 0.8484677

00:26:21.980 --> 00:26:23.655 tiny forward progress towards an

NOTE Confidence: 0.8484677

00:26:23.655 --> 00:26:25.764 achievable and realistic hope is a

NOTE Confidence: 0.8484677

00:26:25.764 --> 00:26:27.288 very positive psychological anchor.

NOTE Confidence: 0.8484677

00:26:27.290 --> 00:26:29.276 And so we help a team.

NOTE Confidence: 0.8484677

00:26:29.280 --> 00:26:29.966 Translate quote.

NOTE Confidence: 0.8484677

00:26:29.966 --> 00:26:32.367 I just want to get through my

NOTE Confidence: 0.8484677

00:26:32.367 --> 00:26:34.587 cancer to something that is

NOTE Confidence: 0.8484677

00:26:34.587 --> 00:26:36.399 actually actionable and measurable.

NOTE Confidence: 0.8484677

00:26:36.400 --> 00:26:38.108 The next thing we do is what's

NOTE Confidence: 0.8484677

00:26:38.108 --> 00:26:39.330 called positive re framing

NOTE Confidence: 0.8484677

00:26:39.330 --> 00:26:40.638 or cognitive restructuring.

NOTE Confidence: 0.8484677

00:26:40.640 --> 00:26:42.754 And here we teach 2 mini skills.

NOTE Confidence: 0.8484677

00:26:42.760 --> 00:26:44.762 The first is how do you recognize

NOTE Confidence: 0.8484677

00:26:44.762 --> 00:26:46.370 all of that negative catastrophic

NOTE Confidence: 0.8484677

00:26:46.370 --> 00:26:49.114 self talk that can keep us up in

NOTE Confidence: 0.8484677

00:26:49.180 --> 00:26:51.316 the middle of the night and the 2nd

NOTE Confidence: 0.8484677

00:26:51.316 --> 00:26:53.370 is how do you change the appraisal?

NOTE Confidence: 0.8484677

00:26:53.370 --> 00:26:55.835 The valence of that appraisal

NOTE Confidence: 0.8484677

00:26:55.835 --> 00:26:57.807 from catastrophic to manageable.

NOTE Confidence: 0.8484677

00:26:57.810 --> 00:26:59.530 The complementary knice of mindfulness,

NOTE Confidence: 0.8484677

00:26:59.530 --> 00:27:00.220 for example,

NOTE Confidence: 0.8484677

00:27:00.220 --> 00:27:01.255 recognizing what's stressing

NOTE Confidence: 0.8484677

00:27:01.255 --> 00:27:02.980 you without judgment and then

NOTE Confidence: 0.8484677

00:27:03.028 --> 00:27:04.000 positive re framing,

NOTE Confidence: 0.8484677

00:27:04.000 --> 00:27:06.317 which is actually judging your thoughts and

NOTE Confidence: 0.8484677

00:27:06.317 --> 00:27:08.469 making them manageable and less catastrophic,

NOTE Confidence: 0.8484677

00:27:08.470 --> 00:27:10.155 is a really important psychological

NOTE Confidence: 0.8484677

00:27:10.155 --> 00:27:11.503 combination for helping people

NOTE Confidence: 0.8484677

00:27:11.503 --> 00:27:12.600 cope with adversity.

NOTE Confidence: 0.8484677

00:27:12.600 --> 00:27:14.320 And then the final thing,

00:27:14.320 --> 00:27:17.416 the anchor of all of this is meaning making,

00:27:17.420 --> 00:27:19.668 and here we help teens and young adults

00:27:19.668 --> 00:27:22.230 with the exercise of identifying benefits,

00:27:22.230 --> 00:27:22.610 gratitude,

00:27:22.610 --> 00:27:23.370 purpose, legacy.

00:27:23.370 --> 00:27:25.650 It's sort of asking that existential

00:27:25.650 --> 00:27:27.387 question of why is this happening?

00:27:27.390 --> 00:27:30.486 What are you going to be because of this?

00:27:30.490 --> 00:27:31.358 What matters to you?

00:27:31.358 --> 00:27:32.951 Who do you want to be next

00:27:32.951 --> 00:27:34.367 week when this is all over?

00:27:36.650 --> 00:27:38.582 After all, four of those sessions

00:27:38.582 --> 00:27:40.734 we have the optional meeting with

00:27:40.734 --> 00:27:42.734 the family called coming together,

00:27:42.740 --> 00:27:44.894 and this is essentially designed to

00:27:44.894 --> 00:27:47.388 help the patient share with loved ones.

NOTE Confidence: 0.8734985

00:27:47.390 --> 00:27:49.822 What worked for him or her and to

NOTE Confidence: 0.8734985

00:27:49.822 --> 00:27:52.030 help family members and caregivers

NOTE Confidence: 0.8734985

00:27:52.030 --> 00:27:54.570 reciprocate and reinforce the skills.

NOTE Confidence: 0.8734985

00:27:54.570 --> 00:27:57.210 And then after all sessions in between them,

NOTE Confidence: 0.8734985

00:27:57.210 --> 00:27:59.335 we offer opportunities to practice

NOTE Confidence: 0.8734985

00:27:59.335 --> 00:28:01.035 with boosters and worksheets.

NOTE Confidence: 0.8734985

00:28:01.040 --> 00:28:02.570 Prison, like many psychosocial interventions,

NOTE Confidence: 0.8734985

00:28:02.570 --> 00:28:04.100 is what we call Manualized.

NOTE Confidence: 0.8734985

00:28:04.100 --> 00:28:05.936 That means we have a very

NOTE Confidence: 0.8734985

00:28:05.936 --> 00:28:06.548 reproducible script.

NOTE Confidence: 0.8734985

00:28:06.550 --> 00:28:08.374 We measure Fidelity to make sure

NOTE Confidence: 0.8734985

00:28:08.374 --> 00:28:09.945 it's being delivered in the

NOTE Confidence: 0.8734985

00:28:09.945 --> 00:28:11.435 same dose and delivery style,

NOTE Confidence: 0.8734985

00:28:11.440 --> 00:28:14.455 and we train all of our coaches with at

NOTE Confidence: 0.8734985

00:28:14.455 --> 00:28:17.720 least 8 hours to make sure that they are

NOTE Confidence: 0.8734985

00:28:17.720 --> 00:28:20.148 certified and fluent in the program.

NOTE Confidence: 0.8734985

00:28:20.150 --> 00:28:22.698 All of our coaches are college grads.

NOTE Confidence: 0.8734985

00:28:22.700 --> 00:28:24.520 Some of them have PHD's,

NOTE Confidence: 0.8734985

00:28:24.520 --> 00:28:27.440 but by design we intended this to be

NOTE Confidence: 0.8734985

00:28:27.440 --> 00:28:29.955 coachable by folks who could be lay

NOTE Confidence: 0.8734985

00:28:29.955 --> 00:28:32.547 stuff so that it's more translatable

NOTE Confidence: 0.8734985

00:28:32.547 --> 00:28:34.950 across different institutions.

NOTE Confidence: 0.8734985

00:28:34.950 --> 00:28:36.546 The next thing we did having

NOTE Confidence: 0.8734985

00:28:36.546 --> 00:28:38.474 designed this was we tested prisms

NOTE Confidence: 0.8734985

00:28:38.474 --> 00:28:40.082 feasibility amongst adolescents and

NOTE Confidence: 0.8734985

00:28:40.082 --> 00:28:42.240 young adults with either diabetes,

NOTE Confidence: 0.8734985

00:28:42.240 --> 00:28:43.644 cancer or cystic fibrosis,

NOTE Confidence: 0.8734985

00:28:43.644 --> 00:28:46.400 and we notice that enrollment was very high,

NOTE Confidence: 0.8734985

00:28:46.400 --> 00:28:48.135 83% across the program with

NOTE Confidence: 0.8734985

00:28:48.135 --> 00:28:49.176 high completion rates,

NOTE Confidence: 0.8734985

00:28:49.180 --> 00:28:51.931 and each of these different groups of

NOTE Confidence: 0.8734985

00:28:51.931 --> 00:28:54.900 patients asked us to do PRISM differently.

NOTE Confidence: 0.8734985

00:28:54.900 --> 00:28:55.773 So for example,

NOTE Confidence: 0.8734985

00:28:55.773 --> 00:28:57.519 patients with diabetes here in Seattle

NOTE Confidence: 0.8734985

00:28:57.519 --> 00:28:59.536 will come from thousands of miles away.

NOTE Confidence: 0.8734985

00:28:59.540 --> 00:29:00.114 In Alaska.

NOTE Confidence: 0.8734985

00:29:00.114 --> 00:29:01.262 Our catchment area includes

NOTE Confidence: 0.8734985

00:29:01.262 --> 00:29:03.019 Alaska all the way to Wyoming,

NOTE Confidence: 0.8734985

00:29:03.020 --> 00:29:04.760 and so folks will come into

NOTE Confidence: 0.8734985

00:29:04.760 --> 00:29:05.920 Seattle for their diabetes.

NOTE Confidence: 0.8734985

00:29:05.920 --> 00:29:07.950 Care for one annual Big long day,

NOTE Confidence: 0.8734985

00:29:07.950 --> 00:29:09.861 and then the rest of their care

NOTE Confidence: 0.8734985

00:29:09.861 --> 00:29:11.429 is delivered via Tele Health.

NOTE Confidence: 0.8734985

00:29:11.430 --> 00:29:12.880 And they said, you know,

NOTE Confidence: 0.8734985

00:29:12.880 --> 00:29:15.128 we can sit with you for a long

NOTE Confidence: 0.8734985

00:29:15.128 --> 00:29:16.360 time on one day,

NOTE Confidence: 0.8734985

00:29:16.360 --> 00:29:18.680 or we want to do this through video,

NOTE Confidence: 0.8734985

00:29:18.680 --> 00:29:20.710 but we don't want multiple sessions overtime,

NOTE Confidence: 0.8734985

00:29:20.710 --> 00:29:22.455 and so patients with diabetes

NOTE Confidence: 0.8734985

00:29:22.455 --> 00:29:25.130 preferred to get it all in one chunk.

NOTE Confidence: 0.8734985

00:29:25.130 --> 00:29:25.692 In contrast,

NOTE Confidence: 0.8734985

00:29:25.692 --> 00:29:27.097 patients with cancer and cystic

NOTE Confidence: 0.8734985

00:29:27.097 --> 00:29:28.869 fibrosis tend to be in the hospital.

NOTE Confidence: 0.8734985

00:29:28.870 --> 00:29:30.739 They are often isolated and they said,

NOTE Confidence: 0.8734985

00:29:30.740 --> 00:29:33.134 you know, we want you to come visit us.

NOTE Confidence: 0.8734985

00:29:33.140 --> 00:29:34.736 Well, we're here in the hospital.

NOTE Confidence: 0.8734985

00:29:34.740 --> 00:29:36.876 We want you to sit at our bedside,

NOTE Confidence: 0.8734985

00:29:36.880 --> 00:29:38.749 and we'd rather break up the intervention.

NOTE Confidence: 0.8734985

00:29:38.750 --> 00:29:40.220 All those four sessions into

NOTE Confidence: 0.8734985

00:29:40.220 --> 00:29:41.396 separate four sessions delivered

NOTE Confidence: 0.8734985

00:29:41.396 --> 00:29:42.490 every other week or so.

NOTE Confidence: 0.8659056

00:29:44.620 --> 00:29:46.042 When we asked all of these

NOTE Confidence: 0.8659056

00:29:46.042 --> 00:29:47.440 young folks what they thought,

NOTE Confidence: 0.8659056

00:29:47.440 --> 00:29:48.715 their qualitative feedback or things

NOTE Confidence: 0.8659056

00:29:48.715 --> 00:29:50.254 like this, this is so helpful.

NOTE Confidence: 0.8659056

00:29:50.254 --> 00:29:51.790 I wish we'd done this sooner.

NOTE Confidence: 0.8659056

00:29:51.790 --> 00:29:53.488 Yeah, I was actually telling my

NOTE Confidence: 0.8659056

00:29:53.488 --> 00:29:54.887 friends about it afterwards and

NOTE Confidence: 0.8659056

00:29:54.887 --> 00:29:56.399 they said they would try it out.

NOTE Confidence: 0.8659056

00:29:56.400 --> 00:29:58.185 I think it's good techniques to use.

NOTE Confidence: 0.8659056

00:29:58.190 --> 00:29:59.720 Definitely, I'm teaching my little sister.

NOTE Confidence: 0.8659056

00:29:59.720 --> 00:30:02.114 I'm sure it can help her too.

NOTE Confidence: 0.8659056

00:30:02.120 --> 00:30:03.800 Or I used to be in the hospital

NOTE Confidence: 0.8659056

00:30:03.800 --> 00:30:05.448 and think it was a waste of time,

NOTE Confidence: 0.8659056

00:30:05.450 --> 00:30:06.745 not want to be there doing things

NOTE Confidence: 0.8659056

00:30:06.745 --> 00:30:08.032 like this make you realize you're

NOTE Confidence: 0.8659056

00:30:08.032 --> 00:30:09.400 here to make yourself feel better.

NOTE Confidence: 0.8243645

00:30:12.060 --> 00:30:14.060 So the next thing we did was a

NOTE Confidence: 0.8243645

00:30:14.060 --> 00:30:15.595 randomized control trial amongst 92

NOTE Confidence: 0.8243645

00:30:15.595 --> 00:30:17.563 adolescents and young adults with cancer.

NOTE Confidence: 0.8243645

00:30:17.570 --> 00:30:19.244 These are all of the outcomes

NOTE Confidence: 0.8243645

00:30:19.244 --> 00:30:20.760 we measured in that study.

NOTE Confidence: 0.8243645

00:30:20.760 --> 00:30:23.126 The zero line means there was no

NOTE Confidence: 0.8243645

00:30:23.126 --> 00:30:24.865 difference between patients who received

NOTE Confidence: 0.8243645

00:30:24.865 --> 00:30:27.189 usual care and those who received PRISM.

NOTE Confidence: 0.8243645

00:30:27.190 --> 00:30:29.158 And by the way, usual carrot,

NOTE Confidence: 0.8243645

00:30:29.160 --> 00:30:30.996 our center includes an assigned social

NOTE Confidence: 0.8243645

00:30:30.996 --> 00:30:33.109 worker for every single family available,

NOTE Confidence: 0.8243645

00:30:33.110 --> 00:30:35.315 psychology services and a whole host of

NOTE Confidence: 0.8243645

00:30:35.315 --> 00:30:36.730 other embedded psychosocial services.

NOTE Confidence: 0.8243645

00:30:36.730 --> 00:30:39.354 So moving left to right on this graph,

NOTE Confidence: 0.8243645

00:30:39.360 --> 00:30:41.005 you'll notice that resilience scores

NOTE Confidence: 0.8243645

00:30:41.005 --> 00:30:42.650 went up with the intervention.

NOTE Confidence: 0.8243645

00:30:42.650 --> 00:30:44.300 Distress scores went down with

NOTE Confidence: 0.8243645

00:30:44.300 --> 00:30:44.960 the intervention.

NOTE Confidence: 0.8243645

00:30:44.960 --> 00:30:47.540 Hope went up benefit finding went

NOTE Confidence: 0.8243645

00:30:47.540 --> 00:30:50.439 up and quality of life went up.

NOTE Confidence: 0.8243645

00:30:50.440 --> 00:30:51.805 Perhaps more importantly to me

NOTE Confidence: 0.8243645

00:30:51.805 --> 00:30:53.617 that D there is a statistically

NOTE Confidence: 0.8243645

00:30:53.617 --> 00:30:55.527 using behavioral science is called

NOTE Confidence: 0.8243645

00:30:55.527 --> 00:30:57.967 an effect size and by convention

NOTE Confidence: 0.8243645

00:30:57.967 --> 00:31:00.529 anything greater than .3 is considered

NOTE Confidence: 0.8243645

00:31:00.529 --> 00:31:02.485 clinically significant and in every

NOTE Confidence: 0.8243645

00:31:02.485 --> 00:31:04.675 single way that we could look,

NOTE Confidence: 0.8243645

00:31:04.680 --> 00:31:06.900 there were clinically significant

NOTE Confidence: 0.8243645

00:31:06.900 --> 00:31:10.230 changes in these outcomes of interest.

NOTE Confidence: 0.8243645

00:31:10.230 --> 00:31:12.624 But we weren't looking for was this

NOTE Confidence: 0.8243645

00:31:12.624 --> 00:31:14.909 six months after the study started.

NOTE Confidence: 0.8243645

00:31:14.910 --> 00:31:17.255 We looked at the surviving 74 patients

NOTE Confidence: 0.8243645

00:31:17.255 --> 00:31:19.566 who were still available and we

NOTE Confidence: 0.8243645

00:31:19.566 --> 00:31:21.621 looked at their clinical criteria

NOTE Confidence: 0.8243645

00:31:21.621 --> 00:31:23.628 for depression and we notice that

NOTE Confidence: 0.8243645

00:31:23.628 --> 00:31:25.710 21% of the usual care patients

NOTE Confidence: 0.8243645

00:31:25.710 --> 00:31:27.870 versus 6% of the prison patients

NOTE Confidence: 0.8243645

00:31:27.870 --> 00:31:29.310 met criteria for depression,

NOTE Confidence: 0.8243645

00:31:29.310 --> 00:31:31.470 which translated to a 90% reduction

NOTE Confidence: 0.8243645

00:31:31.470 --> 00:31:33.630 in the odds of developing depression

NOTE Confidence: 0.8243645

00:31:33.630 --> 00:31:35.465 during those first six months

NOTE Confidence: 0.8243645

00:31:35.465 --> 00:31:36.865 of their cancer experience.

NOTE Confidence: 0.83446914

00:31:40.030 --> 00:31:42.082 The next thing we did was we tried to

NOTE Confidence: 0.83446914

00:31:42.082 --> 00:31:43.765 figure out are things getting better

NOTE Confidence: 0.83446914

00:31:43.765 --> 00:31:45.831 or they staying the same like what's

NOTE Confidence: 0.83446914

00:31:45.831 --> 00:31:47.667 happening when you get prison versus

NOTE Confidence: 0.83446914

64

00:31:47.667 --> 00:31:49.852 usual care and so each of these pairs

NOTE Confidence: 0.83446914

00:31:49.852 --> 00:31:51.765 of graphs has the usual care group

NOTE Confidence: 0.83446914

00:31:51.765 --> 00:31:54.060 on the left and PRISM on the right,

NOTE Confidence: 0.83446914

00:31:54.060 --> 00:31:55.435 and you're looking at clusters

NOTE Confidence: 0.83446914

00:31:55.435 --> 00:31:56.260 of resilience scores.

NOTE Confidence: 0.83446914

00:31:56.260 --> 00:31:57.268 Hope benefit finding,

NOTE Confidence: 0.83446914

00:31:57.268 --> 00:31:58.948 quality of life and distress

NOTE Confidence: 0.83446914

00:31:58.948 --> 00:32:00.169 moving left to right.

NOTE Confidence: 0.83446914

00:32:00.170 --> 00:32:02.282 In red means that their scores

NOTE Confidence: 0.83446914

00:32:02.282 --> 00:32:04.077 deteriorated overtime in pink means

NOTE Confidence: 0.83446914

00:32:04.077 --> 00:32:06.338 they started at risk and stayed there.

NOTE Confidence: 0.83446914

00:32:06.340 --> 00:32:08.284 Light blue means they were well

NOTE Confidence: 0.83446914

00:32:08.284 --> 00:32:10.460 at the beginning and stayed there.

NOTE Confidence: 0.83446914

00:32:10.460 --> 00:32:12.500 An blue means they got better

NOTE Confidence: 0.83446914

00:32:12.500 --> 00:32:14.260 overtime and the takeaways here

NOTE Confidence: 0.83446914

00:32:14.260 --> 00:32:16.288 are that in every single scenario,

NOTE Confidence: 0.83446914

00:32:16.290 --> 00:32:17.850 folks who got prism improved

NOTE Confidence: 0.83446914

00:32:17.850 --> 00:32:19.861 and folks who didn't get prison

NOTE Confidence: 0.83446914

00:32:19.861 --> 00:32:21.776 were more likely to deteriorate.

NOTE Confidence: 0.88339365

00:32:25.180 --> 00:32:27.256 Finally, anecdotally, this is one of

NOTE Confidence: 0.88339365

00:32:27.256 --> 00:32:29.310 my favorite findings from this study.

NOTE Confidence: 0.88339365

00:32:29.310 --> 00:32:31.854 We gave each of the participants in each

NOTE Confidence: 0.88339365

00:32:31.854 --> 00:32:34.807 arm $50 at the end of their participation,

NOTE Confidence: 0.88339365

00:32:34.810 --> 00:32:38.586 and then we got this in the Mail.

NOTE Confidence: 0.88339365

00:32:38.590 --> 00:32:40.234 This is a letter that said, Dear Abby,

NOTE Confidence: 0.88339365

00:32:40.234 --> 00:32:42.110 thank you so much for the $50.00 gift card.

NOTE Confidence: 0.88339365

00:32:42.110 --> 00:32:43.964 I had a great time doing this study and

NOTE Confidence: 0.88339365

00:32:43.964 --> 00:32:45.953 learn a lot of great life skills that I

NOTE Confidence: 0.88339365

00:32:45.953 --> 00:32:47.488 will continue to use for a long time.

NOTE Confidence: 0.88339365

00:32:47.490 --> 00:32:49.961 So thank you so much for letting

NOTE Confidence: 0.88339365

00:32:49.961 --> 00:32:50.667 me participate.

NOTE Confidence: 0.88339365

00:32:50.670 --> 00:32:52.495 Like the perfect example of

NOTE Confidence: 0.88339365

00:32:52.495 --> 00:32:53.955 a well mannered teenager.

NOTE Confidence: 0.8754678

00:32:56.530 --> 00:32:58.794 The other thing we heard from patients was,

NOTE Confidence: 0.8754678

00:32:58.800 --> 00:33:01.221 hey, my mom needs this too for my dad

NOTE Confidence: 0.8754678

00:33:01.221 --> 00:33:03.625 needs us too and we heard from parents.

NOTE Confidence: 0.8754678

00:33:03.630 --> 00:33:05.618 Hey, can you do something like this?

NOTE Confidence: 0.8754678

00:33:05.620 --> 00:33:07.186 For me this seems really helpful

NOTE Confidence: 0.8754678

00:33:07.186 --> 00:33:09.201 and so we went back to that

NOTE Confidence: 0.8754678

00:33:09.201 --> 00:33:10.726 original question we had about.

NOTE Confidence: 0.8754678

00:33:10.730 --> 00:33:12.994 How do we support parents and we said,

NOTE Confidence: 0.8754678

00:33:13.000 --> 00:33:14.673 well maybe we should have tried that

NOTE Confidence: 0.8754678

00:33:14.673 --> 00:33:16.537 also and we adapted the program using

NOTE Confidence: 0.8754678

00:33:16.537 --> 00:33:18.560 the same for PRISM skills but with

NOTE Confidence: 0.8754678

00:33:18.560 --> 00:33:20.200 language that was more appropriate

NOTE Confidence: 0.8754678

00:33:20.200 --> 00:33:22.088 for parent experiences and we piloted

NOTE Confidence: 0.8754678

00:33:22.088 --> 00:33:23.508 the program amongst 24 parents.

NOTE Confidence: 0.8754678

00:33:23.510 --> 00:33:25.015 And again they reported that

NOTE Confidence: 0.8754678

00:33:25.015 --> 00:33:26.219 it was very valuable.

NOTE Confidence: 0.8754678

00:33:26.220 --> 00:33:26.468 Qualitatively,

NOTE Confidence: 0.8754678

00:33:26.468 --> 00:33:27.956 they said this should be part

NOTE Confidence: 0.8754678

00:33:27.956 --> 00:33:29.060 of every parent's toolbox.

NOTE Confidence: 0.8754678

00:33:29.060 --> 00:33:31.154 These skills help us to take

NOTE Confidence: 0.8754678

00:33:31.154 --> 00:33:33.000 better care of our kids.

NOTE Confidence: 0.8754678

00:33:33.000 --> 00:33:34.848 And before and after the intervention,

NOTE Confidence: 0.8754678

00:33:34.850 --> 00:33:36.390 their resilience went up in

NOTE Confidence: 0.8754678

00:33:36.390 --> 00:33:37.930 their distress scores went down.

NOTE Confidence: 0.86991674

00:33:40.230 --> 00:33:41.100 The challenges, though,

NOTE Confidence: 0.86991674

00:33:41.100 --> 00:33:42.840 that parents reported to us was

NOTE Confidence: 0.86991674

00:33:42.840 --> 00:33:44.673 that it was really hard for them to

NOTE Confidence: 0.86991674

00:33:44.673 --> 00:33:46.278 get away from their kids bedside.

NOTE Confidence: 0.86991674

00:33:46.280 --> 00:33:47.575 This was exactly our concern

NOTE Confidence: 0.86991674

00:33:47.575 --> 00:33:49.440 when we started to do this work,

NOTE Confidence: 0.86991674

00:33:49.440 --> 00:33:51.464 and so we tried to brainstorm what would

NOTE Confidence: 0.86991674

00:33:51.464 --> 00:33:53.910 be an easier way for parents to do this.

NOTE Confidence: 0.86991674

00:33:53.910 --> 00:33:55.877 And maybe it would be a symposium

NOTE Confidence: 0.86991674

00:33:55.877 --> 00:33:57.242 style coaching program where we

NOTE Confidence: 0.86991674

00:33:57.242 --> 00:33:58.634 have a whole lot of parents.

NOTE Confidence: 0.86991674

00:33:58.640 --> 00:34:00.864 Together they sit with us for four hours

NOTE Confidence: 0.86991674

00:34:00.864 --> 00:34:03.258 and we deliver the program that clap.

NOTE Confidence: 0.86991674

00:34:03.260 --> 00:34:05.094 And so we we hold a symposium.

NOTE Confidence: 0.86991674

00:34:05.100 --> 00:34:07.730 We had about 72 people show up at the door.

NOTE Confidence: 0.86991674

00:34:07.730 --> 00:34:09.738 We had turn folks away and we put

NOTE Confidence: 0.86991674

00:34:09.738 --> 00:34:11.814 them at Round Top tables in a big

NOTE Confidence: 0.86991674

00:34:11.814 --> 00:34:14.359 room and we did group coaching of the

NOTE Confidence: 0.86991674

00:34:14.359 --> 00:34:16.567 PRISM intervention of RFR Hour period.

NOTE Confidence: 0.86991674

00:34:16.570 --> 00:34:18.634 92% of parents said they gained

NOTE Confidence: 0.86991674

00:34:18.634 --> 00:34:20.010 new insights and skills.

NOTE Confidence: 0.86991674

00:34:20.010 --> 00:34:22.418 98% said it was easy to understand

NOTE Confidence: 0.86991674

00:34:22.418 --> 00:34:25.880 and 100% felt like the group format

NOTE Confidence: 0.86991674

00:34:25.880 --> 00:34:28.096 was helpful to them.

NOTE Confidence: 0.86991674

00:34:28.100 --> 00:34:30.109 So then we said, OK, well,

NOTE Confidence: 0.86991674

00:34:30.109 --> 00:34:31.505 what's better group coaching

NOTE Confidence: 0.86991674

00:34:31.505 --> 00:34:33.729 versus usual care or one on one?

NOTE Confidence: 0.86991674

00:34:33.730 --> 00:34:35.042 Coaching versus usual care.

NOTE Confidence: 0.86991674

00:34:35.042 --> 00:34:37.010 So we did another randomized trial

NOTE Confidence: 0.86991674

00:34:37.072 --> 00:34:38.980 this time amongst 102 parents or

NOTE Confidence: 0.86991674

00:34:38.980 --> 00:34:40.680 caregivers of children with cancer.

NOTE Confidence: 0.86991674

00:34:40.680 --> 00:34:42.899 And here you're looking at a forest

NOTE Confidence: 0.86991674

00:34:42.899 --> 00:34:44.942 plot of usual care compared to

NOTE Confidence: 0.86991674

00:34:44.942 --> 00:34:46.310 one on one coaching.

NOTE Confidence: 0.86991674

00:34:46.310 --> 00:34:49.040 And what we found was that the

NOTE Confidence: 0.86991674

00:34:49.040 --> 00:34:51.172 intervention when delivered one on

NOTE Confidence: 0.86991674

00:34:51.172 --> 00:34:53.392 one improved parent resilience and

NOTE Confidence: 0.86991674

00:34:53.392 --> 00:34:55.739 benefit finding compared to usual care.

NOTE Confidence: 0.86991674

00:34:55.740 --> 00:34:58.196 But when we compared group to usual care,

NOTE Confidence: 0.86991674

00:34:58.200 --> 00:35:00.048 we actually couldn't see any differences,

NOTE Confidence: 0.86991674

00:35:00.050 --> 00:35:02.766 but in outcomes it looked like the

NOTE Confidence: 0.86991674

00:35:02.766 --> 00:35:05.396 group delivery didn't seem to have an

NOTE Confidence: 0.86991674

00:35:05.396 --> 00:35:07.478 effect on parent resilience or any

NOTE Confidence: 0.86991674

00:35:07.549 --> 00:35:09.907 of our other outcomes of interest.

NOTE Confidence: 0.86991674

00:35:09.910 --> 00:35:12.694 And there's more to the story than what

NOTE Confidence: 0.86991674

00:35:12.694 --> 00:35:15.708 we could see in those quantifiable data.

NOTE Confidence: 0.86991674

00:35:15.710 --> 00:35:17.593 So I want to share her story

NOTE Confidence: 0.86991674

00:35:17.593 --> 00:35:19.819 with you of a particular parent.

NOTE Confidence: 0.86991674

00:35:19.820 --> 00:35:21.992 This was a father whose daughter

NOTE Confidence: 0.86991674

00:35:21.992 --> 00:35:23.867 died unexpectedly about two weeks

NOTE Confidence: 0.86991674

00:35:23.867 --> 00:35:25.677 after his group PRISM session.

NOTE Confidence: 0.86991674

00:35:25.680 --> 00:35:26.800 And when she died,

NOTE Confidence: 0.86991674

00:35:26.800 --> 00:35:28.871 we as of study team were trying

NOTE Confidence: 0.86991674

00:35:28.871 --> 00:35:30.496 to figure out you know,

NOTE Confidence: 0.86991674

00:35:30.500 --> 00:35:32.600 how do we re engage this dad?

NOTE Confidence: 0.86991674

00:35:32.600 --> 00:35:33.202 Do we?

NOTE Confidence: 0.86991674

00:35:33.202 --> 00:35:34.707 What would his resilience skills

NOTE Confidence: 0.86991674

00:35:34.707 --> 00:35:36.844 scores look like in the context of

NOTE Confidence: 0.86991674

00:35:36.844 --> 00:35:38.614 this immediate death of his daughter?

NOTE Confidence: 0.86991674

00:35:38.620 --> 00:35:41.028 And so at the end of the day,

NOTE Confidence: 0.86991674

00:35:41.030 --> 00:35:42.878 we decided to reach out to him

NOTE Confidence: 0.86991674

00:35:42.878 --> 00:35:44.424 and express our condolences and

NOTE Confidence: 0.86991674

00:35:44.424 --> 00:35:46.149 our gratitude and say hey,

NOTE Confidence: 0.86991674

00:35:46.150 --> 00:35:48.859 we're here and he wrote back and he said,

NOTE Confidence: 0.86991674

00:35:48.860 --> 00:35:49.462 you know,

NOTE Confidence: 0.86991674

00:35:49.462 --> 00:35:51.870 I'm actually really happy to hear from you.

NOTE Confidence: 0.86991674

00:35:51.870 --> 00:35:53.676 I talked with my group and

NOTE Confidence: 0.86991674

00:35:53.676 --> 00:35:54.579 with their permission,

NOTE Confidence: 0.86991674

00:35:54.580 --> 00:35:56.518 I'm going to share with you.

NOTE Confidence: 0.86991674

00:35:56.520 --> 00:35:59.220 Email string that we have been

NOTE Confidence: 0.86991674

00:35:59.220 --> 00:36:00.570 had going around.

NOTE Confidence: 0.86991674

00:36:00.570 --> 00:36:02.058 He forward this email This is

NOTE Confidence: 0.86991674

00:36:02.058 --> 00:36:03.420 him writing to his group.

NOTE Confidence: 0.86991674

00:36:03.420 --> 00:36:05.484 He says, I think of all of you.

NOTE Confidence: 0.86991674

00:36:05.490 --> 00:36:07.744 Often I've had many chances to use

NOTE Confidence: 0.86991674

00:36:07.744 --> 00:36:09.399 the coping strategies we learned.

NOTE Confidence: 0.86991674

00:36:09.400 --> 00:36:12.048 And then one by one he lists every

NOTE Confidence: 0.86991674

00:36:12.048 --> 00:36:14.020 single one of those resilient

NOTE Confidence: 0.86991674

00:36:14.020 --> 00:36:16.474 skills and how they helped him.

NOTE Confidence: 0.86991674

00:36:16.480 --> 00:36:17.810 He goes on interesting Lee.

NOTE Confidence: 0.86991674

00:36:17.810 --> 00:36:19.658 I feel better as I type this.

NOTE Confidence: 0.86991674

00:36:19.660 --> 00:36:21.515 I don't have an extensive support network.

NOTE Confidence: 0.8741202

00:36:21.520 --> 00:36:23.110 It's literally myself and my wife.

73

NOTE Confidence: 0.8741202

00:36:23.110 --> 00:36:24.868 This is the only time I've

NOTE Confidence: 0.8741202

00:36:24.868 --> 00:36:26.590 talked about what I'm feeling.

NOTE Confidence: 0.8741202

00:36:26.590 --> 00:36:27.485 Thank you all for reading

NOTE Confidence: 0.8741202

00:36:27.485 --> 00:36:28.626 this and staying in touch and

NOTE Confidence: 0.8741202

00:36:28.626 --> 00:36:29.676 helping each other through this.

NOTE Confidence: 0.8732671

00:36:33.760 --> 00:36:36.238 My takeaway, by the way from that

NOTE Confidence: 0.8732671

00:36:36.238 --> 00:36:38.418 experience with that Dad is 2 things.

NOTE Confidence: 0.8732671

00:36:38.420 --> 00:36:40.702 One I am not convinced that the

NOTE Confidence: 0.8732671

00:36:40.702 --> 00:36:43.118 group by itself isn't doing something

NOTE Confidence: 0.8732671

00:36:43.118 --> 00:36:45.848 'cause clearly it helped this father.

NOTE Confidence: 0.8732671

00:36:45.850 --> 00:36:48.286 I also think that the cumulative shared

NOTE Confidence: 0.8732671

00:36:48.286 --> 00:36:50.172 grief of watching another parents

NOTE Confidence: 0.8732671

00:36:50.172 --> 00:36:52.902 child be ill was something we hadn't

NOTE Confidence: 0.8732671

00:36:52.902 --> 00:36:55.321 anticipated and so that idea of how do

NOTE Confidence: 0.8732671

00:36:55.321 --> 00:36:57.319 we support families needs to include?

NOTE Confidence: 0.8732671

00:36:57.319 --> 00:37:00.000 How do we examine this shared grief

NOTE Confidence: 0.8732671

00:37:00.076 --> 00:37:02.158 in this shared stress that can

NOTE Confidence: 0.8732671

00:37:02.158 --> 00:37:04.560 come from a group intervention?

NOTE Confidence: 0.8732671

00:37:04.560 --> 00:37:06.709 Which leads me to what's next for

NOTE Confidence: 0.8732671

00:37:06.709 --> 00:37:09.008 PRISM and where we're moving forward.

NOTE Confidence: 0.8732671

00:37:09.010 --> 00:37:11.404 We have a whole bunch of different

NOTE Confidence: 0.8732671

00:37:11.404 --> 00:37:12.430 projects in progress,

NOTE Confidence: 0.8732671

00:37:12.430 --> 00:37:14.175 including several multi site trials

NOTE Confidence: 0.8732671

00:37:14.175 --> 00:37:15.920 for adolescents and young adults

NOTE Confidence: 0.8732671

00:37:15.979 --> 00:37:17.624 with advanced cancer or diabetes

NOTE Confidence: 0.8732671

00:37:17.624 --> 00:37:19.269 in the advanced cancer studies.

NOTE Confidence: 0.8732671

00:37:19.270 --> 00:37:21.322 We're looking both at the integration

NOTE Confidence: 0.8732671

00:37:21.322 --> 00:37:23.372 of Advanced care planning, for example,

NOTE Confidence: 0.8732671

00:37:23.372 --> 00:37:25.077 for teens with incurable cancer.

NOTE Confidence: 0.8732671

00:37:25.080 --> 00:37:27.614 Can Prism help be a platform for

NOTE Confidence: 0.8732671

00:37:27.614 --> 00:37:28.700 integrating larger conversations

NOTE Confidence: 0.8732671

00:37:28.756 --> 00:37:29.868 about goals of care,

NOTE Confidence: 0.8732671

00:37:29.870 --> 00:37:31.916 and how does it influence anxiety,

NOTE Confidence: 0.8732671

00:37:31.920 --> 00:37:32.329 depression,

NOTE Confidence: 0.8732671

00:37:32.329 --> 00:37:34.374 and other mental health outcomes

NOTE Confidence: 0.8732671

00:37:34.374 --> 00:37:36.854 amongst kids and caregivers who are

NOTE Confidence: 0.8732671

00:37:36.854 --> 00:37:38.410 receiving bone marrow transplant?

NOTE Confidence: 0.8732671

00:37:38.410 --> 00:37:40.005 We're doing a dissemination implementation

NOTE Confidence: 0.8732671

00:37:40.005 --> 00:37:41.600 pilot here at Seattle Children's,

NOTE Confidence: 0.8732671

00:37:41.600 --> 00:37:43.316 where we're essentially putting the program

NOTE Confidence: 0.8732671

00:37:43.316 --> 00:37:45.429 Alex to make it publicly available,

NOTE Confidence: 0.8732671

00:37:45.430 --> 00:37:47.392 and we're trying to see how

NOTE Confidence: 0.8732671

00:37:47.392 --> 00:37:48.940 different clinical teams use it.

NOTE Confidence: 0.8732671

00:37:48.940 --> 00:37:50.854 We are adapting their program for

NOTE Confidence: 0.8732671

00:37:50.854 --> 00:37:52.130 adolescents with chronic pain.

NOTE Confidence: 0.8732671

00:37:52.130 --> 00:37:54.410 The Pi of that study is at the

NOTE Confidence: 0.8732671

00:37:54.410 --> 00:37:55.959 Children's Hospital of Philadelphia.

NOTE Confidence: 0.8732671

00:37:55.960 --> 00:37:57.913 We have an adaptation for patients of

NOTE Confidence: 0.8732671

00:37:57.913 --> 00:38:00.099 adult with adult congenital heart disease.

NOTE Confidence: 0.8732671

00:38:00.100 --> 00:38:01.966 So folks who are transitioning from

NOTE Confidence: 0.8732671

00:38:01.966 --> 00:38:03.909 pediatric to adult care in the

NOTE Confidence: 0.8732671

00:38:03.909 --> 00:38:05.524 setting of congenital heart disease,

NOTE Confidence: 0.8732671

00:38:05.530 --> 00:38:07.847 that pie is here at the University

NOTE Confidence: 0.8732671

00:38:07.847 --> 00:38:08.509 of Washington.

NOTE Confidence: 0.8732671

00:38:08.510 --> 00:38:10.170 We have a different investigator,

NOTE Confidence: 0.8732671

00:38:10.170 --> 00:38:11.982 Doctor Crystal Brown who is using

NOTE Confidence: 0.8732671

00:38:11.982 --> 00:38:13.950 PRISM to help support caregivers who

NOTE Confidence: 0.8732671

00:38:13.950 --> 00:38:15.705 experienced racism in critical care

NOTE Confidence: 0.8732671

00:38:15.705 --> 00:38:17.808 units here in the United States.

NOTE Confidence: 0.8732671

00:38:17.810 --> 00:38:19.470 We have a different investigator,

NOTE Confidence: 0.8732671

00:38:19.470 --> 00:38:20.114 Amoeba O'Donnell,

NOTE Confidence: 0.8732671

00:38:20.114 --> 00:38:22.046 who is studying Prism adaptation for

NOTE Confidence: 0.8732671

00:38:22.046 --> 00:38:24.110 health care workers during the pandemic.

NOTE Confidence: 0.8732671

00:38:24.110 --> 00:38:26.186 We have preliminary data from that

NOTE Confidence: 0.8732671

00:38:26.186 --> 00:38:27.951 study which essentially shows that

NOTE Confidence: 0.8732671

00:38:27.951 --> 00:38:29.865 PRISM compared to usual care for

NOTE Confidence: 0.8732671

00:38:29.865 --> 00:38:31.750 healthcare workers on the front lines,

NOTE Confidence: 0.8732671

00:38:31.750 --> 00:38:33.410 improves their burnout and improve

NOTE Confidence: 0.8732671

00:38:33.410 --> 00:38:35.070 their resilience in significant ways.

NOTE Confidence: 0.8732671

00:38:35.070 --> 00:38:37.387 And then finally, we have an investigator,

NOTE Confidence: 0.8732671

00:38:37.390 --> 00:38:38.104 Kiske Smith,

NOTE Confidence: 0.8732671

00:38:38.104 --> 00:38:39.889 who is translating the program

NOTE Confidence: 0.8732671

00:38:39.889 --> 00:38:41.959 and implementing it here in the

NOTE Confidence: 0.8732671

00:38:41.959 --> 00:38:43.519 Seattle Public Schools for kids.

NOTE Confidence: 0.8732671

00:38:43.520 --> 00:38:44.744 We're schooling at home.

NOTE Confidence: 0.8732671

00:38:44.744 --> 00:38:46.948 This is for school aged kids who

NOTE Confidence: 0.8732671

00:38:46.948 --> 00:38:48.784 are really struggling with this new

NOTE Confidence: 0.8732671

00:38:48.784 --> 00:38:51.080 world that we live in and helping

NOTE Confidence: 0.8732671

00:38:51.080 --> 00:38:53.054 them to manifest their own resilience

NOTE Confidence: 0.8732671

00:38:53.060 --> 00:38:54.968 resources early on in their childhood.

NOTE Confidence: 0.8732671

00:38:54.970 --> 00:38:56.560 Within all of these studies,

NOTE Confidence: 0.8732671

00:38:56.560 --> 00:38:58.462 we have analysis to evaluate cost

NOTE Confidence: 0.8732671

00:38:58.462 --> 00:38:59.734 effectiveness, adherence, for example,

NOTE Confidence: 0.8732671

00:38:59.734 --> 00:39:01.642 to oral chemotherapy caregiver well being,

NOTE Confidence: 0.8732671

00:39:01.650 --> 00:39:02.286 resource utilization,

NOTE Confidence: 0.8732671

00:39:02.286 --> 00:39:03.240 optimal delivery strategies.

NOTE Confidence: 0.8732671

00:39:03.240 --> 00:39:06.420 So is it better to do it all at once,

NOTE Confidence: 0.8732671

00:39:06.420 --> 00:39:09.600 or is it better to do it one on line?

NOTE Confidence: 0.8732671

00:39:09.600 --> 00:39:11.496 How can we integrate digital health?

NOTE Confidence: 0.8732671

00:39:11.500 --> 00:39:12.184 And finally,

NOTE Confidence: 0.8732671

00:39:12.184 --> 00:39:13.894 we're looking at biomarkers of

NOTE Confidence: 0.8732671

00:39:13.894 --> 00:39:15.190 stress and resilience and.

NOTE Confidence: 0.8732671

00:39:15.190 --> 00:39:17.740 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

00:39:51.300 --> 00:39:53.141 These are the ways that people can

NOTE Confidence: 0.88783324

00:39:53.141 --> 00:39:54.517 practice the skills between sessions

NOTE Confidence: 0.88783324

00:39:54.517 --> 00:39:56.393 and when we go to our stakeholders

NOTE Confidence: 0.88783324

00:39:56.393 --> 00:39:57.880 and we asked him about this.

NOTE Confidence: 0.88783324

00:39:57.880 --> 00:39:59.190 They say, you know, hey,

NOTE Confidence: 0.88783324

00:39:59.190 --> 00:40:00.768 this isn't how we learn anymore.

NOTE Confidence: 0.88783324

00:40:00.770 --> 00:40:02.085 Everything's on line and be

NOTE Confidence: 0.88783324

00:40:02.085 --> 00:40:03.400 when we really need prism.

NOTE Confidence: 0.88783324

00:40:03.400 --> 00:40:04.798 It's 2:00 o'clock in the morning

NOTE Confidence: 0.88783324

00:40:04.798 --> 00:40:06.652 when we wake up and we're having

NOTE Confidence: 0.88783324

00:40:06.652 --> 00:40:08.398 those negative thoughts in our heads.

NOTE Confidence: 0.88783324

00:40:08.400 --> 00:40:10.496 I don't want to go get a worksheet,

NOTE Confidence: 0.88783324

00:40:10.500 --> 00:40:12.724 I want to pick up my smart phone

NOTE Confidence: 0.88783324

00:40:12.724 --> 00:40:14.920 and have prism at my fingertips.

NOTE Confidence: 0.88783324

00:40:14.920 --> 00:40:16.726 And so we listened to our stakeholders

NOTE Confidence: 0.88783324

00:40:16.726 --> 00:40:18.319 and based on their feedback,

NOTE Confidence: 0.88783324

00:40:18.320 --> 00:40:21.368 we created an app that would help them

NOTE Confidence: 0.88783324

00:40:21.368 --> 00:40:23.638 practice their skills in real time.

NOTE Confidence: 0.88783324

00:40:23.640 --> 00:40:25.792 I'm just going to share with you the

NOTE Confidence: 0.88783324

00:40:25.792 --> 00:40:27.093 quick introductory module of what

NOTE Confidence: 0.88783324

00:40:27.093 --> 00:40:28.738 the app looks like when a patient

NOTE Confidence: 0.88783324

00:40:28.792 --> 00:40:29.967 opens it on their phone.

NOTE Confidence: 0.88783324

00:40:29.970 --> 00:40:31.842 This is imagine the first time you're opening

NOTE Confidence: 0.88783324

00:40:31.842 --> 00:40:33.756 it and the orientation to the program.

NOTE Confidence: 0.8469338

00:41:15.000 --> 00:41:17.331 So once folks of how that introduction

NOTE Confidence: 0.8469338

00:41:17.331 --> 00:41:19.996 and they use the app as a compliment

NOTE Confidence: 0.8469338

00:41:19.996 --> 00:41:22.379 to the in person coaching that we do,

NOTE Confidence: 0.8469338

00:41:22.380 --> 00:41:25.269 or the Tele health coaching that we now do,

NOTE Confidence: 0.8469338

00:41:25.270 --> 00:41:26.880 they can personalize their homepage.

NOTE Confidence: 0.8469338

00:41:26.880 --> 00:41:28.480 They can upload their goals,

NOTE Confidence: 0.8469338

00:41:28.480 --> 00:41:30.727 they can sync it with their calendar,

NOTE Confidence: 0.8469338

00:41:30.730 --> 00:41:32.949 so it sets the little reminders for

NOTE Confidence: 0.8469338

00:41:32.949 --> 00:41:35.239 things that they have staged as a

NOTE Confidence: 0.8469338

00:41:35.239 --> 00:41:37.141 way to accomplish that longer goal.

NOTE Confidence: 0.8469338

00:41:37.150 --> 00:41:38.750 They can upload pictures alot,

NOTE Confidence: 0.8469338

00:41:38.750 --> 00:41:40.988 Instagram and ways to remember particular

NOTE Confidence: 0.8469338

00:41:40.988 --> 00:41:43.343 moments of gratitude and so and they

NOTE Confidence: 0.8469338

00:41:43.343 --> 00:41:45.205 can track their own sense of stress

NOTE Confidence: 0.8469338

00:41:45.264 --> 00:41:47.130 and resilience within the app and

NOTE Confidence: 0.8469338

00:41:47.130 --> 00:41:49.100 see how the different modules help.

NOTE Confidence: 0.8469338

00:41:49.100 --> 00:41:51.620 Alleviate those senses of stress or bolster

NOTE Confidence: 0.8469338

00:41:51.620 --> 00:41:53.975 those senses of resilience in real time.

NOTE Confidence: 0.8914943

00:41:56.710 --> 00:41:58.646 So before I close, I have a couple

NOTE Confidence: 0.8914943

00:41:58.646 --> 00:42:00.660 of final thoughts about resilience.

NOTE Confidence: 0.8914943

00:42:00.660 --> 00:42:03.024 The first is what we've learned

NOTE Confidence: 0.8914943

00:42:03.024 --> 00:42:05.889 during the last year of the pandemic.

NOTE Confidence: 0.8914943

00:42:05.890 --> 00:42:07.624 When we started, I had this

00:42:07.624 --> 00:42:09.230 idea that resilience was linear.

00:42:09.230 --> 00:42:11.574 I had this idea of that banana graph

00:42:11.574 --> 00:42:14.031 that there was a line we would follow

00:42:14.031 --> 00:42:15.919 as we marched through our lives,

00:42:15.920 --> 00:42:18.668 and I don't think that's true.

00:42:18.670 --> 00:42:20.160 I think resilience is actually

00:42:20.160 --> 00:42:22.050 something that that exists in phases,

00:42:22.050 --> 00:42:23.892 and the first phase is what

00:42:23.892 --> 00:42:25.120 I call getting through.

00:42:25.120 --> 00:42:27.479 This is where we literally put 1

00:42:27.479 --> 00:42:30.210 foot in front of the other where we

00:42:30.210 --> 00:42:32.888 literally say I got out of bed today.

00:42:32.890 --> 00:42:34.388 It reminds me of that bereaved mom.

00:42:34.390 --> 00:42:36.102 I told you about at the beginning of

00:42:36.102 --> 00:42:37.600 this talk, the one who said, yeah,

00:42:37.600 --> 00:42:39.247 I did get out of bed today and that

NOTE Confidence: 0.8914943

00:42:39.247 --> 00:42:40.590 makes me pretty darn resilient,

NOTE Confidence: 0.8914943

00:42:40.590 --> 00:42:42.074 because if it were me and my

NOTE Confidence: 0.8914943

00:42:42.074 --> 00:42:42.950 childhood childhood just died,

NOTE Confidence: 0.8914943

00:42:42.950 --> 00:42:46.420 I don't know if I'd be able to do the same.

NOTE Confidence: 0.8914943

00:42:46.420 --> 00:42:47.938 However, that was ten years ago,

NOTE Confidence: 0.8914943

00:42:47.940 --> 00:42:49.748 and if I might met her and talk

NOTE Confidence: 0.8914943

00:42:49.748 --> 00:42:51.747 to her today and she still said,

NOTE Confidence: 0.8914943

00:42:51.750 --> 00:42:53.280 well, I got into bed today,

NOTE Confidence: 0.8914943

00:42:53.280 --> 00:42:54.876 then I would worry then I would

NOTE Confidence: 0.8914943

00:42:54.876 --> 00:42:56.734 say I don't know if you're still

NOTE Confidence: 0.8914943

00:42:56.734 --> 00:42:57.850 resilient in my mind.

NOTE Confidence: 0.8914943

00:42:57.850 --> 00:43:00.608 I think you need to do more.

NOTE Confidence: 0.8914943

00:43:00.610 --> 00:43:02.340 And so the next phase,

NOTE Confidence: 0.8914943

00:43:02.340 --> 00:43:03.297 if you will,

NOTE Confidence: 0.8914943

00:43:03.297 --> 00:43:05.211 of how we move through this

NOTE Confidence: 0.8914943

00:43:05.211 --> 00:43:06.480 experience of resilience,

NOTE Confidence: 0.8914943

00:43:06.480 --> 00:43:08.960 is when we start to do the work

NOTE Confidence: 0.8914943

00:43:08.960 --> 00:43:10.620 of harnessing our resources.

NOTE Confidence: 0.8914943

00:43:10.620 --> 00:43:12.699 This is where we begin to leverage

NOTE Confidence: 0.8914943

00:43:12.699 --> 00:43:14.096 those individual community and

NOTE Confidence: 0.8914943

00:43:14.096 --> 00:43:15.449 existential resilience resources.

NOTE Confidence: 0.8914943

00:43:15.450 --> 00:43:17.790 We start to actually figure

NOTE Confidence: 0.8914943

00:43:17.790 --> 00:43:21.050 out how do we move forward.

NOTE Confidence: 0.8914943

00:43:21.050 --> 00:43:22.294 In between getting through

NOTE Confidence: 0.8914943

00:43:22.294 --> 00:43:23.227 and harnessing resources,

NOTE Confidence: 0.8914943

00:43:23.230 --> 00:43:25.295 the psychological thing we do is we

NOTE Confidence: 0.8914943

00:43:25.295 --> 00:43:27.578 start to appraise or assess the situation.

NOTE Confidence: 0.8914943

00:43:27.580 --> 00:43:29.140 What have I done before?

NOTE Confidence: 0.8914943

00:43:29.140 --> 00:43:30.040 Who helps me?

NOTE Confidence: 0.8914943

00:43:30.040 --> 00:43:32.560 How am I going to get through this?

NOTE Confidence: 0.8914943

00:43:32.560 --> 00:43:34.989 We actually start to articulate in our

NOTE Confidence: 0.8914943

00:43:34.989 --> 00:43:37.217 own minds whether we know it or not.

NOTE Confidence: 0.8914943

00:43:37.220 --> 00:43:39.194 What needs to happen for us to

NOTE Confidence: 0.8914943

00:43:39.194 --> 00:43:41.117 move from just simply getting out

NOTE Confidence: 0.8914943

00:43:41.117 --> 00:43:43.127 of bed to starting to thrive?

NOTE Confidence: 0.8900107

00:43:45.450 --> 00:43:47.938 And then the third phase, if you will.

NOTE Confidence: 0.8900107

00:43:47.938 --> 00:43:49.518 Of this overlapping Venn diagram

NOTE Confidence: 0.8900107

00:43:49.518 --> 00:43:51.586 is when we look back and learn.

NOTE Confidence: 0.8900107

00:43:51.590 --> 00:43:53.648 This is when we finally have the

NOTE Confidence: 0.8900107

00:43:53.648 --> 00:43:55.538 brain space to reflect on what

NOTE Confidence: 0.8900107

00:43:55.538 --> 00:43:57.416 we learned and what it means.

NOTE Confidence: 0.8900107

00:43:57.420 --> 00:43:59.569 Sometimes that can be in a day.

NOTE Confidence: 0.8900107

00:43:59.570 --> 00:44:01.406 Sometimes that can take us years,

NOTE Confidence: 0.8900107

00:44:01.410 --> 00:44:03.545 but ultimately almost all human

NOTE Confidence: 0.8900107

00:44:03.545 --> 00:44:06.102 beings will have this capacity to

NOTE Confidence: 0.8900107

00:44:06.102 --> 00:44:08.172 think about what just happened to

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.

00:44:42.080 --> 00:44:42.893 Here's some thoughts.

NOTE Confidence: 0.829280976923077

00:44:42.893 --> 00:44:44.523 First of all, use your palliative

NOTE Confidence: 0.829280976923077

00:44:44.523 --> 00:44:45.336 care psychosocial chaplaincy.

NOTE Confidence: 0.829280976923077

00:44:45.340 --> 00:44:46.695 Child live any other supportive

NOTE Confidence: 0.829280976923077

00:44:46.695 --> 00:44:48.050 care team that you have.

NOTE Confidence: 0.829280976923077

00:44:48.050 --> 00:44:49.670 This is their bread and butter.

NOTE Confidence: 0.829280976923077

00:44:49.670 --> 00:44:51.296 This is what they do in

NOTE Confidence: 0.829280976923077

00:44:51.296 --> 00:44:52.109 their regular assessments.

NOTE Confidence: 0.829280976923077

00:44:52.110 --> 00:44:53.174 Leverage that experience and

NOTE Confidence: 0.829280976923077

00:44:53.174 --> 00:44:55.359 rely on it as part of your team.

NOTE Confidence: 0.8697707

00:44:57.570 --> 00:44:59.622 As clinicians, we need to help

NOTE Confidence: 0.8697707

00:44:59.622 --> 00:45:00.990 families identify their resources

NOTE Confidence: 0.8697707

00:45:01.050 --> 00:45:02.870 and strengths and their struggles.

NOTE Confidence: 0.8697707

00:45:02.870 --> 00:45:05.522 We need to promote the first

NOTE Confidence: 0.8697707

00:45:05.522 --> 00:45:07.910 two and normalize the third.

NOTE Confidence: 0.8697707

00:45:07.910 --> 00:45:09.499 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

00:45:15.640 --> 00:45:16.645 diversify their portfolios.

00:45:16.650 --> 00:45:19.002 Our job is to help them recognize the

00:45:19.002 --> 00:45:21.494 things that they already have in their

00:45:21.494 --> 00:45:23.329 Arsenal or resilience resources so

00:45:23.390 --> 00:45:25.707 they can go from getting through to

00:45:25.707 --> 00:45:28.970 starting to harness those resources.

00:45:28.970 --> 00:45:31.224 And how I do that? Is this?

00:45:31.224 --> 00:45:33.156 I ask about thoughts I'll say.

00:45:33.160 --> 00:45:35.086 How do you see your experiences?

00:45:35.090 --> 00:45:36.695 That helps me understand their

00:45:36.695 --> 00:45:37.658 existential resilience resources.

00:45:37.660 --> 00:45:38.928 I ask that actions.

00:45:38.928 --> 00:45:41.530 What do you do when things are hard?

NOTE Confidence: 0.8697707

00:45:41.530 --> 00:45:43.140 What have you done before?

NOTE Confidence: 0.8697707

00:45:43.140 --> 00:45:44.750 When times have gotten tough?

NOTE Confidence: 0.8697707

00:45:44.750 --> 00:45:46.355 This helps me identify their

NOTE Confidence: 0.8697707

00:45:46.355 --> 00:45:47.322 individual resilience, resources.

NOTE Confidence: 0.8697707

00:45:47.322 --> 00:45:49.254 And finally I ask about supports.

NOTE Confidence: 0.8697707

00:45:49.260 --> 00:45:50.022 Who supports you?

NOTE Confidence: 0.8697707

00:45:50.022 --> 00:45:51.800 This is me taking a sort of

NOTE Confidence: 0.8697707

00:45:51.862 --> 00:45:54.196 categorization and or an inventory of

NOTE Confidence: 0.8697707

00:45:54.196 --> 00:45:55.671 their social resilience, resources.

NOTE Confidence: 0.8697707

00:45:55.671 --> 00:45:57.778 And together I can sort of recognize

NOTE Confidence: 0.8697707

00:45:57.778 --> 00:45:59.481 which of those three buckets

NOTE Confidence: 0.8697707

00:45:59.481 --> 00:46:00.528 is relatively full,

NOTE Confidence: 0.8697707

00:46:00.530 --> 00:46:02.360 or which is relatively empty.

NOTE Confidence: 0.8697707

00:46:02.360 --> 00:46:04.088 And I can help them articulate

NOTE Confidence: 0.8697707

00:46:04.088 --> 00:46:05.240 those resources they'll need.

NOTE Confidence: 0.77159935

00:46:07.700 --> 00:46:09.866 Last I'm going to close with

NOTE Confidence: 0.77159935

00:46:09.866 --> 00:46:11.310 advice from Daniel Maher.

NOTE Confidence: 0.77159935

00:46:11.310 --> 00:46:13.676 Who said you have to work sometimes

NOTE Confidence: 0.77159935

00:46:13.676 --> 00:46:16.346 to be happy to move past the hard?

NOTE Confidence: 0.77159935

00:46:16.350 --> 00:46:20.726 The sad the scary. We all do it.

NOTE Confidence: 0.77159935

00:46:20.730 --> 00:46:22.956 But maybe you need help sometimes.

NOTE Confidence: 0.77159935

00:46:22.960 --> 00:46:24.745 Maybe you need a little bit of

NOTE Confidence: 0.77159935

00:46:24.745 --> 00:46:26.910 learning or a little bit of strength,

NOTE Confidence: 0.77159935

00:46:26.910 --> 00:46:28.382 or remembering what matters

NOTE Confidence: 0.77159935

00:46:28.382 --> 00:46:29.854 or a little after.

NOTE Confidence: 0.77159935

00:46:29.860 --> 00:46:32.209 Poor little love.

NOTE Confidence: 0.77159935

00:46:32.210 --> 00:46:35.306 Figure out what you need and hold on.

NOTE Confidence: 0.77159935

00:46:35.310 --> 00:46:35.972 But please,

NOTE Confidence: 0.77159935

00:46:35.972 --> 00:46:38.289 whatever you do live the time you

NOTE Confidence: 0.77159935

00:46:38.289 --> 00:46:40.348 have with meaning and purpose.

NOTE Confidence: 0.84840804

00:46:44.590 --> 00:46:46.894 I want to thank the many members of the

NOTE Confidence: 0.84840804

00:46:46.894 --> 00:46:48.440 palliative care and Resilience Lab,

NOTE Confidence: 0.84840804

00:46:48.440 --> 00:46:49.544 in particular, Joy C.

NOTE Confidence: 0.84840804

00:46:49.544 --> 00:46:51.135 Fraser, who is my research partner

NOTE Confidence: 0.84840804

00:46:51.135 --> 00:46:52.840 and the Co creator of Prism.

NOTE Confidence: 0.84840804

00:46:52.840 --> 00:46:54.040 We have many mentors,

NOTE Confidence: 0.84840804

00:46:54.040 --> 00:46:55.240 advisors and collaborators who

NOTE Confidence: 0.84840804

00:46:55.240 --> 00:46:56.688 have helped us along the way,

NOTE Confidence: 0.84840804

00:46:56.690 --> 00:46:58.424 as well as multiple funders that

NOTE Confidence: 0.84840804

00:46:58.424 --> 00:47:00.606 I'd like to thank and thank you to

NOTE Confidence: 0.84840804

00:47:00.606 --> 00:47:02.470 all of you for being here today.

NOTE Confidence: 0.84840804

00:47:02.470 --> 00:47:03.952 I'm going to stop sharing my

NOTE Confidence: 0.84840804

00:47:03.952 --> 00:47:05.905 slides so that we can have some

NOTE Confidence: 0.84840804

00:47:05.905 --> 00:47:07.415 time for questions and answers.

NOTE Confidence: 0.84840804

00:47:07.420 --> 00:47:08.242 Appreciate you all.

NOTE Confidence: 0.84840804

00:47:08.242 --> 00:47:08.790 Thank you.

NOTE Confidence: 0.86417437

00:47:14.810 --> 00:47:16.959 Abby, thank you so much for such

NOTE Confidence: 0.86417437

00:47:16.959 --> 00:47:18.929 a powerful and inspiring talk.

NOTE Confidence: 0.86417437

00:47:18.930 --> 00:47:21.024 While we're waiting for folks to

NOTE Confidence: 0.86417437

00:47:21.024 --> 00:47:23.040 pop their questions into the chat,

NOTE Confidence: 0.86417437

00:47:23.040 --> 00:47:25.602 I thought maybe we could start out

NOTE Confidence: 0.86417437

00:47:25.602 --> 00:47:28.720 with a couple of my questions.

NOTE Confidence: 0.86417437

00:47:28.720 --> 00:47:30.685 Uhm, what sorts of obstacles

NOTE Confidence: 0.86417437

00:47:30.685 --> 00:47:32.650 early on did you encounter?

NOTE Confidence: 0.86417437

00:47:32.650 --> 00:47:34.218 Or you know where?

NOTE Confidence: 0.86417437

00:47:34.218 --> 00:47:36.583 There are people who were naysayers

NOTE Confidence: 0.86417437

00:47:36.583 --> 00:47:38.548 or disbelievers in this approach?

NOTE Confidence: 0.86417437

00:47:38.550 --> 00:47:39.790 And how did you?

NOTE Confidence: 0.86417437

00:47:39.790 --> 00:47:42.242 How did you overcome some of those

NOTE Confidence: 0.86417437

00:47:42.242 --> 00:47:44.827 obstacles or address people's concerns?

NOTE Confidence: 0.77937376

00:47:46.110 --> 00:47:48.035 Oh gosh, this is such a good

NOTE Confidence: 0.77937376

00:47:48.035 --> 00:47:51.060 question pressing it, I think.

NOTE Confidence: 0.77937376

00:47:51.060 --> 00:47:51.387 Philosophically,

NOTE Confidence: 0.77937376

00:47:51.387 --> 00:47:53.349 I guess I have two answers.

NOTE Confidence: 0.77937376

00:47:53.350 --> 00:47:55.639 One is, believe in what you're doing.

NOTE Confidence: 0.77937376

00:47:55.640 --> 00:47:58.070 So I one of the first people I talked

NOTE Confidence: 0.77937376

00:47:58.070 --> 00:48:00.683 to here in Seattle about this idea is

NOTE Confidence: 0.77937376

00:48:00.683 --> 00:48:03.487 someone who I really respect and admire.

NOTE Confidence: 0.77937376

00:48:03.490 --> 00:48:05.446 And she said I don't think

NOTE Confidence: 0.77937376

00:48:05.446 --> 00:48:06.424 resilience is changeable.

NOTE Confidence: 0.77937376

00:48:06.430 --> 00:48:08.290 I just don't think that that's

NOTE Confidence: 0.77937376

00:48:08.290 --> 00:48:10.030 going to be a thing.

NOTE Confidence: 0.77937376

00:48:10.030 --> 00:48:12.638 I don't think this is a good idea,

NOTE Confidence: 0.77937376

00:48:12.640 --> 00:48:14.184 and as a young.

NOTE Confidence: 0.77937376

00:48:14.184 --> 00:48:16.114 Faculty member I was devastated,

NOTE Confidence: 0.77937376

00:48:16.120 --> 00:48:18.910 but I felt like my idea still needed some.

NOTE Confidence: 0.77937376

00:48:18.910 --> 00:48:20.863 I don't know unpacking so I moved

NOTE Confidence: 0.77937376

00:48:20.863 --> 00:48:22.640 around to find mentors who would

NOTE Confidence: 0.77937376

00:48:22.640 --> 00:48:24.677 support me and I think for early

NOTE Confidence: 0.77937376

00:48:24.741 --> 00:48:26.835 career faculty that piece of advice

NOTE Confidence: 0.77937376

00:48:26.835 --> 00:48:28.838 is really necessary that you need

NOTE Confidence: 0.77937376

00:48:28.838 --> 00:48:30.632 someone who believes in you and

NOTE Confidence: 0.77937376

00:48:30.632 --> 00:48:32.761 you need people who will also help

NOTE Confidence: 0.77937376

00:48:32.761 --> 00:48:34.780 you find holes in your project.

NOTE Confidence: 0.77937376

00:48:34.780 --> 00:48:38.668 Which leads me to the next thing you know.

NOTE Confidence: 0.77937376

00:48:38.670 --> 00:48:40.110 Science is defined by failures

NOTE Confidence: 0.77937376

00:48:40.110 --> 00:48:41.550 we learn from those failures.

NOTE Confidence: 0.77937376

00:48:41.550 --> 00:48:43.278 And that's maybe one of the

NOTE Confidence: 0.77937376

00:48:43.278 --> 00:48:44.430 messages of resilience too.

NOTE Confidence: 0.77937376

00:48:44.430 --> 00:48:46.140 But you need to be around

NOTE Confidence: 0.77937376

00:48:46.140 --> 00:48:47.600 people who will push you.

NOTE Confidence: 0.77937376

00:48:47.600 --> 00:48:49.040 Who will help challenge you.

NOTE Confidence: 0.77937376

00:48:49.040 --> 00:48:51.384 Who will help you think about the ways

NOTE Confidence: 0.77937376

00:48:51.384 --> 00:48:53.356 that something might or might not work,

NOTE Confidence: 0.77937376

00:48:53.360 --> 00:48:55.076 and so that same person who

NOTE Confidence: 0.77937376

00:48:55.076 --> 00:48:56.847 made me question it is somebody

NOTE Confidence: 0.77937376

00:48:56.847 --> 00:48:58.533 who I now really rely on.

NOTE Confidence: 0.77937376

00:48:58.540 --> 00:49:00.876 When I have an idea 'cause I know

NOTE Confidence: 0.77937376

00:49:00.876 --> 00:49:02.570 she's going to be like Nope,

NOTE Confidence: 0.77937376

00:49:02.570 --> 00:49:03.862 still a bad idea.

NOTE Confidence: 0.77937376

00:49:03.862 --> 00:49:05.800 Abby and that helps me think

NOTE Confidence: 0.77937376

00:49:05.877 --> 00:49:08.285 around all of the barriers so that

NOTE Confidence: 0.77937376

00:49:08.285 --> 00:49:10.519 I can continue to move forward.

NOTE Confidence: 0.77937376

00:49:10.520 --> 00:49:12.572 The last thing I think though

NOTE Confidence: 0.77937376

00:49:12.572 --> 00:49:14.240 about all of this is.

NOTE Confidence: 0.77937376

00:49:14.240 --> 00:49:16.039 Finding meaning and purpose in the work

NOTE Confidence: 0.77937376

00:49:16.039 --> 00:49:18.098 that we do is critically important.

NOTE Confidence: 0.77937376

00:49:18.100 --> 00:49:19.545 As clinicians as scientists would

NOTE Confidence: 0.77937376

00:49:19.545 --> 00:49:21.940 you have to have the passion and the

NOTE Confidence: 0.77937376

00:49:21.940 --> 00:49:24.033 belief that what you were doing matters?

NOTE Confidence: 0.77937376

00:49:24.040 --> 00:49:26.224 And for me this is bad for other

NOTE Confidence: 0.77937376

00:49:26.224 --> 00:49:27.962 people that we can be taking

NOTE Confidence: 0.77937376

00:49:27.962 --> 00:49:30.047 care of a patient or writing a

NOTE Confidence: 0.77937376

00:49:30.047 --> 00:49:31.757 paper or mentoring or teaching.

NOTE Confidence: 0.77937376

00:49:31.760 --> 00:49:33.768 But the thing that we all need to

NOTE Confidence: 0.77937376

00:49:33.768 --> 00:49:35.855 do is to figure out what brings

NOTE Confidence: 0.77937376

00:49:35.855 --> 00:49:38.096 us value in our lives and how

NOTE Confidence: 0.77937376

00:49:38.096 --> 00:49:40.076 can we continue to champion that.

NOTE Confidence: 0.87921274

00:49:46.020 --> 00:49:48.006 Thanks so much. I'm still waiting

NOTE Confidence: 0.87921274

00:49:48.006 --> 00:49:50.040 for anyone who has questions.

NOTE Confidence: 0.87921274

00:49:50.040 --> 00:49:55.287 In the Meanwhile I of course have so many.

NOTE Confidence: 0.87921274

00:49:55.290 --> 00:49:57.470 One thing I was wondering

NOTE Confidence: 0.87921274

00:49:57.470 --> 00:49:59.645 about in terms of scalability.

NOTE Confidence: 0.87921274

00:49:59.650 --> 00:50:03.274 So what do you say now with this

NOTE Confidence: 0.87921274

00:50:03.274 --> 00:50:05.079 robust intervention that now

NOTE Confidence: 0.87921274

00:50:05.079 --> 00:50:07.497 has a mobile option as well?

NOTE Confidence: 0.87921274

00:50:07.500 --> 00:50:10.209 What have you said to folks at

NOTE Confidence: 0.87921274

00:50:10.209 --> 00:50:12.300 various institutions who may be

NOTE Confidence: 0.87921274

00:50:12.300 --> 00:50:14.445 interested in bringing a similar

NOTE Confidence: 0.87921274

00:50:14.445 --> 00:50:16.650 intervention to their institution?

NOTE Confidence: 0.57742035

00:50:18.990 --> 00:50:19.360 Soon.

NOTE Confidence: 0.8216776

00:50:21.890 --> 00:50:23.550 Two things I want.

NOTE Confidence: 0.8216776

00:50:23.550 --> 00:50:26.610 I want prism out there at like.

NOTE Confidence: 0.8216776

00:50:26.610 --> 00:50:28.717 I just think that it has potential

NOTE Confidence: 0.8216776

00:50:28.717 --> 00:50:31.027 and I would welcome anybody who wants

NOTE Confidence: 0.8216776

00:50:31.027 --> 00:50:33.819 to help me figure out how to do that.

NOTE Confidence: 0.8216776

00:50:33.820 --> 00:50:38.068 And as folks in this audience will know.

NOTE Confidence: 0.8216776

00:50:38.070 --> 00:50:38.958 Doing anything takes

NOTE Confidence: 0.8216776

00:50:38.958 --> 00:50:40.438 resources and money and time,

99

NOTE Confidence: 0.8216776

00:50:40.440 --> 00:50:42.536 and so one of the things we have

NOTE Confidence: 0.8216776

00:50:42.536 --> 00:50:44.417 learned in this pilot study that

NOTE Confidence: 0.8216776

00:50:44.417 --> 00:50:46.355 we're doing here in Seattle is,

NOTE Confidence: 0.8216776

00:50:46.360 --> 00:50:48.130 even if we make it available,

NOTE Confidence: 0.8216776

00:50:48.130 --> 00:50:50.306 people don't use it if they don't have

NOTE Confidence: 0.8216776

00:50:50.306 --> 00:50:52.280 the human resources to deliver it.

NOTE Confidence: 0.8216776

00:50:52.280 --> 00:50:53.036 So right now,

NOTE Confidence: 0.8216776

00:50:53.036 --> 00:50:54.548 it's just it's designed to be

NOTE Confidence: 0.8216776

00:50:54.548 --> 00:50:56.192 an in person coaching program

NOTE Confidence: 0.8216776

00:50:56.192 --> 00:50:58.196 because I think that that matters.

NOTE Confidence: 0.8216776

00:50:58.200 --> 00:50:59.680 I think that human connection

NOTE Confidence: 0.8216776

00:50:59.680 --> 00:51:00.568 is really necessary.

NOTE Confidence: 0.8829647

00:51:02.680 --> 00:51:03.960 But we're learning that that

NOTE Confidence: 0.8829647

00:51:03.960 --> 00:51:05.710 might be a huge huge barrier,

NOTE Confidence: 0.8829647

00:51:05.710 --> 00:51:07.747 and so the next study where we're

NOTE Confidence: 0.8829647

00:51:07.747 --> 00:51:09.692 designing right now is in fact trying

NOTE Confidence: 0.8829647

00:51:09.692 --> 00:51:11.803 to ask the question that you just asked

NOTE Confidence: 0.8829647

00:51:11.803 --> 00:51:13.955 how much digital can we get away with?

NOTE Confidence: 0.8829647

00:51:13.960 --> 00:51:15.904 How much can we get away with taking

NOTE Confidence: 0.8829647

00:51:15.904 --> 00:51:17.528 away the in person component?

NOTE Confidence: 0.8829647

00:51:17.530 --> 00:51:18.630 Will that compromise the

NOTE Confidence: 0.8829647

00:51:18.630 --> 00:51:19.730 efficacy of the program?

NOTE Confidence: 0.8829647

00:51:19.730 --> 00:51:21.655 I think the answer is probably yes,

NOTE Confidence: 0.8829647

00:51:21.660 --> 00:51:23.627 but it turns out funders and other

NOTE Confidence: 0.8829647

00:51:23.627 --> 00:51:25.228 organizations need us to prove that,

NOTE Confidence: 0.8829647

00:51:25.230 --> 00:51:28.006 and so that's what we're working on now.

NOTE Confidence: 0.8829647

00:51:28.010 --> 00:51:29.636 And I'll just say, you know,

NOTE Confidence: 0.8829647

00:51:29.640 --> 00:51:31.152 imagine the number of little apps

NOTE Confidence: 0.8829647

00:51:31.152 --> 00:51:32.958 that you have on your phone that

NOTE Confidence: 0.8829647

00:51:32.958 --> 00:51:34.687 are self help or mental health or

NOTE Confidence: 0.8829647

00:51:34.743 --> 00:51:36.408 whatever other programs you have.

NOTE Confidence: 0.8829647

00:51:36.410 --> 00:51:38.849 And most of us don't open them at all.

NOTE Confidence: 0.8829647

00:51:38.850 --> 00:51:40.794 And when we do we open them for a

NOTE Confidence: 0.8829647

00:51:40.794 --> 00:51:42.704 few weeks and then we stop and that

NOTE Confidence: 0.8829647

00:51:42.704 --> 00:51:44.871 to me is why prison works better

NOTE Confidence: 0.8829647

00:51:44.871 --> 00:51:46.971 because there is a human interaction

NOTE Confidence: 0.8829647

00:51:46.980 --> 00:51:48.415 you're engaging with somebody who

NOTE Confidence: 0.8829647

00:51:48.415 --> 00:51:50.230 cares about you who listens to you,

NOTE Confidence: 0.8829647

00:51:50.230 --> 00:51:50.857 who coaches you.

NOTE Confidence: 0.8829647

00:51:50.857 --> 00:51:52.982 And so I worry a little bit about moving

NOTE Confidence: 0.8829647

00:51:52.982 --> 00:51:54.806 things purely to digital health without

NOTE Confidence: 0.8829647

00:51:54.806 --> 00:51:56.469 that degree of human interaction,

NOTE Confidence: 0.8829647

00:51:56.470 --> 00:51:58.090 especially for teens and young adults.

NOTE Confidence: 0.8781899

00:51:59.370 --> 00:52:01.505 Absolutely. How did you adapt

NOTE Confidence: 0.8781899

00:52:01.505 --> 00:52:03.640 during the during the pandemic?

NOTE Confidence: 0.8606684

00:52:05.170 --> 00:52:07.506 Wait, so we switched to the whole thing.

NOTE Confidence: 0.8606684

00:52:07.510 --> 00:52:09.751 We used to go as I said to the

NOTE Confidence: 0.8606684

00:52:09.751 --> 00:52:11.651 patient's bedside and we would sit

NOTE Confidence: 0.8606684

00:52:11.651 --> 00:52:13.929 next to somebody and coach with them.

NOTE Confidence: 0.8606684

00:52:13.930 --> 00:52:16.121 And then we held the program for

NOTE Confidence: 0.8606684

00:52:16.121 --> 00:52:18.437 about six months as many in the world

NOTE Confidence: 0.8606684

00:52:18.437 --> 00:52:20.961 did when when we all kind of had to

NOTE Confidence: 0.8606684

00:52:20.961 --> 00:52:22.990 figure out how this new normal would

NOTE Confidence: 0.8606684

00:52:22.990 --> 00:52:25.390 work and when we came back in about

NOTE Confidence: 0.8606684

00:52:25.390 --> 00:52:27.357 maybe a little over a year ago.

NOTE Confidence: 0.8606684

00:52:27.360 --> 00:52:28.835 Last summer, we started delivering

NOTE Confidence: 0.8606684

00:52:28.835 --> 00:52:30.936 the program purely via Tele Health and

NOTE Confidence: 0.8606684

00:52:30.936 --> 00:52:32.652 what was super fascinating is that

NOTE Confidence: 0.8606684

00:52:32.652 --> 00:52:34.369 especially for teens and young adults,

NOTE Confidence: 0.8606684

00:52:34.370 --> 00:52:35.654 maybe because they're more.

NOTE Confidence: 0.8606684

00:52:35.654 --> 00:52:37.580 Fluent and savvy and things like

NOTE Confidence: 0.8606684

00:52:37.637 --> 00:52:39.779 FaceTime and digital ways of connecting.

NOTE Confidence: 0.8606684

00:52:39.780 --> 00:52:42.525 Anyway, they seem to like it better this way.

NOTE Confidence: 0.8606684

00:52:42.530 --> 00:52:44.834 They seem to feel like this is almost

NOTE Confidence: 0.8606684

00:52:44.834 --> 00:52:47.410 a safer way for them to be vulnerable.

NOTE Confidence: 0.8606684

00:52:47.410 --> 00:52:49.524 They can sort of move back from

NOTE Confidence: 0.8606684

00:52:49.524 --> 00:52:51.370 the screen if they need to.

NOTE Confidence: 0.8606684

00:52:51.370 --> 00:52:55.418 They can engage in a way that is.

NOTE Confidence: 0.8606684

00:52:55.420 --> 00:52:55.696 Psychologically,

NOTE Confidence: 0.8606684

00:52:55.696 --> 00:52:57.628 more appropriate for them to my surprise.

NOTE Confidence: 0.8606684

00:52:57.630 --> 00:52:59.380 And so now I think moving forward

NOTE Confidence: 0.8606684

00:52:59.380 --> 00:53:01.219 we will only deliver the health.

NOTE Confidence: 0.8606684

00:53:01.220 --> 00:53:02.600 The program via Tele health.

NOTE Confidence: 0.8606684

00:53:02.600 --> 00:53:04.525 Unless somebody asks us to do otherwise,

NOTE Confidence: 0.8606684

00:53:04.530 --> 00:53:06.180 and we'll see how it goes.

NOTE Confidence: 0.83027625

00:53:10.260 --> 00:53:12.650 When you were starting out

NOTE Confidence: 0.83027625

00:53:12.650 --> 00:53:14.084 with developing Prism,

NOTE Confidence: 0.83027625

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

NOTE Confidence: 0.85549736

00:53:54.580 --> 00:53:56.425 they would be receiving chemotherapy

NOTE Confidence: 0.85549736

00:53:56.425 --> 00:53:58.898 and in the hospital and needing

NOTE Confidence: 0.85549736

00:53:58.898 --> 00:54:00.197 some additional support.

NOTE Confidence: 0.85549736

00:54:00.200 --> 00:54:01.940 And so in that first study

NOTE Confidence: 0.85549736

00:54:01.940 --> 00:54:03.100 of roughly 92 people,

NOTE Confidence: 0.85549736

00:54:03.100 --> 00:54:05.428 3/4 of them were teens with brand new

NOTE Confidence: 0.85549736

00:54:05.428 --> 00:54:07.736 cancers and then about 1/4 of them work.

NOTE Confidence: 0.85549736

00:54:07.740 --> 00:54:09.228 Folks who had been well and

NOTE Confidence: 0.85549736

00:54:09.228 --> 00:54:10.930 then had had a recurrence.

NOTE Confidence: 0.85549736

00:54:10.930 --> 00:54:13.186 And when we tried to look at the

NOTE Confidence: 0.85549736

00:54:13.186 --> 00:54:14.410 differences between the groups,

NOTE Confidence: 0.85549736

00:54:14.410 --> 00:54:15.830 we couldn't find anything that

NOTE Confidence: 0.85549736

00:54:15.830 --> 00:54:17.600 said prison work better or worse.

NOTE Confidence: 0.85549736

00:54:17.600 --> 00:54:19.824 If you were new to cancer or really

NOTE Confidence: 0.85549736

00:54:19.824 --> 00:54:21.080 experienced with your cancer,

NOTE Confidence: 0.85549736

00:54:21.080 --> 00:54:22.865 the thing that we did notice that

NOTE Confidence: 0.85549736

00:54:22.865 --> 00:54:24.386 was different in the patients

NOTE Confidence: 0.85549736

00:54:24.386 --> 00:54:25.430 with advanced cancer.

NOTE Confidence: 0.85549736

00:54:25.430 --> 00:54:26.885 And then this was replicated

NOTE Confidence: 0.85549736

00:54:26.885 --> 00:54:28.620 amongst teens with CF is hey,

NOTE Confidence: 0.85549736

00:54:28.620 --> 00:54:30.916 Prism just taught me all this stuff about

NOTE Confidence: 0.85549736

00:54:30.916 --> 00:54:33.710 how to identify what matters to me and why.

NOTE Confidence: 0.85549736

00:54:33.710 --> 00:54:36.150 My goals are and now I need help

NOTE Confidence: 0.85549736

00:54:36.150 --> 00:54:38.319 talking to my family about this.

NOTE Confidence: 0.85549736

00:54:38.320 --> 00:54:40.105 And so as I sort of quickly

NOTE Confidence: 0.85549736

00:54:40.105 --> 00:54:41.820 described one of our larger grants

NOTE Confidence: 0.85549736

00:54:41.820 --> 00:54:43.892 right now is building on that for

NOTE Confidence: 0.85549736

00:54:43.950 --> 00:54:45.806 patients specifically with advanced

NOTE Confidence: 0.85549736

00:54:45.806 --> 00:54:47.198 an incurable cancer.

NOTE Confidence: 0.85549736

00:54:47.200 --> 00:54:47.798 I'm saying,

NOTE Confidence: 0.85549736

00:54:47.798 --> 00:54:50.190 can we teach these four skills and then

NOTE Confidence: 0.85549736

00:54:50.251 --> 00:54:52.673 build on that to integrate advanced care

NOTE Confidence: 0.85549736

00:54:52.673 --> 00:54:54.768 planning for teens and young adults?

NOTE Confidence: 0.85549736

00:54:54.770 --> 00:54:56.410 And that's important because maybe

NOTE Confidence: 0.85549736

00:54:56.410 --> 00:54:58.528 20% of teens and young adults in

NOTE Confidence: 0.85549736

00:54:58.528 --> 00:55:00.517 the United States actually fill out

NOTE Confidence: 0.85549736

00:55:00.517 --> 00:55:01.997 advance care planning documents.

NOTE Confidence: 0.85549736

00:55:02.000 --> 00:55:04.499 Fewer than that are involved in care

NOTE Confidence: 0.85549736

00:55:04.499 --> 00:55:06.253 decisions about their ongoing medical

NOTE Confidence: 0.85549736

00:55:06.253 --> 00:55:08.717 care and end of life plans and so.

NOTE Confidence: 0.85549736

00:55:08.720 --> 00:55:10.880 The idea was maybe PRISM can be a

NOTE Confidence: 0.85549736

00:55:10.880 --> 00:55:13.357 safer on tray into some of those

NOTE Confidence: 0.85549736

00:55:13.357 --> 00:55:15.624 really hard conversations that are so

NOTE Confidence: 0.85549736

00:55:15.624 --> 00:55:18.256 important at the end of the patient's life.

NOTE Confidence: 0.85549736

00:55:18.260 --> 00:55:18.895 Absolutely OK.

NOTE Confidence: 0.85549736

00:55:18.895 --> 00:55:21.418 We have a couple of hands race so

NOTE Confidence: 0.81486106

00:55:21.420 --> 00:55:23.088 I'm going to let Jeffrey Towns

NOTE Confidence: 0.81486106

00:55:23.088 --> 00:55:25.209 and go ahead and unmute yourself.

NOTE Confidence: 0.7398858

00:55:32.280 --> 00:55:33.480 Hopefully he can leave.

NOTE Confidence: 0.7841317

00:55:42.940 --> 00:55:45.365 Alright, well, while we're waiting

NOTE Confidence: 0.7841317

00:55:45.365 --> 00:55:47.305 for Doctor Townsend Amanda

NOTE Confidence: 0.7841317

00:55:47.305 --> 00:55:50.220 Gorbaty near you able to unmute.

NOTE Confidence: 0.7637731

00:55:59.840 --> 00:56:01.880 Renee, I may need your help.

NOTE Confidence: 0.79661006

00:56:11.980 --> 00:56:14.255 Yeah, I just mark this a webinar

NOTE Confidence: 0.79661006

00:56:14.255 --> 00:56:16.218 so the attendees can send in

NOTE Confidence: 0.79661006

00:56:16.220 --> 00:56:19.770 something via the chat. Thanks, mark.

NOTE Confidence: 0.8706555

00:56:23.710 --> 00:56:25.348 Alright, so so Amanda and Jeffrey.

NOTE Confidence: 0.8706555

00:56:25.350 --> 00:56:26.994 If you want to put your

NOTE Confidence: 0.8706555

00:56:26.994 --> 00:56:28.090 questions into the chat,

NOTE Confidence: 0.8706555

00:56:28.090 --> 00:56:30.556 will be sure to try to get to them.

NOTE Confidence: 0.83050543

00:56:46.920 --> 00:56:47.624 Overweighting Abby.

NOTE Confidence: 0.83050543

00:56:47.624 --> 00:56:50.088 I wondered if you might be able

NOTE Confidence: 0.83050543

00:56:50.088 --> 00:56:52.400 to share how you thought about

NOTE Confidence: 0.83050543

00:56:52.400 --> 00:56:54.290 measuring some of those longer

NOTE Confidence: 0.83050543

00:56:54.362 --> 00:56:56.189 term psychological outcomes,

NOTE Confidence: 0.83050543

00:56:56.190 --> 00:56:59.263 or in terms of outcomes like.

NOTE Confidence: 0.83050543

00:56:59.263 --> 00:57:03.560 Job attainment or long term mental health.

NOTE Confidence: 0.8551477

00:57:04.160 --> 00:57:06.182 Yeah, oh, such an apropos question

NOTE Confidence: 0.8551477

00:57:06.182 --> 00:57:08.199 we're looking at that right now.

NOTE Confidence: 0.8551477

00:57:08.200 --> 00:57:10.328 So of those 92 patients that we

NOTE Confidence: 0.8551477

00:57:10.328 --> 00:57:12.590 had in that first pilot trial.

NOTE Confidence: 0.8551477

00:57:12.590 --> 00:57:15.422 So now we're talking about a small study

NOTE Confidence: 0.8551477

00:57:15.422 --> 00:57:18.238 because the other big studies are ongoing.

NOTE Confidence: 0.8551477

00:57:18.240 --> 00:57:22.060 But of those 92 patients?

NOTE Confidence: 0.8551477

00:57:22.060 --> 00:57:24.160 A little less than a third

NOTE Confidence: 0.8551477

00:57:24.160 --> 00:57:25.830 30% have died since then.

NOTE Confidence: 0.8551477

00:57:25.830 --> 00:57:28.709 In the two years that followed that project,

NOTE Confidence: 0.8551477

00:57:28.710 --> 00:57:31.426 and that is across both advanced cancer

NOTE Confidence: 0.8551477

00:57:31.426 --> 00:57:34.537 and new cancer patients in equal measure.

NOTE Confidence: 0.8551477

00:57:34.540 --> 00:57:36.745 So we're down to a little over

NOTE Confidence: 0.8551477

00:57:36.745 --> 00:57:39.228 50 folks who we can still follow,

NOTE Confidence: 0.8551477

00:57:39.230 --> 00:57:41.614 and it's harder to gauge long term outcomes

NOTE Confidence: 0.8551477

00:57:41.614 --> 00:57:44.258 in a smaller and smaller sample size.

NOTE Confidence: 0.8551477

00:57:44.260 --> 00:57:45.930 That said, what we're noticing,

NOTE Confidence: 0.8551477

00:57:45.930 --> 00:57:48.275 which is really interesting to me is,

NOTE Confidence: 0.8551477

00:57:48.280 --> 00:57:50.290 and this is like an ongoing

NOTE Confidence: 0.8551477

00:57:50.290 --> 00:57:51.630 work in progress data,

NOTE Confidence: 0.8551477

00:57:51.630 --> 00:57:53.586 so forgive me 'cause it might

NOTE Confidence: 0.8551477

00:57:53.586 --> 00:57:55.649 change when we finally publish it.

NOTE Confidence: 0.8551477

00:57:55.650 --> 00:57:58.338 But the initial analysis that we're

NOTE Confidence: 0.8551477

00:57:58.338 --> 00:58:00.940 looking at right now suggests.

NOTE Confidence: 0.8551477

00:58:00.940 --> 00:58:03.328 Two really interesting things.

NOTE Confidence: 0.8551477

00:58:03.330 --> 00:58:03.677 First,

NOTE Confidence: 0.8551477

00:58:03.677 --> 00:58:05.759 people who responded to PRISM in

NOTE Confidence: 0.8551477

00:58:05.759 --> 00:58:07.488 that beginning six months phase

NOTE Confidence: 0.8551477

00:58:07.488 --> 00:58:09.672 have a long term protection of it.

NOTE Confidence: 0.8551477

00:58:09.680 --> 00:58:12.112 So if you if you were in the

NOTE Confidence: 0.8551477

00:58:12.112 --> 00:58:13.680 group who got prison.

NOTE Confidence: 0.8078167

00:58:16.430 --> 00:58:18.090 Khalaj Ikle benefit seems

NOTE Confidence: 0.8078167

00:58:18.090 --> 00:58:20.165 to indoor two years later,

NOTE Confidence: 0.8078167

00:58:20.170 --> 00:58:22.660 so that sense of new resilience.

NOTE Confidence: 0.8078167

00:58:22.660 --> 00:58:25.691 Hope for the future and ability to

NOTE Confidence: 0.8078167

00:58:25.691 --> 00:58:28.858 find meaning and benefit those indoor.

NOTE Confidence: 0.8078167

00:58:28.860 --> 00:58:30.116 What is more interesting,

NOTE Confidence: 0.8078167

00:58:30.116 --> 00:58:32.615 in a different way is that while

NOTE Confidence: 0.8078167

00:58:32.615 --> 00:58:34.250 distress immediately improved,

NOTE Confidence: 0.8078167

00:58:34.250 --> 00:58:36.180 and as I showed you,

NOTE Confidence: 0.8078167

00:58:36.180 --> 00:58:38.100 depression risk went way down.

NOTE Confidence: 0.8078167

00:58:38.100 --> 00:58:39.680 That risk of endurable,

NOTE Confidence: 0.8078167

00:58:39.680 --> 00:58:40.865 non negative psychological

NOTE Confidence: 0.8078167

00:58:40.865 --> 00:58:42.720 outcome doesn't seem to persist,

NOTE Confidence: 0.8078167

00:58:42.720 --> 00:58:44.992 and So what I mean by that is

NOTE Confidence: 0.8078167

00:58:44.992 --> 00:58:47.073 people were no longer distress

NOTE Confidence: 0.8078167

00:58:47.073 --> 00:58:48.989 during their immediate cancer

NOTE Confidence: 0.8078167

00:58:48.989 --> 00:58:51.190 experience when they got PRISM,

NOTE Confidence: 0.8078167

00:58:51.190 --> 00:58:53.015 but overtime there's a regression

NOTE Confidence: 0.8078167

00:58:53.015 --> 00:58:55.352 to the mean between usual Karen

NOTE Confidence: 0.8078167

00:58:55.352 --> 00:58:57.116 Prism participants with respect

NOTE Confidence: 0.8078167

00:58:57.116 --> 00:58:58.880 to their overall distress.

NOTE Confidence: 0.8078167

00:58:58.880 --> 00:59:00.610 And the combination of those

NOTE Confidence: 0.8078167

00:59:00.610 --> 00:59:02.340 things tells me two things.

NOTE Confidence: 0.8078167

00:59:02.340 --> 00:59:03.024 Number one,

NOTE Confidence: 0.8078167

00:59:03.024 --> 00:59:05.076 we do want to alleviate negative

NOTE Confidence: 0.8078167

00:59:05.076 --> 00:59:06.490 pathology in the moment,

NOTE Confidence: 0.8078167

00:59:06.490 --> 00:59:08.566 so we do want to alleviate

NOTE Confidence: 0.8078167

00:59:08.566 --> 00:59:09.950 distress in real time.

NOTE Confidence: 0.8078167

00:59:09.950 --> 00:59:11.390 But the long term benefit

NOTE Confidence: 0.8078167

00:59:11.390 --> 00:59:13.284 of PRISM might be that that

NOTE Confidence: 0.8078167

00:59:13.284 --> 00:59:15.234 positive psychological gain is an

NOTE Confidence: 0.8078167

00:59:15.234 --> 00:59:17.220 inoculation for later well being.

NOTE Confidence: 0.8078167

00:59:17.220 --> 00:59:19.924 And what I mean by that is you

NOTE Confidence: 0.8078167

00:59:19.924 --> 00:59:21.718 want somebody's hope for the

NOTE Confidence: 0.8078167

00:59:21.718 --> 00:59:24.140 future to be the thing that lasts.

NOTE Confidence: 0.8078167

00:59:24.140 --> 00:59:26.359 I care less that they are not

NOTE Confidence: 0.8078167

00:59:26.359 --> 00:59:28.499 distressed overtime as much as that

NOTE Confidence: 0.8078167

00:59:28.499 --> 00:59:30.369 they maintain that positive outlook,

NOTE Confidence: 0.8078167

00:59:30.370 --> 00:59:32.300 because I believe that when

NOTE Confidence: 0.8078167

00:59:32.300 --> 00:59:33.844 the next stressor comes.

NOTE Confidence: 0.8078167

00:59:33.850 --> 00:59:35.032 That positive psychological

NOTE Confidence: 0.8078167

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

NOTE Confidence: 0.8328513

01:00:10.975 --> 01:00:13.672 it looks like people aren't able to

NOTE Confidence: 0.8328513

01:00:13.672 --> 01:00:16.006 actually put messages into the chat,

NOTE Confidence: 0.8328513

01:00:16.010 --> 01:00:18.481 so I apologize so this this question

NOTE Confidence: 0.8328513

01:00:18.481 --> 01:00:20.520 is from Amanda Garber Teeny.

NOTE Confidence: 0.8328513

01:00:20.520 --> 01:00:22.400 She is a social worker

NOTE Confidence: 0.8328513

01:00:22.400 --> 01:00:23.904 in in pediatric oncology.

NOTE Confidence: 0.8328513

01:00:23.910 --> 01:00:26.454 She said she's traded a few emails with

NOTE Confidence: 0.8328513

01:00:26.454 --> 01:00:29.167 you so she's focused on adolescents,

NOTE Confidence: 0.8328513

01:00:29.170 --> 01:00:32.082 young adults and currently uses many prism

NOTE Confidence: 0.8328513

01:00:32.082 --> 01:00:34.767 techniques and models with her patients at.

NOTE Confidence: 0.8328513

01:00:34.770 --> 01:00:36.914 At Yale, so she was wondering if

NOTE Confidence: 0.8328513

01:00:36.914 --> 01:00:38.832 it would be possible to to have

NOTE Confidence: 0.8328513

01:00:38.832 --> 01:00:41.179 access to the app or other PRISM

NOTE Confidence: 0.8328513

01:00:41.179 --> 01:00:42.563 resources for her patients.

NOTE Confidence: 0.87691396

01:00:43.280 --> 01:00:44.810 Yes, so great question, Amanda.

NOTE Confidence: 0.87691396

116

01:00:44.810 --> 01:00:47.738 And thank you for asking it.

NOTE Confidence: 0.87691396

01:00:47.740 --> 01:00:50.377 The answer is yes and we as I said,

NOTE Confidence: 0.87691396

01:00:50.380 --> 01:00:52.277 we really do want to share this

NOTE Confidence: 0.87691396

01:00:52.277 --> 01:00:54.392 and we have ways to make be

NOTE Confidence: 0.87691396

01:00:54.392 --> 01:00:55.932 able to sustain the program.

NOTE Confidence: 0.87691396

01:00:55.940 --> 01:00:57.385 So we unfortunately right now

NOTE Confidence: 0.87691396

01:00:57.385 --> 01:00:59.170 cannot give it out for free.

NOTE Confidence: 0.87691396

01:00:59.170 --> 01:01:01.288 But please email me and I'm

NOTE Confidence: 0.87691396

01:01:01.288 --> 01:01:03.566 happy to chat with you about

NOTE Confidence: 0.87691396

01:01:03.566 --> 01:01:05.924 how we can provide the program.

NOTE Confidence: 0.87691396

01:01:05.930 --> 01:01:07.466 Cost effective way is we can

NOTE Confidence: 0.87691396

01:01:07.466 --> 01:01:09.403 until we can figure out how to

NOTE Confidence: 0.87691396

01:01:09.403 --> 01:01:10.833 publicly just make it available.

NOTE Confidence: 0.87525314

01:01:12.770 --> 01:01:14.810 Alright, well thank you so much

NOTE Confidence: 0.87525314

01:01:14.810 --> 01:01:16.859 Doctor Rosenberg for being here with

NOTE Confidence: 0.87525314

01:01:16.859 --> 01:01:18.749 us and for sharing your insights.

NOTE Confidence: 0.87525314

01:01:18.750 --> 01:01:20.425 And thanks to everyone who

NOTE Confidence: 0.87525314

01:01:20.425 --> 01:01:21.765 joined the webinar today.