

WEBVTT

NOTE duration:"01:14:46"

NOTE recognizability:0.856

NOTE language:en-us

NOTE Confidence: 0.805016308

00:00:00.000 --> 00:00:01.656 All right, my friends,

NOTE Confidence: 0.805016308

00:00:01.656 --> 00:00:04.757 I'll welcome to the Yale Pediatric Ethics

NOTE Confidence: 0.805016308

00:00:04.757 --> 00:00:07.183 Program Evening Ethics Seminar series,

NOTE Confidence: 0.805016308

00:00:07.183 --> 00:00:09.094 which which is Co hosted with the

NOTE Confidence: 0.805016308

00:00:09.094 --> 00:00:10.630 program for Biomedical Ethics here

NOTE Confidence: 0.805016308

00:00:10.630 --> 00:00:12.490 at the Yale School of Medicine.

NOTE Confidence: 0.805016308

00:00:12.490 --> 00:00:14.638 We have friends joining us from

NOTE Confidence: 0.805016308

00:00:14.638 --> 00:00:17.319 around here and from far away as well.

NOTE Confidence: 0.805016308

00:00:17.320 --> 00:00:19.354 I'm very very excited about tonight's

NOTE Confidence: 0.805016308

00:00:19.354 --> 00:00:21.459 program as I mentioned to you all

NOTE Confidence: 0.805016308

00:00:21.459 --> 00:00:23.427 on the mailing some time ago I was

NOTE Confidence: 0.805016308

00:00:23.427 --> 00:00:25.443 out at Saint Louis for a gathering

NOTE Confidence: 0.805016308

00:00:25.443 --> 00:00:27.163 of pediatric ethicists from around

NOTE Confidence: 0.805016308

00:00:27.163 --> 00:00:29.449 the country and and hurting all
NOTE Confidence: 0.805016308

00:00:29.449 --> 00:00:32.228 of these cats was was an ethicist
NOTE Confidence: 0.805016308

00:00:32.228 --> 00:00:33.780 named Doctor Erica Salter.
NOTE Confidence: 0.805016308

00:00:33.780 --> 00:00:35.670 And I was very impressed by her
NOTE Confidence: 0.805016308

00:00:35.670 --> 00:00:37.858 and and was and trying to get her
NOTE Confidence: 0.805016308

00:00:37.858 --> 00:00:39.808 here as quickly as I could and
NOTE Confidence: 0.805016308

00:00:39.808 --> 00:00:41.782 so if tonight we have Erica here
NOTE Confidence: 0.805016308

00:00:41.782 --> 00:00:45.880 on to lead us in in conversation.
NOTE Confidence: 0.805016308

00:00:45.880 --> 00:00:47.696 I want to introduce Doctor Saul to you.
NOTE Confidence: 0.805016308

00:00:47.700 --> 00:00:49.422 She is an associate professor of
NOTE Confidence: 0.805016308

00:00:49.422 --> 00:00:50.976 health care ethics and Pediatrics
NOTE Confidence: 0.805016308

00:00:50.976 --> 00:00:52.746 at Saint Linus universities on
NOTE Confidence: 0.805016308

00:00:52.746 --> 00:00:54.597 Negi Center for Healthcare Ethics
NOTE Confidence: 0.805016308

00:00:54.597 --> 00:00:56.097 and Department of Pediatrics.
NOTE Confidence: 0.805016308

00:00:56.100 --> 00:00:58.382 She just she directs the center's PhD
NOTE Confidence: 0.805016308

00:00:58.382 --> 00:01:00.298 program in Healthcare Ethics and serves

NOTE Confidence: 0.805016308

00:01:00.298 --> 00:01:02.349 as their vice chair of the Cardinal

NOTE Confidence: 0.805016308

00:01:02.407 --> 00:01:04.724 Glennon Ethics Committee and the Co Chair.

NOTE Confidence: 0.805016308

00:01:04.730 --> 00:01:07.124 She's also the Co chair of the

NOTE Confidence: 0.805016308

00:01:07.124 --> 00:01:09.193 Ethics Special Interest group for

NOTE Confidence: 0.805016308

00:01:09.193 --> 00:01:11.137 the academic pediatric associations.

NOTE Confidence: 0.805016308

00:01:11.140 --> 00:01:13.996 Eric is widely published in the areas of

NOTE Confidence: 0.805016308

00:01:13.996 --> 00:01:15.958 pediatric bioethics and clinical ethics.

NOTE Confidence: 0.805016308

00:01:15.960 --> 00:01:17.500 Consultations on topics ranging

NOTE Confidence: 0.805016308

00:01:17.500 --> 00:01:19.810 from the best interest standard to

NOTE Confidence: 0.805016308

00:01:19.871 --> 00:01:21.881 the mature minor doctrine models

NOTE Confidence: 0.805016308

00:01:21.881 --> 00:01:23.489 of pediatric decision making,

NOTE Confidence: 0.805016308

00:01:23.490 --> 00:01:25.570 parental role and decision making,

NOTE Confidence: 0.805016308

00:01:25.570 --> 00:01:28.180 and decision making for children

NOTE Confidence: 0.805016308

00:01:28.180 --> 00:01:29.224 with disabilities.

NOTE Confidence: 0.805016308

00:01:29.230 --> 00:01:32.072 Dr Salter has a BA in philosophy

NOTE Confidence: 0.805016308

00:01:32.072 --> 00:01:34.207 and cognitive science from Rice
NOTE Confidence: 0.805016308

00:01:34.207 --> 00:01:36.733 University and a PhD in healthcare
NOTE Confidence: 0.805016308

00:01:36.733 --> 00:01:39.379 ethics from Saint Louis University.
NOTE Confidence: 0.805016308

00:01:39.380 --> 00:01:41.675 The way it's gonna go tonight is I'm going
NOTE Confidence: 0.805016308

00:01:41.675 --> 00:01:44.314 to turn this over to Erica in just a moment.
NOTE Confidence: 0.805016308

00:01:44.320 --> 00:01:46.516 She's going to speak to us for 45 minutes,
NOTE Confidence: 0.805016308

00:01:46.520 --> 00:01:47.630 plus or minus.
NOTE Confidence: 0.805016308

00:01:47.630 --> 00:01:48.370 After that,
NOTE Confidence: 0.805016308

00:01:48.370 --> 00:01:50.332 we're going to have a conversation
NOTE Confidence: 0.805016308

00:01:50.332 --> 00:01:52.532 with the audience and I'm going to
NOTE Confidence: 0.805016308

00:01:52.532 --> 00:01:54.350 ask you to submit your questions
NOTE Confidence: 0.805016308

00:01:54.414 --> 00:01:56.360 via Q&A for the Q&A portion,
NOTE Confidence: 0.805016308

00:01:56.360 --> 00:01:59.616 and then I'll read them to Doctor Salter
NOTE Confidence: 0.805016308

00:01:59.616 --> 00:02:03.296 and we will wrap up no later than 6:30.
NOTE Confidence: 0.805016308

00:02:03.300 --> 00:02:04.388 So if it's 625,
NOTE Confidence: 0.805016308

00:02:04.388 --> 00:02:06.372 as I've apologized in the past and
NOTE Confidence: 0.805016308

00:02:06.372 --> 00:02:08.094 we don't get to your question,
NOTE Confidence: 0.805016308

00:02:08.100 --> 00:02:09.288 I I do apologize.
NOTE Confidence: 0.805016308

00:02:09.288 --> 00:02:12.299 We'll get to as many as we can and and
NOTE Confidence: 0.805016308

00:02:12.299 --> 00:02:14.910 I look forward to a great discussion.
NOTE Confidence: 0.805016308

00:02:14.910 --> 00:02:16.410 And without any further ado,
NOTE Confidence: 0.805016308

00:02:16.410 --> 00:02:21.030 I want to introduce Doctor Erica Salter.
NOTE Confidence: 0.805016308

00:02:21.030 --> 00:02:21.696 Take it away,
NOTE Confidence: 0.805016308

00:02:21.696 --> 00:02:21.918 Erica.
NOTE Confidence: 0.928562218

00:02:22.250 --> 00:02:23.250 Thank you so much, Mark,
NOTE Confidence: 0.928562218

00:02:23.250 --> 00:02:24.482 for that lovely introduction.
NOTE Confidence: 0.928562218

00:02:24.482 --> 00:02:26.260 Yes, it's been so fun to get to
NOTE Confidence: 0.928562218

00:02:26.260 --> 00:02:28.116 know you and it's such a pleasure
NOTE Confidence: 0.928562218

00:02:28.116 --> 00:02:29.862 to be with you virtually tonight.
NOTE Confidence: 0.928562218

00:02:29.870 --> 00:02:31.180 I hear the weather isn't
NOTE Confidence: 0.928562218

00:02:31.180 --> 00:02:32.490 so great in New Haven.

NOTE Confidence: 0.928562218

00:02:32.490 --> 00:02:34.122 Here in Saint Louis,

NOTE Confidence: 0.928562218

00:02:34.122 --> 00:02:35.229 it's sunny and clear.

NOTE Confidence: 0.928562218

00:02:35.229 --> 00:02:36.860 But I think the weather there is

NOTE Confidence: 0.928562218

00:02:36.910 --> 00:02:38.536 actually a little more indicative of

NOTE Confidence: 0.928562218

00:02:38.536 --> 00:02:40.478 the topic that we're going to discuss,

NOTE Confidence: 0.928562218

00:02:40.480 --> 00:02:42.730 discuss together on this afternoon.

NOTE Confidence: 0.928562218

00:02:42.730 --> 00:02:45.257 So let me just pull my slides

NOTE Confidence: 0.928562218

00:02:45.257 --> 00:02:47.250 into the right view here.

NOTE Confidence: 0.9734438

00:02:54.490 --> 00:02:58.406 OK. All right. So the project that I'm

NOTE Confidence: 0.9734438

00:02:58.406 --> 00:03:00.604 going to share with you this evening was

NOTE Confidence: 0.9734438

00:03:00.604 --> 00:03:02.843 really motivated out of my work as a

NOTE Confidence: 0.9734438

00:03:02.843 --> 00:03:04.797 clinical ethicist at, as Mark mentioned,

NOTE Confidence: 0.9734438

00:03:04.797 --> 00:03:06.313 Cardinal Glennon Children's Hospital

NOTE Confidence: 0.9734438

00:03:06.313 --> 00:03:08.140 Hospital here in Saint Louis,

NOTE Confidence: 0.9734438

00:03:08.140 --> 00:03:10.534 which where where I'm surrounded by

NOTE Confidence: 0.9734438

00:03:10.534 --> 00:03:12.880 very competent and excellent caregivers,
NOTE Confidence: 0.9734438

00:03:12.880 --> 00:03:15.701 pediatric caregivers that are trying to help
NOTE Confidence: 0.9734438

00:03:15.701 --> 00:03:18.199 families through many difficult decisions.
NOTE Confidence: 0.9734438

00:03:18.200 --> 00:03:21.520 But I was noticing frequently that for
NOTE Confidence: 0.9734438

00:03:21.520 --> 00:03:24.020 especially with very sick children,
NOTE Confidence: 0.9734438

00:03:24.020 --> 00:03:26.090 someone on the treatment team would
NOTE Confidence: 0.9734438

00:03:26.090 --> 00:03:28.359 sometimes mention the fact that the child.
NOTE Confidence: 0.9734438

00:03:28.360 --> 00:03:28.862 Was suffering.
NOTE Confidence: 0.9734438

00:03:28.862 --> 00:03:30.619 This was a claim that would be
NOTE Confidence: 0.9734438

00:03:30.619 --> 00:03:32.389 made sort of in passing sometimes,
NOTE Confidence: 0.9734438

00:03:32.390 --> 00:03:34.775 sometimes a part of as a part of decisions
NOTE Confidence: 0.9734438

00:03:34.775 --> 00:03:37.108 or conversations with family members.
NOTE Confidence: 0.9734438

00:03:37.110 --> 00:03:38.268 And on the face of it,
NOTE Confidence: 0.9734438

00:03:38.270 --> 00:03:40.223 this sort of claim seems very appropriate
NOTE Confidence: 0.9734438

00:03:40.223 --> 00:03:42.650 to bring up as a part of decision making.
NOTE Confidence: 0.9734438

00:03:42.650 --> 00:03:44.030 If a child is suffering,

NOTE Confidence: 0.9734438

00:03:44.030 --> 00:03:45.674 perhaps this ought to compel us

NOTE Confidence: 0.9734438

00:03:45.674 --> 00:03:47.300 to do something very specific,

NOTE Confidence: 0.9734438

00:03:47.300 --> 00:03:48.889 make a tight, certain type of decision,

NOTE Confidence: 0.9734438

00:03:48.890 --> 00:03:51.130 maybe even a dramatic decision.

NOTE Confidence: 0.9734438

00:03:51.130 --> 00:03:53.363 Perhaps it ought to serve a special

NOTE Confidence: 0.9734438

00:03:53.363 --> 00:03:55.349 moral function in decision making,

NOTE Confidence: 0.9734438

00:03:55.350 --> 00:03:56.262 but perhaps not,

NOTE Confidence: 0.9734438

00:03:56.262 --> 00:03:58.810 because of course in most of these cases.

NOTE Confidence: 0.9734438

00:03:58.810 --> 00:04:00.413 The child is either too young or

NOTE Confidence: 0.9734438

00:04:00.413 --> 00:04:02.411 too ill to actually confirm or deny

NOTE Confidence: 0.9734438

00:04:02.411 --> 00:04:04.295 the fact that they were suffering.

NOTE Confidence: 0.9734438

00:04:04.300 --> 00:04:06.617 So there being second hand claims were

NOTE Confidence: 0.9734438

00:04:06.617 --> 00:04:09.358 being made about the experience of the child.

NOTE Confidence: 0.9734438

00:04:09.360 --> 00:04:11.752 So this dilemma what to do with second

NOTE Confidence: 0.9734438

00:04:11.752 --> 00:04:13.705 hand claims of patient suffering invited

NOTE Confidence: 0.9734438

00:04:13.705 --> 00:04:16.304 me to ask a few questions and those
NOTE Confidence: 0.9734438

00:04:16.304 --> 00:04:18.397 questions will kind of serve as the
NOTE Confidence: 0.9734438

00:04:18.397 --> 00:04:20.320 main sections of my presentation today.
NOTE Confidence: 0.9734438

00:04:20.320 --> 00:04:22.808 I hope to offer a few sort of
NOTE Confidence: 0.9734438

00:04:22.808 --> 00:04:24.752 preliminary answers and also some
NOTE Confidence: 0.9734438

00:04:24.752 --> 00:04:26.428 practical suggestions for caregivers
NOTE Confidence: 0.9734438

00:04:26.428 --> 00:04:28.830 in positions of helping families.
NOTE Confidence: 0.9734438

00:04:28.830 --> 00:04:32.690 It is through decision making, process fees.
NOTE Confidence: 0.9734438

00:04:32.690 --> 00:04:34.979 So my central goals for our time
NOTE Confidence: 0.9734438

00:04:34.979 --> 00:04:36.879 together this evening will be first,
NOTE Confidence: 0.9734438

00:04:36.880 --> 00:04:38.784 to explore what we might mean when
NOTE Confidence: 0.9734438

00:04:38.784 --> 00:04:40.847 we claim that a child is suffering.
NOTE Confidence: 0.9734438

00:04:40.850 --> 00:04:42.170 So what does that term mean?
NOTE Confidence: 0.9734438

00:04:42.170 --> 00:04:44.762 How would how do we intend to use it?
NOTE Confidence: 0.9734438

00:04:44.770 --> 00:04:45.203 Second,
NOTE Confidence: 0.9734438

00:04:45.203 --> 00:04:48.234 to describe how appeals to suffering might

NOTE Confidence: 0.9734438

00:04:48.234 --> 00:04:50.810 sometimes enter into treatment decisions,

NOTE Confidence: 0.9734438

00:04:50.810 --> 00:04:52.718 sometimes maybe appropriately and

NOTE Confidence: 0.9734438

00:04:52.718 --> 00:04:54.149 perhaps even inappropriately.

NOTE Confidence: 0.9734438

00:04:54.150 --> 00:04:56.598 And then finally to offer some

NOTE Confidence: 0.9734438

00:04:56.598 --> 00:04:58.709 practical suggestions for how to

NOTE Confidence: 0.9734438

00:04:58.709 --> 00:05:01.121 respond to these second hand claims

NOTE Confidence: 0.9734438

00:05:01.121 --> 00:05:03.350 of patient suffering in Pediatrics.

NOTE Confidence: 0.9734438

00:05:03.350 --> 00:05:04.934 I do want to note that while this

NOTE Confidence: 0.9734438

00:05:04.934 --> 00:05:06.665 project is primarily focused on claims

NOTE Confidence: 0.9734438

00:05:06.665 --> 00:05:08.270 of patient suffering and Pediatrics,

NOTE Confidence: 0.9734438

00:05:08.270 --> 00:05:10.478 I do actually believe that many of the

NOTE Confidence: 0.9734438

00:05:10.478 --> 00:05:12.089 conclusions that ioffer today for you

NOTE Confidence: 0.9734438

00:05:12.089 --> 00:05:14.050 could be applied to the adult context,

NOTE Confidence: 0.9734438

00:05:14.050 --> 00:05:15.650 especially where a surrogate decision

NOTE Confidence: 0.9734438

00:05:15.650 --> 00:05:17.250 maker is making decisions on

NOTE Confidence: 0.9734438

00:05:17.308 --> 00:05:19.008 behalf of an incapacitated patient.
NOTE Confidence: 0.9734438

00:05:19.010 --> 00:05:21.330 So if any of you work with grown-ups,
NOTE Confidence: 0.9734438

00:05:21.330 --> 00:05:22.830 this discussion I hope is useful
NOTE Confidence: 0.9734438

00:05:22.830 --> 00:05:23.830 to you as well.
NOTE Confidence: 0.864683464615385

00:05:26.380 --> 00:05:28.396 So we're actually going to start with a
NOTE Confidence: 0.864683464615385

00:05:28.396 --> 00:05:30.270 little bit of audience participation.
NOTE Confidence: 0.864683464615385

00:05:30.270 --> 00:05:32.340 I don't know if you were prepared for that.
NOTE Confidence: 0.864683464615385

00:05:32.340 --> 00:05:35.210 If I hope that you'll indulge me
NOTE Confidence: 0.864683464615385

00:05:35.210 --> 00:05:38.176 with just a quick question for you.
NOTE Confidence: 0.864683464615385

00:05:38.180 --> 00:05:40.916 What I'm going to ask that you do is
NOTE Confidence: 0.864683464615385

00:05:40.916 --> 00:05:43.520 in the Q&A feature of the zoom meeting,
NOTE Confidence: 0.864683464615385

00:05:43.520 --> 00:05:46.516 if you are willing to do this,
NOTE Confidence: 0.864683464615385

00:05:46.520 --> 00:05:49.439 just briefly give a definition of suffering,
NOTE Confidence: 0.864683464615385

00:05:49.440 --> 00:05:52.032 just whatever comes to mind to you as
NOTE Confidence: 0.864683464615385

00:05:52.032 --> 00:05:54.279 I introduce this concept this term.
NOTE Confidence: 0.864683464615385

00:05:54.280 --> 00:05:55.876 It does not have to be comprehensive.

NOTE Confidence: 0.864683464615385
00:05:55.880 --> 00:05:57.147 It does not have to be deeply.
NOTE Confidence: 0.864683464615385
00:05:57.150 --> 00:05:58.538 Theoretical just whatever comes
NOTE Confidence: 0.864683464615385
00:05:58.538 --> 00:06:00.273 to mind is is great.
NOTE Confidence: 0.864683464615385
00:06:00.280 --> 00:06:01.536 And if you prefer,
NOTE Confidence: 0.864683464615385
00:06:01.536 --> 00:06:03.853 you could also maybe just briefly describe
NOTE Confidence: 0.864683464615385
00:06:03.853 --> 00:06:06.401 an experience that you think would cause
NOTE Confidence: 0.864683464615385
00:06:06.401 --> 00:06:08.006 suffering or incite some suffering,
NOTE Confidence: 0.864683464615385
00:06:08.010 --> 00:06:09.414 or that has caused some suffering
NOTE Confidence: 0.864683464615385
00:06:09.414 --> 00:06:10.116 in your life.
NOTE Confidence: 0.864683464615385
00:06:10.120 --> 00:06:11.495 So while you're doing that
NOTE Confidence: 0.864683464615385
00:06:11.495 --> 00:06:12.595 and thinking about that,
NOTE Confidence: 0.864683464615385
00:06:12.600 --> 00:06:15.072 I do actually want to talk
NOTE Confidence: 0.864683464615385
00:06:15.072 --> 00:06:16.720 through a couple paintings.
NOTE Confidence: 0.864683464615385
00:06:16.720 --> 00:06:19.485 These are maybe some more evocative visual
NOTE Confidence: 0.864683464615385
00:06:19.485 --> 00:06:22.320 depictions of the experience of suffering.
NOTE Confidence: 0.864683464615385

00:06:22.320 --> 00:06:24.063 This is just kind of a reminder
NOTE Confidence: 0.864683464615385

00:06:24.063 --> 00:06:25.848 that suffering is a deeply personal
NOTE Confidence: 0.864683464615385

00:06:25.848 --> 00:06:27.478 experience and sometimes can be
NOTE Confidence: 0.864683464615385

00:06:27.478 --> 00:06:28.949 very difficult to communicate.
NOTE Confidence: 0.864683464615385

00:06:28.950 --> 00:06:30.624 Using words, even though that's what
NOTE Confidence: 0.864683464615385

00:06:30.624 --> 00:06:32.679 I'm asking you to do at the moment,
NOTE Confidence: 0.864683464615385

00:06:32.680 --> 00:06:35.632 what I did is I selected 3 artistic
NOTE Confidence: 0.864683464615385

00:06:35.632 --> 00:06:37.579 depictions of suffering here.
NOTE Confidence: 0.864683464615385

00:06:37.580 --> 00:06:39.625 Two are actually about children
NOTE Confidence: 0.864683464615385

00:06:39.625 --> 00:06:42.359 and one is actually by a child.
NOTE Confidence: 0.864683464615385

00:06:42.360 --> 00:06:44.744 On the far left is an oil painting
NOTE Confidence: 0.864683464615385

00:06:44.744 --> 00:06:46.940 by Picasso entitled Weeping Woman,
NOTE Confidence: 0.864683464615385

00:06:46.940 --> 00:06:48.530 which depicts a mother grieving
NOTE Confidence: 0.864683464615385

00:06:48.530 --> 00:06:50.120 the death of her child.
NOTE Confidence: 0.864683464615385

00:06:50.120 --> 00:06:52.136 In the middle is a charcoal drawing from
NOTE Confidence: 0.864683464615385

00:06:52.136 --> 00:06:54.560 a 13 year old female Holocaust victim,

NOTE Confidence: 0.864683464615385
00:06:54.560 --> 00:06:56.762 Helga Basova, who drew hundreds of
NOTE Confidence: 0.864683464615385
00:06:56.762 --> 00:06:58.959 drawings actually while at a constant.
NOTE Confidence: 0.864683464615385
00:06:58.960 --> 00:07:01.210 Concentration camp outside of Prague.
NOTE Confidence: 0.864683464615385
00:07:01.210 --> 00:07:03.964 Her father told her to draw what she saw,
NOTE Confidence: 0.864683464615385
00:07:03.970 --> 00:07:04.990 and that's what she did.
NOTE Confidence: 0.864683464615385
00:07:04.990 --> 00:07:07.648 I believe this drawing was her
NOTE Confidence: 0.864683464615385
00:07:07.648 --> 00:07:10.330 last drawing before her execution.
NOTE Confidence: 0.864683464615385
00:07:10.330 --> 00:07:11.012 And finally,
NOTE Confidence: 0.864683464615385
00:07:11.012 --> 00:07:11.694 Edvard Munch,
NOTE Confidence: 0.864683464615385
00:07:11.694 --> 00:07:15.348 who we all know as the painter of the Scream,
NOTE Confidence: 0.864683464615385
00:07:15.350 --> 00:07:17.662 this is another one of his more famous
NOTE Confidence: 0.864683464615385
00:07:17.662 --> 00:07:19.089 paintings called the Sick Child,
NOTE Confidence: 0.864683464615385
00:07:19.090 --> 00:07:21.274 and this draws upon his memory of
NOTE Confidence: 0.864683464615385
00:07:21.274 --> 00:07:22.920 his sister's death from tuberculosis
NOTE Confidence: 0.864683464615385
00:07:22.920 --> 00:07:24.545 when he was a child.
NOTE Confidence: 0.864683464615385

00:07:24.550 --> 00:07:26.069 So I'll give you just a moment.
NOTE Confidence: 0.864683464615385

00:07:26.070 --> 00:07:27.230 I see already a few,
NOTE Confidence: 0.864683464615385

00:07:27.230 --> 00:07:29.161 maybe a few answers in the Q&A, but.
NOTE Confidence: 0.864683464615385

00:07:29.161 --> 00:07:30.716 I'd invite a few more.
NOTE Confidence: 0.864683464615385

00:07:30.720 --> 00:07:30.974 Umm,
NOTE Confidence: 0.864683464615385

00:07:30.974 --> 00:07:32.752 and then I'll share some of these
NOTE Confidence: 0.864683464615385

00:07:32.752 --> 00:07:34.179 answers and then keep moving.
NOTE Confidence: 0.91474146125

00:07:39.850 --> 00:07:40.594 All right.
NOTE Confidence: 0.91474146125

00:07:40.594 --> 00:07:42.826 I'm seeing physical or emotional pain,
NOTE Confidence: 0.91474146125

00:07:42.830 --> 00:07:45.358 discomfort, feelings of torture,
NOTE Confidence: 0.91474146125

00:07:45.358 --> 00:07:47.750 excellence, poor quality of life pain,
NOTE Confidence: 0.91474146125

00:07:47.750 --> 00:07:49.950 inability to do things that bring you joy.
NOTE Confidence: 0.91474146125

00:07:49.950 --> 00:07:51.682 It's a great answer.
NOTE Confidence: 0.91474146125

00:07:51.682 --> 00:07:54.206 To me, suffering feels heavy in my body,
NOTE Confidence: 0.91474146125

00:07:54.210 --> 00:07:55.329 mind, and spirit.
NOTE Confidence: 0.91474146125

00:07:55.329 --> 00:07:57.567 It's a state of extreme disease.

NOTE Confidence: 0.91474146125

00:07:57.570 --> 00:07:58.530 I love that.

NOTE Confidence: 0.91474146125

00:07:58.530 --> 00:08:00.130 And emotional and physical pain.

NOTE Confidence: 0.91474146125

00:08:00.130 --> 00:08:02.094 Beautiful answer the state

NOTE Confidence: 0.91474146125

00:08:02.094 --> 00:08:03.567 of prolonged discomfort,

NOTE Confidence: 0.91474146125

00:08:03.570 --> 00:08:05.170 either physical or psychological

NOTE Confidence: 0.91474146125

00:08:05.170 --> 00:08:07.570 anguish felt deeply in my body,

NOTE Confidence: 0.91474146125

00:08:07.570 --> 00:08:08.851 spirit, or mind.

NOTE Confidence: 0.91474146125

00:08:08.851 --> 00:08:10.559 Most likely all three.

NOTE Confidence: 0.91474146125

00:08:10.560 --> 00:08:12.678 Suffering is an experience of a

NOTE Confidence: 0.91474146125

00:08:12.678 --> 00:08:14.230 degree of physical, emotional,

NOTE Confidence: 0.91474146125

00:08:14.230 --> 00:08:16.680 or existential pain or discomfort.

NOTE Confidence: 0.91474146125

00:08:16.680 --> 00:08:17.310 Physical pain.

NOTE Confidence: 0.91474146125

00:08:17.310 --> 00:08:19.515 Someone shares the caregiver for my spouse

NOTE Confidence: 0.91474146125

00:08:19.515 --> 00:08:21.687 who was suffering with terminal cancer,

NOTE Confidence: 0.91474146125

00:08:21.690 --> 00:08:23.300 which was difficult to manage or control.

NOTE Confidence: 0.91474146125

00:08:23.300 --> 00:08:25.939 So an experience that caused much suffering,
NOTE Confidence: 0.91474146125

00:08:25.940 --> 00:08:28.236 longing for a different state, situation,
NOTE Confidence: 0.91474146125

00:08:28.236 --> 00:08:31.568 or set of circumstances that alleviate the
NOTE Confidence: 0.91474146125

00:08:31.568 --> 00:08:34.508 experience of physical or emotional pain.
NOTE Confidence: 0.91474146125

00:08:34.510 --> 00:08:35.088 Beautiful answers.
NOTE Confidence: 0.91474146125

00:08:35.088 --> 00:08:37.720 Thank you so much for indulging me in that.
NOTE Confidence: 0.91474146125

00:08:37.720 --> 00:08:39.414 These are just lovely and I actually
NOTE Confidence: 0.91474146125

00:08:39.414 --> 00:08:41.183 think they serve as a really nice
NOTE Confidence: 0.91474146125

00:08:41.183 --> 00:08:42.418 backdrop for our discussion today
NOTE Confidence: 0.91474146125

00:08:42.418 --> 00:08:43.791 and I might even be referring
NOTE Confidence: 0.91474146125

00:08:43.791 --> 00:08:46.056 back to some of these as we
NOTE Confidence: 0.91474146125

00:08:46.056 --> 00:08:48.428 proceed through this presentation.
NOTE Confidence: 0.91474146125

00:08:48.430 --> 00:08:48.972 All right,
NOTE Confidence: 0.91474146125

00:08:48.972 --> 00:08:50.869 so I'm actually going to jump in
NOTE Confidence: 0.91474146125

00:08:50.869 --> 00:08:52.796 to this topic by using a case.
NOTE Confidence: 0.91474146125

00:08:52.800 --> 00:08:54.568 This is a case from a very popular

NOTE Confidence: 0.91474146125

00:08:54.568 --> 00:08:56.267 and actually pretty widely referenced

NOTE Confidence: 0.91474146125

00:08:56.267 --> 00:08:57.470 pediatric ethics textbook.

NOTE Confidence: 0.91474146125

00:08:57.470 --> 00:08:59.042 It's one that I use frequently

NOTE Confidence: 0.91474146125

00:08:59.042 --> 00:09:00.090 in my undergraduate class,

NOTE Confidence: 0.91474146125

00:09:00.090 --> 00:09:01.572 and I think it represents quite

NOTE Confidence: 0.91474146125

00:09:01.572 --> 00:09:02.993 well the types of situations

NOTE Confidence: 0.91474146125

00:09:02.993 --> 00:09:04.489 that motivated my project.

NOTE Confidence: 0.91474146125

00:09:04.490 --> 00:09:07.415 All right, so the case is Annie is suffering.

NOTE Confidence: 0.91474146125

00:09:07.420 --> 00:09:08.740 Annie is born at full term

NOTE Confidence: 0.91474146125

00:09:08.740 --> 00:09:09.620 with good Apgar scores,

NOTE Confidence: 0.91474146125

00:09:09.620 --> 00:09:11.780 but weighs only 23150 grams.

NOTE Confidence: 0.91474146125

00:09:11.780 --> 00:09:12.737 On physical exam,

NOTE Confidence: 0.91474146125

00:09:12.737 --> 00:09:15.350 she is alert but has somewhat low tone.

NOTE Confidence: 0.91474146125

00:09:15.350 --> 00:09:16.976 She has an abnormal facial features,

NOTE Confidence: 0.91474146125

00:09:16.980 --> 00:09:18.900 short sternum and overriding digits.

NOTE Confidence: 0.91474146125

00:09:18.900 --> 00:09:21.500 After failure to pass an Ng tube ATE,
NOTE Confidence: 0.91474146125

00:09:21.500 --> 00:09:22.805 fistula is diagnosed.
NOTE Confidence: 0.91474146125

00:09:22.805 --> 00:09:24.110 Chromosome studies confirmed
NOTE Confidence: 0.91474146125

00:09:24.110 --> 00:09:26.421 trisomy 18 and an echocardiogram
NOTE Confidence: 0.91474146125

00:09:26.421 --> 00:09:29.415 shows a moderate VSD and moderate
NOTE Confidence: 0.91474146125

00:09:29.415 --> 00:09:30.912 pulmonary valvular dysplasia.
NOTE Confidence: 0.91474146125

00:09:30.920 --> 00:09:33.050 The neonatologist and surgeon meet Annie's
NOTE Confidence: 0.91474146125

00:09:33.050 --> 00:09:34.920 parents to discuss treatment options.
NOTE Confidence: 0.91474146125

00:09:34.920 --> 00:09:36.312 They explained that trisomy
NOTE Confidence: 0.91474146125

00:09:36.312 --> 00:09:38.052 18 is a lethal condition.
NOTE Confidence: 0.91474146125

00:09:38.060 --> 00:09:39.752 And that most children die within
NOTE Confidence: 0.91474146125

00:09:39.752 --> 00:09:41.469 the first few weeks to months.
NOTE Confidence: 0.91474146125

00:09:41.470 --> 00:09:43.528 The team does not recommend surgery,
NOTE Confidence: 0.91474146125

00:09:43.530 --> 00:09:45.553 explaining that surgery is not in the
NOTE Confidence: 0.91474146125

00:09:45.553 --> 00:09:47.409 child's best interest and will result in,
NOTE Confidence: 0.91474146125

00:09:47.410 --> 00:09:48.008 quote,

NOTE Confidence: 0.91474146125

00:09:48.008 --> 00:09:50.400 unnecessary suffering for Annie.

NOTE Confidence: 0.91474146125

00:09:50.400 --> 00:09:52.050 They offer the services of the

NOTE Confidence: 0.91474146125

00:09:52.050 --> 00:09:53.487 neonatal palliative care team and

NOTE Confidence: 0.91474146125

00:09:53.487 --> 00:09:55.191 reassure Annie's parents that they can

NOTE Confidence: 0.91474146125

00:09:55.191 --> 00:09:56.773 provide comfort for Annie by keeping

NOTE Confidence: 0.91474146125

00:09:56.773 --> 00:09:58.848 an IV in place for hydration and pain relief.

NOTE Confidence: 0.91474146125

00:09:58.848 --> 00:10:01.559 All right, So what we have here is an infant

NOTE Confidence: 0.91474146125

00:10:01.559 --> 00:10:03.545 with a serious and unexpected diagnosis,

NOTE Confidence: 0.91474146125

00:10:03.550 --> 00:10:05.164 and her parents are being asked

NOTE Confidence: 0.91474146125

00:10:05.164 --> 00:10:06.920 to make a profoundly significant,

NOTE Confidence: 0.91474146125

00:10:06.920 --> 00:10:07.353 indeed,

NOTE Confidence: 0.91474146125

00:10:07.353 --> 00:10:09.518 a life and death decision.

NOTE Confidence: 0.91474146125

00:10:09.520 --> 00:10:11.158 Her treatment team has an opinion

NOTE Confidence: 0.91474146125

00:10:11.158 --> 00:10:12.719 about what ought to be done.

NOTE Confidence: 0.91474146125

00:10:12.720 --> 00:10:14.379 And as a part of this conversation,

NOTE Confidence: 0.91474146125

00:10:14.380 --> 00:10:17.068 they mentioned the fact that aggressive
NOTE Confidence: 0.91474146125

00:10:17.068 --> 00:10:20.143 life extending treatment might be the cause
NOTE Confidence: 0.91474146125

00:10:20.143 --> 00:10:22.573 of unnecessary suffering for their daughter.
NOTE Confidence: 0.91474146125

00:10:22.580 --> 00:10:23.548 And importantly,
NOTE Confidence: 0.91474146125

00:10:23.548 --> 00:10:24.032 Annie,
NOTE Confidence: 0.91474146125

00:10:24.032 --> 00:10:25.968 who's experienced about which
NOTE Confidence: 0.91474146125

00:10:25.968 --> 00:10:27.820 we are hypothesizing here,
NOTE Confidence: 0.91474146125

00:10:27.820 --> 00:10:29.969 cannot actually tell us anything about her.
NOTE Confidence: 0.91474146125

00:10:29.970 --> 00:10:30.990 Advanced directly,
NOTE Confidence: 0.91474146125

00:10:30.990 --> 00:10:34.560 her experience is somewhat opaque to us.
NOTE Confidence: 0.872342738461539

00:10:34.560 --> 00:10:36.534 So one of my earlier projects prior
NOTE Confidence: 0.872342738461539

00:10:36.534 --> 00:10:38.539 to to writing this paper actually
NOTE Confidence: 0.872342738461539

00:10:38.540 --> 00:10:40.934 was interested in looking at whether
NOTE Confidence: 0.872342738461539

00:10:40.934 --> 00:10:43.255 this this case that I presented
NOTE Confidence: 0.872342738461539

00:10:43.255 --> 00:10:45.720 you here is is a paradigmatic case,
NOTE Confidence: 0.872342738461539

00:10:45.720 --> 00:10:47.940 whether it actually does represent the

NOTE Confidence: 0.872342738461539
00:10:48.006 --> 00:10:49.946 wider clinical and bioethics literature
NOTE Confidence: 0.872342738461539
00:10:49.946 --> 00:10:52.550 when authors use the term suffering.
NOTE Confidence: 0.872342738461539
00:10:52.550 --> 00:10:54.798 So I I'm, I'm going to share the
NOTE Confidence: 0.872342738461539
00:10:54.798 --> 00:10:56.676 results of that study with you here.
NOTE Confidence: 0.872342738461539
00:10:56.680 --> 00:10:59.123 So my co-authors for this project were
NOTE Confidence: 0.872342738461539
00:10:59.123 --> 00:11:01.200 Annie Friedrich and Kirsten Dempsey.
NOTE Confidence: 0.872342738461539
00:11:01.200 --> 00:11:03.510 We were really interested to see how
NOTE Confidence: 0.872342738461539
00:11:03.510 --> 00:11:05.160 bioethicists and clinicians are using
NOTE Confidence: 0.872342738461539
00:11:05.160 --> 00:11:06.978 the term suffering in the literature,
NOTE Confidence: 0.872342738461539
00:11:06.980 --> 00:11:08.760 whether there's a consistent definition,
NOTE Confidence: 0.872342738461539
00:11:08.760 --> 00:11:10.656 if so, what is that definition?
NOTE Confidence: 0.872342738461539
00:11:10.660 --> 00:11:11.770 And most importantly,
NOTE Confidence: 0.872342738461539
00:11:11.770 --> 00:11:13.990 how is the concept utilized in
NOTE Confidence: 0.872342738461539
00:11:13.990 --> 00:11:16.217 the context of decision making.
NOTE Confidence: 0.872342738461539
00:11:16.220 --> 00:11:18.138 So what we did is conduct a
NOTE Confidence: 0.872342738461539

00:11:18.138 --> 00:11:19.277 preliminary content analysis looking
NOTE Confidence: 0.872342738461539

00:11:19.277 --> 00:11:21.097 at the past 10 years of articles
NOTE Confidence: 0.872342738461539

00:11:21.097 --> 00:11:22.600 across eight different journals,
NOTE Confidence: 0.872342738461539

00:11:22.600 --> 00:11:24.280 both clinical pediatric journals
NOTE Confidence: 0.872342738461539

00:11:24.280 --> 00:11:25.540 and bioethics journals,
NOTE Confidence: 0.872342738461539

00:11:25.540 --> 00:11:27.530 looking for the term suffering
NOTE Confidence: 0.872342738461539

00:11:27.530 --> 00:11:29.520 used as a noun specifically
NOTE Confidence: 0.872342738461539

00:11:29.597 --> 00:11:31.657 within the Pediatrics context.
NOTE Confidence: 0.872342738461539

00:11:31.660 --> 00:11:34.918 We found 651 occurrences of the term and we
NOTE Confidence: 0.872342738461539

00:11:34.918 --> 00:11:38.016 coded them according to who was suffering,
NOTE Confidence: 0.872342738461539

00:11:38.020 --> 00:11:39.940 the cause of that suffering,
NOTE Confidence: 0.872342738461539

00:11:39.940 --> 00:11:42.245 the nature of the experience
NOTE Confidence: 0.872342738461539

00:11:42.245 --> 00:11:44.089 described with the term.
NOTE Confidence: 0.872342738461539

00:11:44.090 --> 00:11:45.590 And the influence that that
NOTE Confidence: 0.872342738461539

00:11:45.590 --> 00:11:46.790 had on decision making.
NOTE Confidence: 0.872342738461539

00:11:46.790 --> 00:11:48.574 So here's what we found this these tables

NOTE Confidence: 0.872342738461539
00:11:48.574 --> 00:11:50.348 sort of summarized the results here.
NOTE Confidence: 0.872342738461539
00:11:50.350 --> 00:11:52.270 So most often the party described
NOTE Confidence: 0.872342738461539
00:11:52.270 --> 00:11:54.090 as suffering was the patient.
NOTE Confidence: 0.872342738461539
00:11:54.090 --> 00:11:55.950 This is perhaps not very surprising,
NOTE Confidence: 0.872342738461539
00:11:55.950 --> 00:11:57.972 although I do want to importantly
NOTE Confidence: 0.872342738461539
00:11:57.972 --> 00:12:00.119 note that suffering is also described
NOTE Confidence: 0.872342738461539
00:12:00.119 --> 00:12:01.964 as an experience of parents.
NOTE Confidence: 0.872342738461539
00:12:01.970 --> 00:12:03.962 And we saw that in some of the
NOTE Confidence: 0.872342738461539
00:12:03.962 --> 00:12:05.640 paintings that we just viewed the
NOTE Confidence: 0.872342738461539
00:12:05.640 --> 00:12:07.740 cause of the patient suffering which
NOTE Confidence: 0.872342738461539
00:12:07.740 --> 00:12:10.128 was coded either as a result of
NOTE Confidence: 0.872342738461539
00:12:10.128 --> 00:12:12.042 treatment or intervention as a result
NOTE Confidence: 0.872342738461539
00:12:12.107 --> 00:12:14.377 of the patients underlying condition.
NOTE Confidence: 0.872342738461539
00:12:14.380 --> 00:12:17.165 Or there was ambiguity with
NOTE Confidence: 0.872342738461539
00:12:17.165 --> 00:12:19.393 regard to the cause.
NOTE Confidence: 0.872342738461539

00:12:19.400 --> 00:12:20.928 Authors were overwhelmingly unclear
NOTE Confidence: 0.872342738461539

00:12:20.928 --> 00:12:23.220 about the cause of suffering and
NOTE Confidence: 0.872342738461539

00:12:23.284 --> 00:12:24.884 these occurrences of the term
NOTE Confidence: 0.872342738461539

00:12:24.884 --> 00:12:26.944 the the claim was typically made
NOTE Confidence: 0.872342738461539

00:12:26.944 --> 00:12:28.520 without any clear attribution.
NOTE Confidence: 0.872342738461539

00:12:28.520 --> 00:12:30.176 When we looked at whether authors
NOTE Confidence: 0.872342738461539

00:12:30.176 --> 00:12:31.889 specified in any way what they
NOTE Confidence: 0.872342738461539

00:12:31.889 --> 00:12:33.274 meant by the term suffering,
NOTE Confidence: 0.872342738461539

00:12:33.280 --> 00:12:35.240 was there a definition or a characterization?
NOTE Confidence: 0.872342738461539

00:12:35.240 --> 00:12:37.802 After offered 75% of occurrences of
NOTE Confidence: 0.872342738461539

00:12:37.802 --> 00:12:40.600 the term were coded as ambiguous,
NOTE Confidence: 0.872342738461539

00:12:40.600 --> 00:12:43.564 so very infrequently did authors describe
NOTE Confidence: 0.872342738461539

00:12:43.564 --> 00:12:47.137 what they meant when they used the term.
NOTE Confidence: 0.872342738461539

00:12:47.140 --> 00:12:49.114 Of the remaining 166 occurrences that
NOTE Confidence: 0.872342738461539

00:12:49.114 --> 00:12:51.752 were a little more explicit about their
NOTE Confidence: 0.872342738461539

00:12:51.752 --> 00:12:53.847 understanding of the term suffering,

NOTE Confidence: 0.872342738461539
00:12:53.850 --> 00:12:56.066 20% use the term to refer to physical
NOTE Confidence: 0.872342738461539
00:12:56.066 --> 00:12:57.820 symptoms of pain and discomfort.
NOTE Confidence: 0.821514718333333
00:13:00.470 --> 00:13:02.935 68% referred to a negative
NOTE Confidence: 0.821514718333333
00:13:02.935 --> 00:13:03.953 psychological, emotional,
NOTE Confidence: 0.821514718333333
00:13:03.953 --> 00:13:06.568 or existential experience distinct from,
NOTE Confidence: 0.821514718333333
00:13:06.570 --> 00:13:09.050 although perhaps related to pain.
NOTE Confidence: 0.821514718333333
00:13:09.050 --> 00:13:10.954 And then 12% use the term to refer
NOTE Confidence: 0.821514718333333
00:13:10.954 --> 00:13:13.302 to a combination of both physical
NOTE Confidence: 0.821514718333333
00:13:13.302 --> 00:13:15.106 pain and existential distress.
NOTE Confidence: 0.821514718333333
00:13:15.110 --> 00:13:16.595 You know, I actually think
NOTE Confidence: 0.821514718333333
00:13:16.595 --> 00:13:19.002 this maps on quite well to the
NOTE Confidence: 0.821514718333333
00:13:19.002 --> 00:13:20.710 definitions you've provided tonight.
NOTE Confidence: 0.821514718333333
00:13:20.710 --> 00:13:23.334 There were lots of mentions of sort of
NOTE Confidence: 0.821514718333333
00:13:23.334 --> 00:13:25.448 a combination of sites of suffering,
NOTE Confidence: 0.821514718333333
00:13:25.450 --> 00:13:27.634 not just physical but also emotional
NOTE Confidence: 0.821514718333333

00:13:27.634 --> 00:13:29.300 and even spiritual. I think we.

NOTE Confidence: 0.821514718333333

00:13:29.300 --> 00:13:30.440 And I saw the terms body,

NOTE Confidence: 0.821514718333333

00:13:30.440 --> 00:13:33.480 mind and spirit multiple times.

NOTE Confidence: 0.821514718333333

00:13:33.480 --> 00:13:35.265 It does seem like when authors in

NOTE Confidence: 0.821514718333333

00:13:35.265 --> 00:13:36.627 bioethics and clinical journals utilize

NOTE Confidence: 0.821514718333333

00:13:36.627 --> 00:13:38.538 the term suffering and they offer some

NOTE Confidence: 0.821514718333333

00:13:38.538 --> 00:13:40.141 sort of characterization very similar

NOTE Confidence: 0.821514718333333

00:13:40.141 --> 00:13:41.736 to the types of characterizations

NOTE Confidence: 0.821514718333333

00:13:41.736 --> 00:13:44.340 you yourselves are offering.

NOTE Confidence: 0.821514718333333

00:13:44.340 --> 00:13:45.702 Another really important

NOTE Confidence: 0.821514718333333

00:13:45.702 --> 00:13:47.518 note about these data,

NOTE Confidence: 0.821514718333333

00:13:47.520 --> 00:13:49.326 52% of occurrences of the term

NOTE Confidence: 0.821514718333333

00:13:49.326 --> 00:13:51.453 suffering were used as a part of

NOTE Confidence: 0.821514718333333

00:13:51.453 --> 00:13:52.898 a specific medical decision and

NOTE Confidence: 0.821514718333333

00:13:52.898 --> 00:13:54.595 claims of patient suffering and

NOTE Confidence: 0.821514718333333

00:13:54.595 --> 00:13:56.707 Pediatrics were three times as likely

NOTE Confidence: 0.821514718333333
00:13:56.707 --> 00:13:59.300 to support a life ending decision
NOTE Confidence: 0.821514718333333
00:13:59.300 --> 00:14:01.540 as a life extending decision.
NOTE Confidence: 0.821514718333333
00:14:01.540 --> 00:14:04.600 So 32% versus 10% here.
NOTE Confidence: 0.821514718333333
00:14:04.600 --> 00:14:07.106 So the the trends that I'm describing
NOTE Confidence: 0.821514718333333
00:14:07.106 --> 00:14:09.328 with this study and how the term
NOTE Confidence: 0.821514718333333
00:14:09.328 --> 00:14:10.848 suffering is typically deployed in
NOTE Confidence: 0.821514718333333
00:14:10.848 --> 00:14:12.415 the clinical and bioethics literature
NOTE Confidence: 0.821514718333333
00:14:12.415 --> 00:14:14.209 does actually map on quite well
NOTE Confidence: 0.821514718333333
00:14:14.209 --> 00:14:15.979 to the case that I presented.
NOTE Confidence: 0.821514718333333
00:14:15.980 --> 00:14:18.230 The concern is that Annie the
NOTE Confidence: 0.821514718333333
00:14:18.230 --> 00:14:19.355 patient is suffering.
NOTE Confidence: 0.821514718333333
00:14:19.360 --> 00:14:21.175 The cause of her suffering
NOTE Confidence: 0.821514718333333
00:14:21.175 --> 00:14:22.627 is is mostly ambiguous.
NOTE Confidence: 0.821514718333333
00:14:22.630 --> 00:14:24.970 We we could surmise that the
NOTE Confidence: 0.821514718333333
00:14:24.970 --> 00:14:26.530 practitioners are attributing her
NOTE Confidence: 0.821514718333333

00:14:26.602 --> 00:14:28.564 suffering to the surgery or perhaps
NOTE Confidence: 0.8215147183333333

00:14:28.564 --> 00:14:31.038 just the sort of state of bear
NOTE Confidence: 0.8215147183333333

00:14:31.038 --> 00:14:32.863 existence that would result from
NOTE Confidence: 0.8215147183333333

00:14:32.863 --> 00:14:35.052 the surgery and it's being deployed.
NOTE Confidence: 0.8215147183333333

00:14:35.052 --> 00:14:36.867 In this case by clinicians,
NOTE Confidence: 0.8215147183333333

00:14:36.870 --> 00:14:38.150 in a very specific way,
NOTE Confidence: 0.8215147183333333

00:14:38.150 --> 00:14:39.885 it's being deployed to influence
NOTE Confidence: 0.8215147183333333

00:14:39.885 --> 00:14:40.926 a treatment decision,
NOTE Confidence: 0.8215147183333333

00:14:40.930 --> 00:14:42.770 specifically a life ending
NOTE Confidence: 0.8215147183333333

00:14:42.770 --> 00:14:43.690 treatment decision.
NOTE Confidence: 0.9220973

00:14:46.330 --> 00:14:48.416 OK, so let's move forward and ask,
NOTE Confidence: 0.9220973

00:14:48.420 --> 00:14:50.028 you know, one of our first sort of
NOTE Confidence: 0.9220973

00:14:50.028 --> 00:14:51.329 main framing questions for today.
NOTE Confidence: 0.9220973

00:14:51.330 --> 00:14:53.928 What kind of phenomenon is suffering?
NOTE Confidence: 0.9220973

00:14:53.930 --> 00:14:55.238 What is its nature? What's it?
NOTE Confidence: 0.9220973

00:14:55.240 --> 00:14:56.496 What is its essence?

NOTE Confidence: 0.9220973

00:14:56.496 --> 00:14:58.194 Simply, just what is it?

NOTE Confidence: 0.9220973

00:14:58.194 --> 00:14:59.924 In the context of medicine,

NOTE Confidence: 0.9220973

00:14:59.930 --> 00:15:01.830 the primary definition offered

NOTE Confidence: 0.9220973

00:15:01.830 --> 00:15:04.205 is that by Eric Cassell,

NOTE Confidence: 0.9220973

00:15:04.210 --> 00:15:06.744 who asserts he's a physician and ethicist,

NOTE Confidence: 0.9220973

00:15:06.750 --> 00:15:08.906 and he's written widely on this topic.

NOTE Confidence: 0.9220973

00:15:08.910 --> 00:15:10.650 Again, if you've encountered this term,

NOTE Confidence: 0.9220973

00:15:10.650 --> 00:15:11.475 any philosophical exploration

NOTE Confidence: 0.9220973

00:15:11.475 --> 00:15:12.850 of this term in medicine,

NOTE Confidence: 0.9220973

00:15:12.850 --> 00:15:15.890 it's likely through the work of Eric Cassell.

NOTE Confidence: 0.9220973

00:15:15.890 --> 00:15:17.674 He essentially asserts that

NOTE Confidence: 0.9220973

00:15:17.674 --> 00:15:19.458 suffering requires 2 necessary

NOTE Confidence: 0.9220973

00:15:19.458 --> 00:15:21.090 and sufficient conditions.

NOTE Confidence: 0.9220973

00:15:21.090 --> 00:15:23.550 So first, suffering is a subjective,

NOTE Confidence: 0.9220973

00:15:23.550 --> 00:15:24.480 phenomenological experience.

NOTE Confidence: 0.9220973

00:15:24.480 --> 00:15:26.805 Thus there is no suffering
NOTE Confidence: 0.9220973

00:15:26.805 --> 00:15:28.720 unless a specific person.
NOTE Confidence: 0.9220973

00:15:28.720 --> 00:15:29.614 Experiences it.
NOTE Confidence: 0.9220973

00:15:29.614 --> 00:15:32.743 And 2nd, the nature of that experience,
NOTE Confidence: 0.9220973

00:15:32.750 --> 00:15:34.310 first of suffering for Cassell,
NOTE Confidence: 0.9220973

00:15:34.310 --> 00:15:36.405 is one of severe distress
NOTE Confidence: 0.9220973

00:15:36.405 --> 00:15:38.500 associated with events that threaten
NOTE Confidence: 0.9220973

00:15:38.569 --> 00:15:40.529 the intactness of the person.
NOTE Confidence: 0.9220973

00:15:40.530 --> 00:15:41.870 So there's sort of a
NOTE Confidence: 0.9220973

00:15:41.870 --> 00:15:42.674 narrative explanation here.
NOTE Confidence: 0.9220973

00:15:42.680 --> 00:15:45.352 It's evoking sort of a disruption in the
NOTE Confidence: 0.9220973

00:15:45.352 --> 00:15:47.796 person's life narrative in such a way
NOTE Confidence: 0.9220973

00:15:47.796 --> 00:15:50.368 that feels like severe distress and a threat,
NOTE Confidence: 0.9220973

00:15:50.370 --> 00:15:52.950 a threat to that person's
NOTE Confidence: 0.9220973

00:15:52.950 --> 00:15:54.498 identity and intactness.
NOTE Confidence: 0.9220973

00:15:54.500 --> 00:15:56.836 I just want to mention a couple important

NOTE Confidence: 0.9220973

00:15:56.836 --> 00:15:58.659 implications of a definition like this.

NOTE Confidence: 0.9220973

00:15:58.660 --> 00:15:59.980 These are implications that

NOTE Confidence: 0.9220973

00:15:59.980 --> 00:16:01.300 are troubling for some.

NOTE Confidence: 0.9220973

00:16:01.300 --> 00:16:03.120 I won't go into much detail here,

NOTE Confidence: 0.9220973

00:16:03.120 --> 00:16:04.478 but I do want to explore this

NOTE Confidence: 0.9220973

00:16:04.478 --> 00:16:05.939 definition just a little bit with you.

NOTE Confidence: 0.9220973

00:16:05.940 --> 00:16:08.958 I think it offers us some

NOTE Confidence: 0.9220973

00:16:08.958 --> 00:16:09.964 instructive insights.

NOTE Confidence: 0.9220973

00:16:09.970 --> 00:16:10.430 First,

NOTE Confidence: 0.9220973

00:16:10.430 --> 00:16:13.190 because suffering is a subjective experience,

NOTE Confidence: 0.9220973

00:16:13.190 --> 00:16:14.810 primary epistemic access,

NOTE Confidence: 0.9220973

00:16:14.810 --> 00:16:17.510 meaning who has access to

NOTE Confidence: 0.9220973

00:16:17.510 --> 00:16:19.969 knowledge about this experience,

NOTE Confidence: 0.9220973

00:16:19.970 --> 00:16:21.630 belongs only to the individual

NOTE Confidence: 0.9220973

00:16:21.630 --> 00:16:22.626 who is suffering.

NOTE Confidence: 0.9220973

00:16:22.630 --> 00:16:25.855 There really is no truly
NOTE Confidence: 0.9220973

00:16:25.855 --> 00:16:27.790 dependable objective assessment.
NOTE Confidence: 0.9220973

00:16:27.790 --> 00:16:29.678 Here's a good spot to mention that the
NOTE Confidence: 0.9220973

00:16:29.678 --> 00:16:31.970 work of actually a friend and fellow
NOTE Confidence: 0.9220973

00:16:31.970 --> 00:16:33.382 pediatric ethicist and physician.
NOTE Confidence: 0.9220973

00:16:33.390 --> 00:16:34.410 His name is Tyler Tate.
NOTE Confidence: 0.9220973

00:16:34.410 --> 00:16:36.306 He's also done work on the
NOTE Confidence: 0.9220973

00:16:36.306 --> 00:16:37.570 topic of pediatric suffering.
NOTE Confidence: 0.9220973

00:16:37.570 --> 00:16:39.145 He actually disagrees with Cassell
NOTE Confidence: 0.9220973

00:16:39.145 --> 00:16:41.504 on this point on the the subjective
NOTE Confidence: 0.9220973

00:16:41.504 --> 00:16:43.304 nature of suffering and head,
NOTE Confidence: 0.9220973

00:16:43.310 --> 00:16:45.374 and instead sort of is encouraging
NOTE Confidence: 0.9220973

00:16:45.374 --> 00:16:47.449 a more objective and teleological
NOTE Confidence: 0.9220973

00:16:47.449 --> 00:16:49.330 understanding of suffering.
NOTE Confidence: 0.9220973

00:16:49.330 --> 00:16:49.928 Very briefly,
NOTE Confidence: 0.9220973

00:16:49.928 --> 00:16:51.722 he thinks that suffering should be

NOTE Confidence: 0.9220973

00:16:51.722 --> 00:16:53.739 defined as the inverse of flourishing,

NOTE Confidence: 0.9220973

00:16:53.740 --> 00:16:56.615 something that could be dependably

NOTE Confidence: 0.9220973

00:16:56.615 --> 00:16:58.340 assessed by others.

NOTE Confidence: 0.9220973

00:16:58.340 --> 00:16:58.863 Second,

NOTE Confidence: 0.9220973

00:16:58.863 --> 00:17:01.478 an implication of Cassells definition,

NOTE Confidence: 0.9220973

00:17:01.480 --> 00:17:03.136 one he explores a little bit is the

NOTE Confidence: 0.9220973

00:17:03.136 --> 00:17:05.101 fact that pain and pain and suffering

NOTE Confidence: 0.9220973

00:17:05.101 --> 00:17:06.305 are actually distinct concepts.

NOTE Confidence: 0.9220973

00:17:06.310 --> 00:17:08.980 They're often Co occurring and interrelated,

NOTE Confidence: 0.9220973

00:17:08.980 --> 00:17:10.708 but again distinct.

NOTE Confidence: 0.9220973

00:17:10.708 --> 00:17:11.860 For example,

NOTE Confidence: 0.9220973

00:17:11.860 --> 00:17:13.920 just because you experience pain,

NOTE Confidence: 0.9220973

00:17:13.920 --> 00:17:15.600 a stubbed toe for instance,

NOTE Confidence: 0.9220973

00:17:15.600 --> 00:17:17.740 or perhaps even childbirth does

NOTE Confidence: 0.9220973

00:17:17.740 --> 00:17:19.880 not mean you experience suffering.

NOTE Confidence: 0.9220973

00:17:19.880 --> 00:17:21.268 Because suffering for Cassel
NOTE Confidence: 0.9220973

00:17:21.268 --> 00:17:22.656 requires that the pain,
NOTE Confidence: 0.9220973

00:17:22.660 --> 00:17:25.025 cause and experience of distress
NOTE Confidence: 0.9220973

00:17:25.025 --> 00:17:26.917 that threatens the narrative
NOTE Confidence: 0.9220973

00:17:26.917 --> 00:17:28.378 intactness of the person.
NOTE Confidence: 0.9220973

00:17:28.380 --> 00:17:30.005 So take the experience of
NOTE Confidence: 0.9220973

00:17:30.005 --> 00:17:30.980 childbirth for example.
NOTE Confidence: 0.9220973

00:17:30.980 --> 00:17:32.636 I would guess that most persons
NOTE Confidence: 0.9220973

00:17:32.636 --> 00:17:34.372 who labor and deliver a baby
NOTE Confidence: 0.9220973

00:17:34.372 --> 00:17:35.520 will admit to significant,
NOTE Confidence: 0.9220973

00:17:35.520 --> 00:17:36.848 perhaps even severe pain.
NOTE Confidence: 0.9220973

00:17:36.848 --> 00:17:40.038 I would raise my hand as an example of
NOTE Confidence: 0.9220973

00:17:40.038 --> 00:17:42.294 someone who did have that experience,
NOTE Confidence: 0.9220973

00:17:42.300 --> 00:17:44.136 but I think far fewer individuals
NOTE Confidence: 0.9220973

00:17:44.136 --> 00:17:45.797 would say that this experience
NOTE Confidence: 0.9220973

00:17:45.797 --> 00:17:47.277 was one of suffering,

NOTE Confidence: 0.9220973

00:17:47.280 --> 00:17:48.560 probably because the experience

NOTE Confidence: 0.9220973

00:17:48.560 --> 00:17:50.480 is often well integrated into a

NOTE Confidence: 0.865866799166667

00:17:50.537 --> 00:17:51.299 life narrative.

NOTE Confidence: 0.865866799166667

00:17:51.300 --> 00:17:53.976 For many, childbirth is a celebrated

NOTE Confidence: 0.865866799166667

00:17:53.976 --> 00:17:56.499 and joyous experience of new life,

NOTE Confidence: 0.865866799166667

00:17:56.500 --> 00:17:58.580 and similarly you might experience.

NOTE Confidence: 0.865866799166667

00:17:58.580 --> 00:18:00.008 Deep existential suffering.

NOTE Confidence: 0.865866799166667

00:18:00.008 --> 00:18:02.088 For example, the death of a loved one.

NOTE Confidence: 0.865866799166667

00:18:02.090 --> 00:18:04.282 Again, we called to mind the paintings of

NOTE Confidence: 0.865866799166667

00:18:04.282 --> 00:18:06.650 a mother grieving the death of her child,

NOTE Confidence: 0.865866799166667

00:18:06.650 --> 00:18:09.034 the brother grieving the death of his sister.

NOTE Confidence: 0.865866799166667

00:18:09.040 --> 00:18:10.808 But not experience any

NOTE Confidence: 0.865866799166667

00:18:10.808 --> 00:18:12.576 physical symptoms of pain.

NOTE Confidence: 0.865866799166667

00:18:12.580 --> 00:18:15.361 So again, the point here is that pain and

NOTE Confidence: 0.865866799166667

00:18:15.361 --> 00:18:17.429 suffering are not equivalent concepts.

NOTE Confidence: 0.865866799166667

00:18:17.430 --> 00:18:19.880 Finally, and this is an important point
NOTE Confidence: 0.865866799166667

00:18:19.880 --> 00:18:22.389 to make about cassell's definition.
NOTE Confidence: 0.865866799166667

00:18:22.390 --> 00:18:24.850 One major critique of the implication
NOTE Confidence: 0.865866799166667

00:18:24.850 --> 00:18:27.490 of his definition is that for him,
NOTE Confidence: 0.865866799166667

00:18:27.490 --> 00:18:29.638 certain people cannot suffer,
NOTE Confidence: 0.865866799166667

00:18:29.638 --> 00:18:31.786 in particular young children,
NOTE Confidence: 0.865866799166667

00:18:31.790 --> 00:18:34.190 infants, or those with profound
NOTE Confidence: 0.865866799166667

00:18:34.190 --> 00:18:35.150 developmental disabilities,
NOTE Confidence: 0.865866799166667

00:18:35.150 --> 00:18:37.830 because of their cognitive abilities,
NOTE Confidence: 0.865866799166667

00:18:37.830 --> 00:18:40.476 their their inability to interpret an event
NOTE Confidence: 0.865866799166667

00:18:40.476 --> 00:18:42.494 as threatening to their interactionists
NOTE Confidence: 0.865866799166667

00:18:42.494 --> 00:18:45.766 or understanding it as a a broken narrative.
NOTE Confidence: 0.865866799166667

00:18:45.770 --> 00:18:46.871 So for Cassell,
NOTE Confidence: 0.865866799166667

00:18:46.871 --> 00:18:48.706 baby Annie in our case,
NOTE Confidence: 0.865866799166667

00:18:48.710 --> 00:18:49.742 simply can't suffer.
NOTE Confidence: 0.865866799166667

00:18:49.742 --> 00:18:52.650 So a claim like that is just wrong.

NOTE Confidence: 0.865866799166667
00:18:52.650 --> 00:18:54.925 And it should not be a part
NOTE Confidence: 0.865866799166667
00:18:54.925 --> 00:18:56.510 of our decision making.
NOTE Confidence: 0.865866799166667
00:18:56.510 --> 00:18:58.670 He thinks that we would just be simply
NOTE Confidence: 0.865866799166667
00:18:58.670 --> 00:19:00.821 mistaken if we made a second hand claim
NOTE Confidence: 0.865866799166667
00:19:00.821 --> 00:19:02.779 about a patient like Annie suffering.
NOTE Confidence: 0.865866799166667
00:19:02.780 --> 00:19:03.800 Isn't that simple?
NOTE Confidence: 0.865866799166667
00:19:03.800 --> 00:19:05.648 Well, you know, I don't think so.
NOTE Confidence: 0.865866799166667
00:19:05.648 --> 00:19:07.592 I I don't think we have a lot of
NOTE Confidence: 0.865866799166667
00:19:07.592 --> 00:19:08.894 time to engage deeply in that
NOTE Confidence: 0.865866799166667
00:19:08.894 --> 00:19:10.636 sort of theoretical concept of
NOTE Confidence: 0.865866799166667
00:19:10.636 --> 00:19:11.740 suffering or definitions.
NOTE Confidence: 0.865866799166667
00:19:11.740 --> 00:19:12.586 And in fact,
NOTE Confidence: 0.865866799166667
00:19:12.586 --> 00:19:14.278 the major thrust of my argument
NOTE Confidence: 0.865866799166667
00:19:14.278 --> 00:19:16.682 today does not really rely on a
NOTE Confidence: 0.865866799166667
00:19:16.682 --> 00:19:18.058 particular definition of suffering.
NOTE Confidence: 0.865866799166667

00:19:18.060 --> 00:19:19.884 But I do think it's appropriate to offer
NOTE Confidence: 0.865866799166667

00:19:19.884 --> 00:19:21.434 you some preliminary claims that if
NOTE Confidence: 0.865866799166667

00:19:21.434 --> 00:19:23.419 you'd like to discuss more in the Q&A,
NOTE Confidence: 0.865866799166667

00:19:23.420 --> 00:19:24.458 please feel free to do this.
NOTE Confidence: 0.865866799166667

00:19:24.460 --> 00:19:26.490 But I'm just going to very briefly
NOTE Confidence: 0.865866799166667

00:19:26.490 --> 00:19:28.430 describe to you what my priorities
NOTE Confidence: 0.865866799166667

00:19:28.430 --> 00:19:30.782 would be for a definition of suffering.
NOTE Confidence: 0.865866799166667

00:19:30.790 --> 00:19:34.206 Again we have Cassells definition of top.
NOTE Confidence: 0.865866799166667

00:19:34.210 --> 00:19:35.608 So my priorities for a definition
NOTE Confidence: 0.865866799166667

00:19:35.608 --> 00:19:36.920 are a little bit looser.
NOTE Confidence: 0.865866799166667

00:19:36.920 --> 00:19:39.250 Suffering is a negative subjective
NOTE Confidence: 0.865866799166667

00:19:39.250 --> 00:19:40.648 experience of significance.
NOTE Confidence: 0.865866799166667

00:19:40.650 --> 00:19:43.744 Note here that the words I'm using,
NOTE Confidence: 0.865866799166667

00:19:43.750 --> 00:19:47.720 it does require some sort of perhaps limited,
NOTE Confidence: 0.865866799166667

00:19:47.720 --> 00:19:50.090 but some sort of conscious experience
NOTE Confidence: 0.865866799166667

00:19:50.090 --> 00:19:52.824 and the ability to in some way

NOTE Confidence: 0.865866799166667
00:19:52.824 --> 00:19:54.324 understand events as negative.
NOTE Confidence: 0.865866799166667
00:19:54.330 --> 00:19:56.100 So I think this does include
NOTE Confidence: 0.865866799166667
00:19:56.100 --> 00:19:57.923 far more patients and that this
NOTE Confidence: 0.865866799166667
00:19:57.923 --> 00:19:59.789 experience does in fact go beyond
NOTE Confidence: 0.865866799166667
00:19:59.789 --> 00:20:01.870 the physical experience of pain.
NOTE Confidence: 0.865866799166667
00:20:01.870 --> 00:20:03.545 So these priorities I think
NOTE Confidence: 0.865866799166667
00:20:03.545 --> 00:20:05.220 largely do align with Cassel.
NOTE Confidence: 0.865866799166667
00:20:05.220 --> 00:20:05.548 Um,
NOTE Confidence: 0.865866799166667
00:20:05.548 --> 00:20:07.188 although one important departure that
NOTE Confidence: 0.865866799166667
00:20:07.188 --> 00:20:09.229 we're he would argue certain categories
NOTE Confidence: 0.865866799166667
00:20:09.229 --> 00:20:11.574 of people cannot suffer again for him.
NOTE Confidence: 0.865866799166667
00:20:11.580 --> 00:20:12.078 Infants,
NOTE Confidence: 0.865866799166667
00:20:12.078 --> 00:20:13.572 very young children,
NOTE Confidence: 0.865866799166667
00:20:13.572 --> 00:20:16.062 and those with profound developmental
NOTE Confidence: 0.865866799166667
00:20:16.062 --> 00:20:16.560 disabilities.
NOTE Confidence: 0.865866799166667

00:20:16.560 --> 00:20:18.016 I would like to leave a little
NOTE Confidence: 0.865866799166667

00:20:18.016 --> 00:20:19.644 more room for the possibility that
NOTE Confidence: 0.865866799166667

00:20:19.644 --> 00:20:21.239 these individuals can suffer,
NOTE Confidence: 0.865866799166667

00:20:21.240 --> 00:20:23.315 because my definition is less
NOTE Confidence: 0.865866799166667

00:20:23.315 --> 00:20:24.975 specific about how negative
NOTE Confidence: 0.865866799166667

00:20:24.975 --> 00:20:26.659 experiences must be interpreted.
NOTE Confidence: 0.865866799166667

00:20:26.660 --> 00:20:27.968 I'd like to,
NOTE Confidence: 0.865866799166667

00:20:27.968 --> 00:20:28.840 you know,
NOTE Confidence: 0.865866799166667

00:20:28.840 --> 00:20:30.598 leave some room for the possibility
NOTE Confidence: 0.865866799166667

00:20:30.598 --> 00:20:32.679 that Annie is in fact suffering,
NOTE Confidence: 0.865866799166667

00:20:32.680 --> 00:20:35.248 even if she is unable to understand this.
NOTE Confidence: 0.865866799166667

00:20:35.250 --> 00:20:37.308 Event in a sort of more
NOTE Confidence: 0.865866799166667

00:20:37.308 --> 00:20:39.078 cognitive or intellectual way as
NOTE Confidence: 0.865866799166667

00:20:39.078 --> 00:20:40.698 a threat to her intactness.
NOTE Confidence: 0.865866799166667

00:20:40.700 --> 00:20:42.618 Why is this a priority for me?
NOTE Confidence: 0.865866799166667

00:20:42.620 --> 00:20:44.522 I'll just give you 3 really

NOTE Confidence: 0.865866799166667
00:20:44.522 --> 00:20:45.790 brief reasons before we
NOTE Confidence: 0.86350973
00:20:45.853 --> 00:20:47.403 move on. So epistemically, again,
NOTE Confidence: 0.86350973
00:20:47.403 --> 00:20:50.237 sort of in terms of what we were
NOTE Confidence: 0.86350973
00:20:50.237 --> 00:20:52.078 able to know, I believe it's wise
NOTE Confidence: 0.86350973
00:20:52.078 --> 00:20:53.949 to err on the side of believing
NOTE Confidence: 0.86350973
00:20:53.949 --> 00:20:56.029 that these populations can suffer,
NOTE Confidence: 0.86350973
00:20:56.030 --> 00:20:57.920 because I just think it's more
NOTE Confidence: 0.86350973
00:20:57.920 --> 00:20:59.870 dangerous to assume that they can't.
NOTE Confidence: 0.86350973
00:20:59.870 --> 00:21:01.795 You could look at the troubling but
NOTE Confidence: 0.86350973
00:21:01.795 --> 00:21:03.973 pretty wise, widespread and commonly
NOTE Confidence: 0.86350973
00:21:03.973 --> 00:21:06.137 accepted practice of unanesthetized
NOTE Confidence: 0.86350973
00:21:06.137 --> 00:21:09.010 surgery on infants for many decades.
NOTE Confidence: 0.86350973
00:21:09.010 --> 00:21:10.510 Anesthesia infants really wasn't
NOTE Confidence: 0.86350973
00:21:10.510 --> 00:21:13.050 common practice until the 1970s or 80s,
NOTE Confidence: 0.86350973
00:21:13.050 --> 00:21:15.222 because for a very long time
NOTE Confidence: 0.86350973

00:21:15.222 --> 00:21:16.670 we wrongly assumed that.
NOTE Confidence: 0.86350973

00:21:16.670 --> 00:21:19.598 Infants can't feel pain, and we turned out.
NOTE Confidence: 0.86350973

00:21:19.600 --> 00:21:22.246 Turns out we were wrong about that.
NOTE Confidence: 0.86350973

00:21:22.250 --> 00:21:23.542 The second reason is,
NOTE Confidence: 0.86350973

00:21:23.542 --> 00:21:25.480 I believe the empirical research is
NOTE Confidence: 0.86350973

00:21:25.543 --> 00:21:27.529 actually quite clear on this point,
NOTE Confidence: 0.86350973

00:21:27.530 --> 00:21:29.384 that caregivers, parents,
NOTE Confidence: 0.86350973

00:21:29.384 --> 00:21:31.124 clinicians, nurses, physicians,
NOTE Confidence: 0.86350973

00:21:31.124 --> 00:21:33.140 others of these populations,
NOTE Confidence: 0.86350973

00:21:33.140 --> 00:21:34.955 infants, young children,
NOTE Confidence: 0.86350973

00:21:34.955 --> 00:21:37.375 those with profound developmental
NOTE Confidence: 0.86350973

00:21:37.375 --> 00:21:39.598 disabilities consistently believe that
NOTE Confidence: 0.86350973

00:21:39.598 --> 00:21:42.286 they can and in fact sometimes do suffer.
NOTE Confidence: 0.86350973

00:21:42.290 --> 00:21:43.238 So that's this.
NOTE Confidence: 0.86350973

00:21:43.238 --> 00:21:45.134 It aligns with the most common
NOTE Confidence: 0.86350973

00:21:45.134 --> 00:21:46.528 scholarly usage of the term,

NOTE Confidence: 0.86350973

00:21:46.530 --> 00:21:49.086 as we explored in previous slides

NOTE Confidence: 0.86350973

00:21:49.086 --> 00:21:51.921 with that empirical study in the

NOTE Confidence: 0.86350973

00:21:51.921 --> 00:21:54.037 bioethics and Pediatrics communities.

NOTE Confidence: 0.86350973

00:21:54.040 --> 00:21:54.700 And finally,

NOTE Confidence: 0.86350973

00:21:54.700 --> 00:21:57.010 I think sort of the summary point

NOTE Confidence: 0.86350973

00:21:57.010 --> 00:21:59.886 about these priorities would be that a

NOTE Confidence: 0.86350973

00:21:59.886 --> 00:22:02.015 definition like this prioritizes the

NOTE Confidence: 0.86350973

00:22:02.015 --> 00:22:04.080 lived experience of the individual,

NOTE Confidence: 0.86350973

00:22:04.080 --> 00:22:06.318 but again not limiting the phenomenon

NOTE Confidence: 0.86350973

00:22:06.318 --> 00:22:08.165 only to those individuals with

NOTE Confidence: 0.86350973

00:22:08.165 --> 00:22:09.595 an intact sense of self.

NOTE Confidence: 0.86350973

00:22:09.600 --> 00:22:11.760 So this does imply though,

NOTE Confidence: 0.86350973

00:22:11.760 --> 00:22:12.920 which might be a problem,

NOTE Confidence: 0.86350973

00:22:12.920 --> 00:22:14.852 limited epistemic access to

NOTE Confidence: 0.86350973

00:22:14.852 --> 00:22:15.818 another suffering,

NOTE Confidence: 0.86350973

00:22:15.820 --> 00:22:17.272 which makes it particularly
NOTE Confidence: 0.86350973

00:22:17.272 --> 00:22:19.087 difficult as a phenomenon that
NOTE Confidence: 0.86350973

00:22:19.087 --> 00:22:21.057 we want to assess or assuage,
NOTE Confidence: 0.86350973

00:22:21.060 --> 00:22:22.413 especially in children.
NOTE Confidence: 0.86350973

00:22:22.413 --> 00:22:22.864 This,
NOTE Confidence: 0.86350973

00:22:22.864 --> 00:22:24.668 again as a reminder,
NOTE Confidence: 0.86350973

00:22:24.670 --> 00:22:26.974 does not stop caregivers from making
NOTE Confidence: 0.86350973

00:22:26.974 --> 00:22:28.510 claims about pediatric suffering,
NOTE Confidence: 0.86350973

00:22:28.510 --> 00:22:30.610 about the children that they're
NOTE Confidence: 0.86350973

00:22:30.610 --> 00:22:32.290 caring for experiencing suffering.
NOTE Confidence: 0.86350973

00:22:32.290 --> 00:22:33.826 And in many cases,
NOTE Confidence: 0.86350973

00:22:33.826 --> 00:22:36.130 these claims are not entirely ungrounded.
NOTE Confidence: 0.86350973

00:22:36.130 --> 00:22:36.496 Typically,
NOTE Confidence: 0.86350973

00:22:36.496 --> 00:22:38.692 they're based on assessments of physical
NOTE Confidence: 0.86350973

00:22:38.692 --> 00:22:40.501 symptoms and behaviors that are
NOTE Confidence: 0.86350973

00:22:40.501 --> 00:22:42.469 typically associated with pain and distress,

NOTE Confidence: 0.86350973

00:22:42.470 --> 00:22:44.374 things like air, hunger,

NOTE Confidence: 0.86350973

00:22:44.374 --> 00:22:45.565 agitation, crying,

NOTE Confidence: 0.86350973

00:22:45.565 --> 00:22:47.710 certain facial expressions,

NOTE Confidence: 0.86350973

00:22:47.710 --> 00:22:49.140 and sleeplessness.

NOTE Confidence: 0.86350973

00:22:49.140 --> 00:22:50.630 Again, as a reminder, however,

NOTE Confidence: 0.86350973

00:22:50.630 --> 00:22:52.709 while these may be signs of suffering,

NOTE Confidence: 0.86350973

00:22:52.710 --> 00:22:53.778 and in some cases may be.

NOTE Confidence: 0.86350973

00:22:53.780 --> 00:22:55.476 Very dependable or reliable

NOTE Confidence: 0.86350973

00:22:55.476 --> 00:22:56.748 signs of suffering.

NOTE Confidence: 0.86350973

00:22:56.750 --> 00:22:58.620 They can't necessarily be equated

NOTE Confidence: 0.86350973

00:22:58.620 --> 00:23:00.490 with the experience of suffering,

NOTE Confidence: 0.86350973

00:23:00.490 --> 00:23:02.190 and the frequency and intensity

NOTE Confidence: 0.86350973

00:23:02.190 --> 00:23:03.890 of these behaviors are not

NOTE Confidence: 0.86350973

00:23:03.951 --> 00:23:05.707 necessarily indicative of the

NOTE Confidence: 0.86350973

00:23:05.707 --> 00:23:07.463 intensity of actual suffering.

NOTE Confidence: 0.86350973

00:23:07.470 --> 00:23:08.096 And again,
NOTE Confidence: 0.86350973

00:23:08.096 --> 00:23:10.600 an absence of this these behaviors does not
NOTE Confidence: 0.86350973

00:23:10.667 --> 00:23:13.049 necessarily mean an absence of suffering.
NOTE Confidence: 0.86350973

00:23:13.050 --> 00:23:14.738 So that's what I do want to distinguish
NOTE Confidence: 0.86350973

00:23:14.738 --> 00:23:15.770 between pain and suffering.
NOTE Confidence: 0.86350973

00:23:15.770 --> 00:23:18.038 It seems reasonable to me to assume
NOTE Confidence: 0.86350973

00:23:18.038 --> 00:23:20.341 that an individuals with a limited
NOTE Confidence: 0.86350973

00:23:20.341 --> 00:23:21.189 conscious experience,
NOTE Confidence: 0.86350973

00:23:21.190 --> 00:23:24.767 again we might think here of neonates.
NOTE Confidence: 0.86350973

00:23:24.770 --> 00:23:25.998 Experience of suffering might
NOTE Confidence: 0.86350973

00:23:25.998 --> 00:23:27.866 overlap a little bit more, though,
NOTE Confidence: 0.86350973

00:23:27.866 --> 00:23:29.496 with the experience of pain,
NOTE Confidence: 0.86350973

00:23:29.500 --> 00:23:31.865 perhaps to a greater extent
NOTE Confidence: 0.86350973

00:23:31.865 --> 00:23:33.757 than in other populations.
NOTE Confidence: 0.86350973

00:23:33.760 --> 00:23:35.880 OK.
NOTE Confidence: 0.86350973

00:23:35.880 --> 00:23:39.888 So I have presented you a claim that

NOTE Confidence: 0.86350973

00:23:39.888 --> 00:23:43.458 children can and sometimes do suffer,

NOTE Confidence: 0.86350973

00:23:43.460 --> 00:23:46.057 but because of how we define suffering,

NOTE Confidence: 0.86350973

00:23:46.060 --> 00:23:48.300 or how I'm proposing that we understand

NOTE Confidence: 0.86350973

00:23:48.300 --> 00:23:49.880 the experience of suffering,

NOTE Confidence: 0.86350973

00:23:49.880 --> 00:23:52.120 we don't have great access to that suffering.

NOTE Confidence: 0.86350973

00:23:52.120 --> 00:23:53.452 It's very hard to know because

NOTE Confidence: 0.86350973

00:23:53.452 --> 00:23:54.610 we simply can't ask them.

NOTE Confidence: 0.86350973

00:23:54.610 --> 00:23:55.882 As a reminder,

NOTE Confidence: 0.86350973

00:23:55.882 --> 00:23:57.578 in our adult populations,

NOTE Confidence: 0.820556771428571

00:23:57.580 --> 00:23:59.365 if we're concerned about a patient suffering,

NOTE Confidence: 0.820556771428571

00:23:59.370 --> 00:24:01.230 we would just communicate with them

NOTE Confidence: 0.820556771428571

00:24:01.230 --> 00:24:02.470 verbally about that experience.

NOTE Confidence: 0.820556771428571

00:24:02.470 --> 00:24:03.292 What's distressing?

NOTE Confidence: 0.820556771428571

00:24:03.292 --> 00:24:04.936 What are you feeling?

NOTE Confidence: 0.820556771428571

00:24:04.940 --> 00:24:05.830 It would be much more.

NOTE Confidence: 0.820556771428571

00:24:05.830 --> 00:24:08.526 It's much easier to have access to that

NOTE Confidence: 0.820556771428571

00:24:08.526 --> 00:24:11.089 because of the ability to communicate.

NOTE Confidence: 0.820556771428571

00:24:11.090 --> 00:24:13.666 With this line, I just want to mention

NOTE Confidence: 0.820556771428571

00:24:13.666 --> 00:24:16.259 a couple ways in which suffering is

NOTE Confidence: 0.820556771428571

00:24:16.259 --> 00:24:18.717 already treated as a morally special

NOTE Confidence: 0.820556771428571

00:24:18.717 --> 00:24:21.227 concept by the Pediatrics community,

NOTE Confidence: 0.820556771428571

00:24:21.230 --> 00:24:22.226 but in different ways.

NOTE Confidence: 0.820556771428571

00:24:22.226 --> 00:24:24.248 So there's sort of opposing ways in which

NOTE Confidence: 0.820556771428571

00:24:24.248 --> 00:24:25.907 the concept of suffering is used here.

NOTE Confidence: 0.820556771428571

00:24:25.910 --> 00:24:27.188 So on the on the left,

NOTE Confidence: 0.820556771428571

00:24:27.190 --> 00:24:28.422 I'm summarizing what's known

NOTE Confidence: 0.820556771428571

00:24:28.422 --> 00:24:29.654 as the Groningen protocol,

NOTE Confidence: 0.820556771428571

00:24:29.660 --> 00:24:32.593 which is a medical protocol in the

NOTE Confidence: 0.820556771428571

00:24:32.593 --> 00:24:34.416 Netherlands which allows physicians

NOTE Confidence: 0.820556771428571

00:24:34.416 --> 00:24:36.866 to actively euthanize a seriously

NOTE Confidence: 0.820556771428571

00:24:36.866 --> 00:24:39.401 ill but medically stable newborn

NOTE Confidence: 0.820556771428571

00:24:39.401 --> 00:24:41.886 without fear of legal prosecution.

NOTE Confidence: 0.820556771428571

00:24:41.890 --> 00:24:43.715 The protocol here outlines several

NOTE Confidence: 0.820556771428571

00:24:43.715 --> 00:24:45.930 requirements that must be met for

NOTE Confidence: 0.820556771428571

00:24:45.930 --> 00:24:47.550 this practice to be justified,

NOTE Confidence: 0.820556771428571

00:24:47.550 --> 00:24:50.025 including one that hopeless and

NOTE Confidence: 0.820556771428571

00:24:50.025 --> 00:24:52.005 unbearable suffering must be

NOTE Confidence: 0.820556771428571

00:24:52.005 --> 00:24:54.107 present and to the diagnosis.

NOTE Confidence: 0.820556771428571

00:24:54.110 --> 00:24:56.486 Prognosis and suffering must be confirmed

NOTE Confidence: 0.820556771428571

00:24:56.486 --> 00:24:59.469 by at least one independent doctor.

NOTE Confidence: 0.820556771428571

00:24:59.470 --> 00:25:01.355 So we aren't actually told

NOTE Confidence: 0.820556771428571

00:25:01.355 --> 00:25:02.486 specifically what constitutes

NOTE Confidence: 0.820556771428571

00:25:02.486 --> 00:25:04.449 hopeless and unbearable suffering,

NOTE Confidence: 0.820556771428571

00:25:04.450 --> 00:25:06.795 nor are we really given tools for

NOTE Confidence: 0.820556771428571

00:25:06.795 --> 00:25:08.630 adequately assessing it in a newborn.

NOTE Confidence: 0.820556771428571

00:25:08.630 --> 00:25:11.563 But in this case it can actually

NOTE Confidence: 0.820556771428571

00:25:11.563 --> 00:25:12.820 justify active euthanasia.
NOTE Confidence: 0.820556771428571

00:25:12.820 --> 00:25:13.582 And in fact,
NOTE Confidence: 0.820556771428571

00:25:13.582 --> 00:25:15.779 it's not even just an assessment of current
NOTE Confidence: 0.820556771428571

00:25:15.779 --> 00:25:17.957 suffering that might justify a decision,
NOTE Confidence: 0.820556771428571

00:25:17.960 --> 00:25:20.225 but an assessment of possible
NOTE Confidence: 0.820556771428571

00:25:20.225 --> 00:25:22.037 or probable future suffering.
NOTE Confidence: 0.820556771428571

00:25:22.040 --> 00:25:24.693 A study reporting end of life decisions
NOTE Confidence: 0.820556771428571

00:25:24.693 --> 00:25:27.429 in Dutch Nick use in 92% of patients
NOTE Confidence: 0.820556771428571

00:25:27.429 --> 00:25:29.244 with quote poor prognosis decisions
NOTE Confidence: 0.820556771428571

00:25:29.244 --> 00:25:31.920 were made to end the child's life not
NOTE Confidence: 0.820556771428571

00:25:31.920 --> 00:25:33.840 actually based on current suffering,
NOTE Confidence: 0.820556771428571

00:25:33.840 --> 00:25:36.828 but on predictions of future suffering.
NOTE Confidence: 0.820556771428571

00:25:36.830 --> 00:25:37.930 As I'm sure you know,
NOTE Confidence: 0.820556771428571

00:25:37.930 --> 00:25:39.154 if you're if you're at all
NOTE Confidence: 0.820556771428571

00:25:39.154 --> 00:25:39.970 familiar with this protocol,
NOTE Confidence: 0.820556771428571

00:25:39.970 --> 00:25:41.980 it's been met with fairly

NOTE Confidence: 0.820556771428571

00:25:41.980 --> 00:25:42.784 widespread criticism.

NOTE Confidence: 0.820556771428571

00:25:42.790 --> 00:25:44.742 And I think at this point in the

NOTE Confidence: 0.820556771428571

00:25:44.742 --> 00:25:46.215 presentation you can suspect why that

NOTE Confidence: 0.820556771428571

00:25:46.215 --> 00:25:48.295 might be the case for many of the

NOTE Confidence: 0.820556771428571

00:25:48.295 --> 00:25:49.860 reasons that we've already discussed.

NOTE Confidence: 0.820556771428571

00:25:49.860 --> 00:25:52.515 Another example of legislation that

NOTE Confidence: 0.820556771428571

00:25:52.515 --> 00:25:54.639 specifically mentions factors like

NOTE Confidence: 0.820556771428571

00:25:54.639 --> 00:25:56.737 quality of life and suffering,

NOTE Confidence: 0.820556771428571

00:25:56.740 --> 00:25:58.700 although with the opposite impact,

NOTE Confidence: 0.820556771428571

00:25:58.700 --> 00:25:59.950 are the baby DOE regulations,

NOTE Confidence: 0.820556771428571

00:25:59.950 --> 00:26:02.713 which were passed in the US in the 1980s.

NOTE Confidence: 0.820556771428571

00:26:02.720 --> 00:26:04.700 I won't go into details about

NOTE Confidence: 0.820556771428571

00:26:04.700 --> 00:26:05.360 these regulations,

NOTE Confidence: 0.820556771428571

00:26:05.360 --> 00:26:07.796 but a central feature of this legislation

NOTE Confidence: 0.820556771428571

00:26:07.796 --> 00:26:10.664 is that it explicitly rejects subjective

NOTE Confidence: 0.820556771428571

00:26:10.664 --> 00:26:13.000 quality of life considerations,
NOTE Confidence: 0.820556771428571

00:26:13.000 --> 00:26:15.150 including claims of present or
NOTE Confidence: 0.820556771428571

00:26:15.150 --> 00:26:17.300 future suffering as a justification
NOTE Confidence: 0.820556771428571

00:26:17.365 --> 00:26:19.577 for withholding medical treatment.
NOTE Confidence: 0.820556771428571

00:26:19.580 --> 00:26:20.666 To disabled newborns.
NOTE Confidence: 0.820556771428571

00:26:20.666 --> 00:26:23.200 So again we see two examples here
NOTE Confidence: 0.820556771428571

00:26:23.274 --> 00:26:25.488 where the concept is being deployed
NOTE Confidence: 0.820556771428571

00:26:25.488 --> 00:26:27.844 either as a possible rationale or
NOTE Confidence: 0.820556771428571

00:26:27.844 --> 00:26:29.869 reason for a medical decision,
NOTE Confidence: 0.820556771428571

00:26:29.870 --> 00:26:32.229 or as an explicit exclusion as a
NOTE Confidence: 0.820556771428571

00:26:32.229 --> 00:26:34.539 criteria for a medical decision.
NOTE Confidence: 0.86752312875

00:26:37.730 --> 00:26:41.306 OK, moving into slightly more practical
NOTE Confidence: 0.86752312875

00:26:41.306 --> 00:26:43.703 spaces here, the question is,
NOTE Confidence: 0.86752312875

00:26:43.703 --> 00:26:46.109 is suffering a morally special concept
NOTE Confidence: 0.86752312875

00:26:46.109 --> 00:26:48.870 in terms of medical decision making?
NOTE Confidence: 0.86752312875

00:26:48.870 --> 00:26:51.230 So, so far we've concluded that we probably

NOTE Confidence: 0.86752312875

00:26:51.230 --> 00:26:53.548 ought to assume that the vast majority

NOTE Confidence: 0.86752312875

00:26:53.548 --> 00:26:55.680 of our pediatric patients can suffer,

NOTE Confidence: 0.86752312875

00:26:55.680 --> 00:26:57.546 that we don't have great epics

NOTE Confidence: 0.86752312875

00:26:57.546 --> 00:26:59.420 epistemic access to this suffering.

NOTE Confidence: 0.86752312875

00:26:59.420 --> 00:27:01.744 But again this does not stop caregivers

NOTE Confidence: 0.86752312875

00:27:01.744 --> 00:27:04.178 from making claims about patient suffering.

NOTE Confidence: 0.86752312875

00:27:04.180 --> 00:27:06.824 So knowing all these things is,

NOTE Confidence: 0.86752312875

00:27:06.824 --> 00:27:09.372 does this suggest to us that suffering

NOTE Confidence: 0.86752312875

00:27:09.372 --> 00:27:11.219 should somehow serve a special

NOTE Confidence: 0.86752312875

00:27:11.219 --> 00:27:13.676 function in our in our decision making.

NOTE Confidence: 0.86752312875

00:27:13.680 --> 00:27:15.132 So let's look at what decision

NOTE Confidence: 0.86752312875

00:27:15.132 --> 00:27:16.360 making might typically look like.

NOTE Confidence: 0.86752312875

00:27:16.360 --> 00:27:19.909 Here's this is a very simple graphic.

NOTE Confidence: 0.86752312875

00:27:19.910 --> 00:27:22.437 Only made possible by my very rudimentary

NOTE Confidence: 0.86752312875

00:27:22.437 --> 00:27:24.644 understanding of Google Slides and the

NOTE Confidence: 0.86752312875

00:27:24.644 --> 00:27:26.414 features available in Google Slides,
NOTE Confidence: 0.86752312875

00:27:26.420 --> 00:27:28.135 so I I acknowledge this is a
NOTE Confidence: 0.86752312875

00:27:28.135 --> 00:27:29.610 very stripped down version here,
NOTE Confidence: 0.86752312875

00:27:29.610 --> 00:27:31.986 but I'll walk you through what I think
NOTE Confidence: 0.86752312875

00:27:31.986 --> 00:27:34.190 this graphic kind of describes about
NOTE Confidence: 0.86752312875

00:27:34.190 --> 00:27:37.040 the medical decision making process.
NOTE Confidence: 0.86752312875

00:27:37.040 --> 00:27:39.380 So when you consider whether which
NOTE Confidence: 0.86752312875

00:27:39.380 --> 00:27:41.779 treatment option to pursue in medicine,
NOTE Confidence: 0.86752312875

00:27:41.780 --> 00:27:43.544 you might first consider the benefits
NOTE Confidence: 0.86752312875

00:27:43.544 --> 00:27:45.100 of a particular treatment option.
NOTE Confidence: 0.86752312875

00:27:45.100 --> 00:27:46.258 And you can include all sorts
NOTE Confidence: 0.86752312875

00:27:46.258 --> 00:27:47.280 of things on this list.
NOTE Confidence: 0.86752312875

00:27:47.280 --> 00:27:48.280 What counts as a benefit.
NOTE Confidence: 0.86752312875

00:27:48.280 --> 00:27:50.224 And of course we get we let allow
NOTE Confidence: 0.86752312875

00:27:50.224 --> 00:27:51.934 parents very frequently to to define
NOTE Confidence: 0.86752312875

00:27:51.934 --> 00:27:53.680 for themselves what counts as a

NOTE Confidence: 0.86752312875

00:27:53.736 --> 00:27:55.402 benefit and those sort of are added

NOTE Confidence: 0.86752312875

00:27:55.402 --> 00:27:58.620 up in the plus column, so to speak.

NOTE Confidence: 0.86752312875

00:27:58.620 --> 00:28:01.030 Then we might subtract potential

NOTE Confidence: 0.86752312875

00:28:01.030 --> 00:28:02.476 risks or burdens.

NOTE Confidence: 0.86752312875

00:28:02.480 --> 00:28:04.700 So risks here are the possibilities

NOTE Confidence: 0.86752312875

00:28:04.700 --> 00:28:06.740 for bad things to happen.

NOTE Confidence: 0.86752312875

00:28:06.740 --> 00:28:08.876 Burdens are the things that we like side

NOTE Confidence: 0.86752312875

00:28:08.876 --> 00:28:10.827 effects that we know will be burdensome.

NOTE Confidence: 0.86752312875

00:28:10.830 --> 00:28:12.210 So we might, you know,

NOTE Confidence: 0.86752312875

00:28:12.210 --> 00:28:14.070 subtract things like the chance of

NOTE Confidence: 0.86752312875

00:28:14.070 --> 00:28:15.456 complication, the chance of death.

NOTE Confidence: 0.86752312875

00:28:15.456 --> 00:28:17.070 And then we might again subtract

NOTE Confidence: 0.86752312875

00:28:17.126 --> 00:28:19.090 things like pain, functional loss,

NOTE Confidence: 0.86752312875

00:28:19.090 --> 00:28:21.290 again things like relational,

NOTE Confidence: 0.86752312875

00:28:21.290 --> 00:28:21.680 emotional,

NOTE Confidence: 0.86752312875

00:28:21.680 --> 00:28:23.630 or spiritual burdens if they're
NOTE Confidence: 0.86752312875

00:28:23.630 --> 00:28:25.839 important to the patient or family.
NOTE Confidence: 0.86752312875

00:28:25.840 --> 00:28:26.960 Again, as a reminder,
NOTE Confidence: 0.86752312875

00:28:26.960 --> 00:28:29.079 value judgments do have to be made
NOTE Confidence: 0.86752312875

00:28:29.079 --> 00:28:30.959 here about what constitutes benefit,
NOTE Confidence: 0.86752312875

00:28:30.960 --> 00:28:31.935 what constitutes burden,
NOTE Confidence: 0.86752312875

00:28:31.935 --> 00:28:33.560 and how much these different
NOTE Confidence: 0.86752312875

00:28:33.560 --> 00:28:35.224 variables should quote, UN quote,
NOTE Confidence: 0.86752312875

00:28:35.224 --> 00:28:37.276 weigh in a in a calculus.
NOTE Confidence: 0.86752312875

00:28:37.280 --> 00:28:38.920 And obviously the possible suffering
NOTE Confidence: 0.86752312875

00:28:38.920 --> 00:28:40.560 of the patient is relevant.
NOTE Confidence: 0.86752312875

00:28:40.560 --> 00:28:42.737 I think typically we would think that
NOTE Confidence: 0.86752312875

00:28:42.737 --> 00:28:44.958 suffering would come under risks or burdens,
NOTE Confidence: 0.86752312875

00:28:44.960 --> 00:28:46.570 right?
NOTE Confidence: 0.86752312875

00:28:46.570 --> 00:28:48.370 So we would maybe want to add to the
NOTE Confidence: 0.86752312875

00:28:48.370 --> 00:28:50.435 list if if there's a possibility that

NOTE Confidence: 0.86752312875

00:28:50.435 --> 00:28:52.190 this intervention could cause suffering,

NOTE Confidence: 0.86752312875

00:28:52.190 --> 00:28:54.482 it it it should be subtracted

NOTE Confidence: 0.86752312875

00:28:54.482 --> 00:28:55.628 alongside other risks.

NOTE Confidence: 0.86752312875

00:28:55.630 --> 00:28:56.930 And if there's a possibility,

NOTE Confidence: 0.86752312875

00:28:56.930 --> 00:28:58.512 or if we are fairly confident that

NOTE Confidence: 0.86752312875

00:28:58.512 --> 00:29:00.657 there will be a side effect of some

NOTE Confidence: 0.86752312875

00:29:00.657 --> 00:29:01.789 suffering with our intervention,

NOTE Confidence: 0.86752312875

00:29:01.790 --> 00:29:05.787 we should probably include it under burdens.

NOTE Confidence: 0.86752312875

00:29:05.790 --> 00:29:06.879 But my fear,

NOTE Confidence: 0.86752312875

00:29:06.879 --> 00:29:09.718 and really the kind of claim that

NOTE Confidence: 0.86752312875

00:29:09.718 --> 00:29:11.903 motivated much of this project,

NOTE Confidence: 0.86752312875

00:29:11.910 --> 00:29:15.066 is that suffering actually tends to

NOTE Confidence: 0.86752312875

00:29:15.066 --> 00:29:17.430 affect the process. In this way.

NOTE Confidence: 0.870437349

00:29:21.430 --> 00:29:23.050 So when the concept of suffering

NOTE Confidence: 0.870437349

00:29:23.050 --> 00:29:24.130 enters into the discussion,

NOTE Confidence: 0.870437349

00:29:24.130 --> 00:29:25.750 what can sometimes happen is
NOTE Confidence: 0.870437349

00:29:25.750 --> 00:29:27.370 that the rhetorical power of
NOTE Confidence: 0.870437349

00:29:27.433 --> 00:29:28.968 the word simply takes over.
NOTE Confidence: 0.870437349

00:29:28.970 --> 00:29:30.850 It obscures all other risks,
NOTE Confidence: 0.870437349

00:29:30.850 --> 00:29:32.041 benefits, and burdens,
NOTE Confidence: 0.870437349

00:29:32.041 --> 00:29:34.820 and I think the term itself carries
NOTE Confidence: 0.870437349

00:29:34.894 --> 00:29:36.946 with it this sort of mystical,
NOTE Confidence: 0.870437349

00:29:36.950 --> 00:29:41.090 mystical, and forceful gestalt quality.
NOTE Confidence: 0.870437349

00:29:41.090 --> 00:29:43.196 And sometimes claims of suffering can
NOTE Confidence: 0.870437349

00:29:43.196 --> 00:29:45.588 really eclipse the rest of the decision,
NOTE Confidence: 0.870437349

00:29:45.590 --> 00:29:48.078 all the other sort of important factors that
NOTE Confidence: 0.870437349

00:29:48.078 --> 00:29:49.807 we're considering as we make decisions,
NOTE Confidence: 0.870437349

00:29:49.810 --> 00:29:50.970 and it might even encourage.
NOTE Confidence: 0.870437349

00:29:50.970 --> 00:29:53.124 Is to make some dramatic decisions
NOTE Confidence: 0.870437349

00:29:53.124 --> 00:29:55.333 because the presence of suffering simply
NOTE Confidence: 0.870437349

00:29:55.333 --> 00:29:58.157 feels so bad that it must be eliminated,

NOTE Confidence: 0.870437349

00:29:58.160 --> 00:29:59.296 even if it means,

NOTE Confidence: 0.870437349

00:29:59.296 --> 00:30:01.000 in the words of dansel Macy,

NOTE Confidence: 0.870437349

00:30:01.000 --> 00:30:04.018 eliminating the sufferer.

NOTE Confidence: 0.870437349

00:30:04.020 --> 00:30:05.802 And importantly and this is really

NOTE Confidence: 0.870437349

00:30:05.802 --> 00:30:08.312 kind of one of the terms that I

NOTE Confidence: 0.870437349

00:30:08.312 --> 00:30:10.202 think important terms that my paper

NOTE Confidence: 0.870437349

00:30:10.266 --> 00:30:12.274 takes is that I think second hand

NOTE Confidence: 0.870437349

00:30:12.274 --> 00:30:14.109 claims of patient suffering might

NOTE Confidence: 0.870437349

00:30:14.109 --> 00:30:16.223 actually tell us more about the

NOTE Confidence: 0.870437349

00:30:16.223 --> 00:30:18.119 speaker than they do the patient.

NOTE Confidence: 0.870437349

00:30:18.120 --> 00:30:20.520 So when a caregiver, a parent,

NOTE Confidence: 0.870437349

00:30:20.520 --> 00:30:22.708 a physician, a nurse says, gosh,

NOTE Confidence: 0.870437349

00:30:22.708 --> 00:30:24.436 I wonder, I wonder and worry,

NOTE Confidence: 0.870437349

00:30:24.440 --> 00:30:25.750 is this patient suffering or

NOTE Confidence: 0.870437349

00:30:25.750 --> 00:30:27.676 even more sort of to the point

NOTE Confidence: 0.870437349

00:30:27.676 --> 00:30:29.344 this patient is suffering and we
NOTE Confidence: 0.870437349

00:30:29.344 --> 00:30:30.978 should do something about it,
NOTE Confidence: 0.870437349

00:30:30.980 --> 00:30:34.040 I wonder if what we might actually be saying.
NOTE Confidence: 0.870437349

00:30:34.040 --> 00:30:36.609 Is when we say that a child
NOTE Confidence: 0.870437349

00:30:36.609 --> 00:30:37.710 is suffering unbearably.
NOTE Confidence: 0.870437349

00:30:37.710 --> 00:30:39.330 It might be, you know,
NOTE Confidence: 0.870437349

00:30:39.330 --> 00:30:41.040 this is distressing to cause pain
NOTE Confidence: 0.870437349

00:30:41.040 --> 00:30:42.939 for what I consider to be little,
NOTE Confidence: 0.870437349

00:30:42.940 --> 00:30:43.496 little benefit.
NOTE Confidence: 0.870437349

00:30:43.496 --> 00:30:44.608 Or you know what,
NOTE Confidence: 0.870437349

00:30:44.610 --> 00:30:47.058 I wouldn't want to live this way or I
NOTE Confidence: 0.870437349

00:30:47.058 --> 00:30:49.546 would not make this choice for my child.
NOTE Confidence: 0.870437349

00:30:49.550 --> 00:30:51.626 Or perhaps more to the point,
NOTE Confidence: 0.870437349

00:30:51.630 --> 00:30:53.454 I the caregiver, caregiver,
NOTE Confidence: 0.870437349

00:30:53.454 --> 00:30:57.110 and I'm in distress and I'm suffering.
NOTE Confidence: 0.870437349

00:30:57.110 --> 00:30:59.566 The problems with this are when

NOTE Confidence: 0.870437349

00:30:59.566 --> 00:31:00.982 we use when we deploy second

NOTE Confidence: 0.870437349

00:31:00.982 --> 00:31:02.629 hand claims of patient suffering.

NOTE Confidence: 0.870437349

00:31:02.630 --> 00:31:04.802 We aren't specific about what we

NOTE Confidence: 0.870437349

00:31:04.802 --> 00:31:07.125 mean and we could be referring

NOTE Confidence: 0.870437349

00:31:07.125 --> 00:31:09.513 to a whole variety of concerns.

NOTE Confidence: 0.870437349

00:31:09.520 --> 00:31:11.298 Second, as we've already sort of discussed,

NOTE Confidence: 0.870437349

00:31:11.300 --> 00:31:14.060 second hand assessments of patient suffering,

NOTE Confidence: 0.870437349

00:31:14.060 --> 00:31:16.500 especially pediatric or child suffering,

NOTE Confidence: 0.870437349

00:31:16.500 --> 00:31:17.920 are generally, you know,

NOTE Confidence: 0.870437349

00:31:17.920 --> 00:31:19.340 not not very reliable.

NOTE Confidence: 0.870437349

00:31:19.340 --> 00:31:20.720 We can make educated guesses,

NOTE Confidence: 0.870437349

00:31:20.720 --> 00:31:24.136 but we can't know with strict confidence.

NOTE Confidence: 0.870437349

00:31:24.140 --> 00:31:24.509 Again,

NOTE Confidence: 0.870437349

00:31:24.509 --> 00:31:26.723 it easily invites in the smuggling

NOTE Confidence: 0.870437349

00:31:26.723 --> 00:31:28.360 in of personal values.

NOTE Confidence: 0.870437349

00:31:28.360 --> 00:31:29.900 For those of you that are familiar
NOTE Confidence: 0.870437349

00:31:29.900 --> 00:31:31.179 with the debate that happens,
NOTE Confidence: 0.870437349

00:31:31.180 --> 00:31:31.528 you know,
NOTE Confidence: 0.870437349

00:31:31.528 --> 00:31:33.200 it's it's sort of died down at this point.
NOTE Confidence: 0.870437349

00:31:33.200 --> 00:31:35.510 But there was a very widespread
NOTE Confidence: 0.870437349

00:31:35.510 --> 00:31:37.467 bioethical debate around the concept
NOTE Confidence: 0.870437349

00:31:37.467 --> 00:31:39.555 of futility and how it should,
NOTE Confidence: 0.870437349

00:31:39.560 --> 00:31:41.373 how that concept should or should not
NOTE Confidence: 0.870437349

00:31:41.373 --> 00:31:42.939 operate in medical decision making.
NOTE Confidence: 0.870437349

00:31:42.940 --> 00:31:44.634 And one of the critiques of utility,
NOTE Confidence: 0.870437349

00:31:44.640 --> 00:31:44.986 actually,
NOTE Confidence: 0.870437349

00:31:44.986 --> 00:31:47.062 was that the term easily smuggles
NOTE Confidence: 0.870437349

00:31:47.062 --> 00:31:48.100 in personal values,
NOTE Confidence: 0.870437349

00:31:48.100 --> 00:31:50.135 value judgments that don't necessarily
NOTE Confidence: 0.870437349

00:31:50.135 --> 00:31:52.170 require an explanation because they're
NOTE Confidence: 0.870437349

00:31:52.227 --> 00:31:54.283 just sort of smuggled in with the term.

NOTE Confidence: 0.870437349

00:31:54.290 --> 00:31:55.874 I wonder if something similar here

NOTE Confidence: 0.870437349

00:31:55.874 --> 00:31:57.690 is happening with the term suffering.

NOTE Confidence: 0.870437349

00:31:57.690 --> 00:32:00.056 And again, the point here is that

NOTE Confidence: 0.870437349

00:32:00.056 --> 00:32:01.830 perhaps a claim like this,

NOTE Confidence: 0.870437349

00:32:01.830 --> 00:32:03.510 a second hand claim,

NOTE Confidence: 0.870437349

00:32:03.510 --> 00:32:05.518 is saying something more about the

NOTE Confidence: 0.870437349

00:32:05.518 --> 00:32:07.770 speaker than it is about the patient.

NOTE Confidence: 0.870437349

00:32:07.770 --> 00:32:09.995 It's describing a speaker who

NOTE Confidence: 0.870437349

00:32:09.995 --> 00:32:12.220 feels very troubled by what

NOTE Confidence: 0.864357733

00:32:12.302 --> 00:32:14.212 appears to be a child

NOTE Confidence: 0.864357733

00:32:14.212 --> 00:32:16.122 that's in pain or distress.

NOTE Confidence: 0.864357733

00:32:16.130 --> 00:32:17.705 And I want to be very clear.

NOTE Confidence: 0.864357733

00:32:17.710 --> 00:32:20.068 I think caregivers should be empowered

NOTE Confidence: 0.864357733

00:32:20.068 --> 00:32:21.640 to communicate these observations

NOTE Confidence: 0.864357733

00:32:21.701 --> 00:32:23.446 to parents and other caregivers,

NOTE Confidence: 0.864357733

00:32:23.450 --> 00:32:25.280 and parents do and should
NOTE Confidence: 0.864357733

00:32:25.280 --> 00:32:26.744 depend on the observational.
NOTE Confidence: 0.864357733

00:32:26.750 --> 00:32:29.072 Expertise of clinicians to help them
NOTE Confidence: 0.864357733

00:32:29.072 --> 00:32:31.240 make decisions about their children.
NOTE Confidence: 0.864357733

00:32:31.240 --> 00:32:34.120 What I find problematic is not not that.
NOTE Confidence: 0.864357733

00:32:34.120 --> 00:32:36.910 What I find problematic instead is
NOTE Confidence: 0.864357733

00:32:36.910 --> 00:32:38.770 that sometimes these communications
NOTE Confidence: 0.864357733

00:32:38.845 --> 00:32:41.119 can a be offered without really
NOTE Confidence: 0.864357733

00:32:41.119 --> 00:32:43.137 any further clarity about the
NOTE Confidence: 0.864357733

00:32:43.137 --> 00:32:45.297 specific concerns of the clinician.
NOTE Confidence: 0.864357733

00:32:45.300 --> 00:32:46.945 What is it specifically about
NOTE Confidence: 0.864357733

00:32:46.945 --> 00:32:48.980 the experience of the child that
NOTE Confidence: 0.864357733

00:32:48.980 --> 00:32:50.960 you're worried and and then second,
NOTE Confidence: 0.864357733

00:32:50.960 --> 00:32:52.535 that sometimes exaggerated
NOTE Confidence: 0.864357733

00:32:52.535 --> 00:32:54.635 descriptions aimed at prop
NOTE Confidence: 0.864357733

00:32:54.635 --> 00:32:56.910 prompting a particular decision.

NOTE Confidence: 0.864357733

00:32:56.910 --> 00:32:58.554 Are what we're aiming for when

NOTE Confidence: 0.864357733

00:32:58.554 --> 00:33:00.310 we use the term suffering.

NOTE Confidence: 0.864357733

00:33:00.310 --> 00:33:01.286 And then finally again.

NOTE Confidence: 0.864357733

00:33:01.286 --> 00:33:02.750 As we've seen with some of

NOTE Confidence: 0.864357733

00:33:02.800 --> 00:33:04.018 the empirical literature,

NOTE Confidence: 0.864357733

00:33:04.020 --> 00:33:05.936 this particular decision is

NOTE Confidence: 0.864357733

00:33:05.936 --> 00:33:08.810 often one that is life ending.

NOTE Confidence: 0.864357733

00:33:08.810 --> 00:33:10.215 So perhaps the moral significance

NOTE Confidence: 0.864357733

00:33:10.215 --> 00:33:11.620 again of these claims actually

NOTE Confidence: 0.864357733

00:33:11.666 --> 00:33:12.926 has less to do with the child

NOTE Confidence: 0.864357733

00:33:12.926 --> 00:33:14.387 and more to do with the speaker.

NOTE Confidence: 0.860713069310345

00:33:18.760 --> 00:33:20.392 Again, second hand claims of patient

NOTE Confidence: 0.860713069310345

00:33:20.392 --> 00:33:22.344 suffering may or may not align with

NOTE Confidence: 0.860713069310345

00:33:22.344 --> 00:33:23.704 the with actual patient suffering

NOTE Confidence: 0.860713069310345

00:33:23.704 --> 00:33:25.459 and that should be accounted for

NOTE Confidence: 0.860713069310345

00:33:25.459 --> 00:33:26.914 in the decision making process.
NOTE Confidence: 0.860713069310345

00:33:26.920 --> 00:33:28.928 So we do need to take seriously the
NOTE Confidence: 0.860713069310345

00:33:28.928 --> 00:33:30.445 possibility that a patient is suffering
NOTE Confidence: 0.860713069310345

00:33:30.445 --> 00:33:32.217 and we need to explore that claim
NOTE Confidence: 0.860713069310345

00:33:32.217 --> 00:33:34.114 further and get more specific about it.
NOTE Confidence: 0.860713069310345

00:33:34.120 --> 00:33:37.396 But it also should prompt another response.
NOTE Confidence: 0.860713069310345

00:33:37.400 --> 00:33:40.440 In us it often indicates that the speaker,
NOTE Confidence: 0.860713069310345

00:33:40.440 --> 00:33:41.784 the physician, nurse,
NOTE Confidence: 0.860713069310345

00:33:41.784 --> 00:33:44.024 caregiver parent is themselves experiencing
NOTE Confidence: 0.860713069310345

00:33:44.024 --> 00:33:46.299 distress and may in fact themselves.
NOTE Confidence: 0.860713069310345

00:33:46.300 --> 00:33:46.938 Be suffering.
NOTE Confidence: 0.860713069310345

00:33:46.938 --> 00:33:49.171 And this is sort of the crux
NOTE Confidence: 0.860713069310345

00:33:49.171 --> 00:33:51.130 of my presentation today.
NOTE Confidence: 0.860713069310345

00:33:51.130 --> 00:33:52.194 This deserves our attention.
NOTE Confidence: 0.860713069310345

00:33:52.194 --> 00:33:54.309 This is not something that should be ignored.
NOTE Confidence: 0.860713069310345

00:33:54.310 --> 00:33:56.739 We think it this sort of claim

NOTE Confidence: 0.860713069310345

00:33:56.739 --> 00:33:59.311 has to result in influences or

NOTE Confidence: 0.860713069310345

00:33:59.311 --> 00:34:01.726 impacts on the medical decision.

NOTE Confidence: 0.860713069310345

00:34:01.730 --> 00:34:04.178 But I think perhaps this sort of claim might

NOTE Confidence: 0.860713069310345

00:34:04.178 --> 00:34:06.365 invite us to a different sort of response,

NOTE Confidence: 0.860713069310345

00:34:06.370 --> 00:34:08.478 attending compassionately and empathetically

NOTE Confidence: 0.860713069310345

00:34:08.478 --> 00:34:11.640 to the experience of our colleagues

NOTE Confidence: 0.860713069310345

00:34:11.706 --> 00:34:14.066 and fellow caregivers when people,

NOTE Confidence: 0.860713069310345

00:34:14.066 --> 00:34:15.530 caregivers, physicians, nurses,

NOTE Confidence: 0.860713069310345

00:34:15.530 --> 00:34:17.060 parents make claims of patients.

NOTE Confidence: 0.860713069310345

00:34:17.060 --> 00:34:17.462 Suffering.

NOTE Confidence: 0.860713069310345

00:34:17.462 --> 00:34:20.276 I believe they are rarely intending to

NOTE Confidence: 0.860713069310345

00:34:20.276 --> 00:34:22.430 influence decisions in a manipulative way,

NOTE Confidence: 0.860713069310345

00:34:22.430 --> 00:34:24.030 and again, in many cases,

NOTE Confidence: 0.860713069310345

00:34:24.030 --> 00:34:25.236 are themselves suffering.

NOTE Confidence: 0.860713069310345

00:34:25.236 --> 00:34:26.844 We should not underestimate

NOTE Confidence: 0.860713069310345

00:34:26.844 --> 00:34:27.976 the psychological, emotional,
NOTE Confidence: 0.860713069310345

00:34:27.976 --> 00:34:29.932 and spiritual effects of providing care
NOTE Confidence: 0.860713069310345

00:34:29.932 --> 00:34:32.227 for someone that they believe is suffering,
NOTE Confidence: 0.860713069310345

00:34:32.230 --> 00:34:34.090 especially if we believe that
NOTE Confidence: 0.860713069310345

00:34:34.090 --> 00:34:35.578 they're suffering directly because
NOTE Confidence: 0.860713069310345

00:34:35.578 --> 00:34:37.010 of what we are doing.
NOTE Confidence: 0.860713069310345

00:34:37.010 --> 00:34:39.068 This is notable, this is powerful.
NOTE Confidence: 0.860713069310345

00:34:39.070 --> 00:34:41.205 And this really it can't be ignored.
NOTE Confidence: 0.860713069310345

00:34:41.210 --> 00:34:42.430 In fact, at Cardinal Glennon,
NOTE Confidence: 0.860713069310345

00:34:42.430 --> 00:34:43.570 where I served as the Vice
NOTE Confidence: 0.860713069310345

00:34:43.570 --> 00:34:44.790 chair of the Ethics Committee,
NOTE Confidence: 0.860713069310345

00:34:44.790 --> 00:34:47.070 we've actually shifted a lot of our ethics.
NOTE Confidence: 0.860713069310345

00:34:47.070 --> 00:34:47.978 Consultation services,
NOTE Confidence: 0.860713069310345

00:34:47.978 --> 00:34:48.432 or,
NOTE Confidence: 0.860713069310345

00:34:48.432 --> 00:34:49.340 excuse me,
NOTE Confidence: 0.860713069310345

00:34:49.340 --> 00:34:51.725 Ethics Committee services to preventive

NOTE Confidence: 0.860713069310345
00:34:51.725 --> 00:34:54.641 ethics work toward attending to these
NOTE Confidence: 0.860713069310345
00:34:54.641 --> 00:34:56.936 sorts of experiences of caregivers,
NOTE Confidence: 0.860713069310345
00:34:56.940 --> 00:34:57.840 you know,
NOTE Confidence: 0.860713069310345
00:34:57.840 --> 00:35:00.540 attending to the moral distress of
NOTE Confidence: 0.860713069310345
00:35:00.540 --> 00:35:03.098 caregivers just attending to the the,
NOTE Confidence: 0.860713069310345
00:35:03.100 --> 00:35:05.186 the stress that is put on caregivers
NOTE Confidence: 0.860713069310345
00:35:05.186 --> 00:35:06.578 when they're confronted with
NOTE Confidence: 0.860713069310345
00:35:06.578 --> 00:35:07.919 morally challenging situations.
NOTE Confidence: 0.860713069310345
00:35:07.920 --> 00:35:09.450 We have a program called care
NOTE Confidence: 0.860713069310345
00:35:09.450 --> 00:35:10.215 for the caregiver.
NOTE Confidence: 0.860713069310345
00:35:10.220 --> 00:35:12.159 We also, we do moral distress rounds.
NOTE Confidence: 0.860713069310345
00:35:12.160 --> 00:35:14.260 We do debriefings after difficult
NOTE Confidence: 0.860713069310345
00:35:14.260 --> 00:35:15.940 deaths or patient events.
NOTE Confidence: 0.860713069310345
00:35:15.940 --> 00:35:17.449 And we've also.
NOTE Confidence: 0.860713069310345
00:35:17.449 --> 00:35:20.467 Uh, recently started doing Schwartz rounds.
NOTE Confidence: 0.860713069310345

00:35:20.470 --> 00:35:20.884 You know,
NOTE Confidence: 0.860713069310345

00:35:20.884 --> 00:35:21.091 I'm,
NOTE Confidence: 0.860713069310345

00:35:21.091 --> 00:35:22.126 I'm actually not very familiar
NOTE Confidence: 0.860713069310345

00:35:22.126 --> 00:35:23.409 with what your institution does,
NOTE Confidence: 0.860713069310345

00:35:23.410 --> 00:35:24.700 but if you're interested in
NOTE Confidence: 0.860713069310345

00:35:24.700 --> 00:35:26.230 sharing with me during the Q&A,
NOTE Confidence: 0.860713069310345

00:35:26.230 --> 00:35:28.114 some of the initiatives that your
NOTE Confidence: 0.860713069310345

00:35:28.114 --> 00:35:30.167 hospital has put into place to to
NOTE Confidence: 0.860713069310345

00:35:30.167 --> 00:35:32.349 in a similar way kind of attend to
NOTE Confidence: 0.860713069310345

00:35:32.349 --> 00:35:33.949 these experiences of caregivers.
NOTE Confidence: 0.860713069310345

00:35:33.950 --> 00:35:36.190 I would really love to hear those.
NOTE Confidence: 0.97621727

00:35:38.640 --> 00:35:43.389 OK. So this is kind of the final big summary
NOTE Confidence: 0.97621727

00:35:43.389 --> 00:35:45.720 slide where I just want to offer you,
NOTE Confidence: 0.97621727

00:35:45.720 --> 00:35:48.597 I hope, some very practical suggestions
NOTE Confidence: 0.97621727

00:35:48.597 --> 00:35:52.093 and thoughts on how to respond to the
NOTE Confidence: 0.97621727

00:35:52.093 --> 00:35:55.006 experience of hearing someone else or even

NOTE Confidence: 0.97621727

00:35:55.006 --> 00:35:58.116 in you yourself wanting to make a claim

NOTE Confidence: 0.97621727

00:35:58.116 --> 00:36:00.680 about a patient that is suffering that

NOTE Confidence: 0.97621727

00:36:00.680 --> 00:36:04.748 you believe is suffering in your care.

NOTE Confidence: 0.97621727

00:36:04.750 --> 00:36:06.948 So first and really this actually should

NOTE Confidence: 0.97621727

00:36:06.948 --> 00:36:09.230 be at the top, it's not at the top.

NOTE Confidence: 0.97621727

00:36:09.230 --> 00:36:09.968 Well, it is at the top.

NOTE Confidence: 0.97621727

00:36:09.970 --> 00:36:11.769 I'm sorry, it's at the top of

NOTE Confidence: 0.97621727

00:36:11.769 --> 00:36:13.468 the the very top box there.

NOTE Confidence: 0.97621727

00:36:13.470 --> 00:36:14.370 If at all possible,

NOTE Confidence: 0.97621727

00:36:14.370 --> 00:36:16.380 we should do our very best to actually

NOTE Confidence: 0.97621727

00:36:16.380 --> 00:36:17.885 hear directly from the patient.

NOTE Confidence: 0.97621727

00:36:17.890 --> 00:36:19.052 You know, in the case that I

NOTE Confidence: 0.97621727

00:36:19.052 --> 00:36:20.698 described to you, Annie is an infant.

NOTE Confidence: 0.97621727

00:36:20.698 --> 00:36:22.857 It's very hard to sort of communicate

NOTE Confidence: 0.97621727

00:36:22.857 --> 00:36:25.426 at any real direct way with Annie,

NOTE Confidence: 0.97621727

00:36:25.430 --> 00:36:27.260 although certainly we can use some
NOTE Confidence: 0.97621727

00:36:27.260 --> 00:36:29.310 cues for her body and behavior.
NOTE Confidence: 0.97621727

00:36:29.310 --> 00:36:31.004 But in many other cases in Pediatrics,
NOTE Confidence: 0.97621727

00:36:31.010 --> 00:36:33.404 actually we can talk to our patients,
NOTE Confidence: 0.97621727

00:36:33.410 --> 00:36:35.816 we can in very creative ways.
NOTE Confidence: 0.97621727

00:36:35.820 --> 00:36:38.630 Utilize the resources around us like
NOTE Confidence: 0.97621727

00:36:38.630 --> 00:36:41.118 child life specialists or play therapists
NOTE Confidence: 0.97621727

00:36:41.118 --> 00:36:42.942 or psychologists to help us learn
NOTE Confidence: 0.97621727

00:36:42.942 --> 00:36:44.907 how to communicate more effectively
NOTE Confidence: 0.97621727

00:36:44.907 --> 00:36:47.077 with children and more importantly,
NOTE Confidence: 0.97621727

00:36:47.080 --> 00:36:49.866 to listen and really try to understand
NOTE Confidence: 0.97621727

00:36:49.866 --> 00:36:52.160 the experience that they're having.
NOTE Confidence: 0.97621727

00:36:52.160 --> 00:36:53.172 And this is perhaps,
NOTE Confidence: 0.97621727

00:36:53.172 --> 00:36:53.678 you know,
NOTE Confidence: 0.97621727

00:36:53.680 --> 00:36:55.592 the first thing we should think of is
NOTE Confidence: 0.97621727

00:36:55.592 --> 00:36:57.737 can we actually get a report directly

NOTE Confidence: 0.97621727

00:36:57.737 --> 00:37:00.000 from the patient about their experience.

NOTE Confidence: 0.97621727

00:37:00.000 --> 00:37:00.753 So beyond that,

NOTE Confidence: 0.97621727

00:37:00.753 --> 00:37:01.004 though,

NOTE Confidence: 0.97621727

00:37:01.004 --> 00:37:02.839 we will still have many cases where

NOTE Confidence: 0.97621727

00:37:02.839 --> 00:37:04.513 there are claims of patient suffering

NOTE Confidence: 0.97621727

00:37:04.513 --> 00:37:06.400 and the patient really can't give us.

NOTE Confidence: 0.97621727

00:37:06.400 --> 00:37:08.410 Any direct insight into that experience?

NOTE Confidence: 0.97621727

00:37:08.410 --> 00:37:09.898 So in these cases,

NOTE Confidence: 0.97621727

00:37:09.898 --> 00:37:13.609 the first thing to do is to get specific.

NOTE Confidence: 0.97621727

00:37:13.610 --> 00:37:15.248 We should ask follow up questions.

NOTE Confidence: 0.97621727

00:37:15.250 --> 00:37:16.648 What do you mean by suffering?

NOTE Confidence: 0.97621727

00:37:16.650 --> 00:37:18.790 What specifically indicates to you

NOTE Confidence: 0.97621727

00:37:18.790 --> 00:37:20.930 that this patient is suffering

NOTE Confidence: 0.97621727

00:37:21.005 --> 00:37:23.417 or what concerns you the most

NOTE Confidence: 0.97621727

00:37:23.417 --> 00:37:25.025 about this patients experience?

NOTE Confidence: 0.97621727

00:37:25.030 --> 00:37:26.806 Then we sort of moved down to this,
NOTE Confidence: 0.97621727

00:37:26.810 --> 00:37:27.366 you know,
NOTE Confidence: 0.97621727

00:37:27.366 --> 00:37:29.034 down down an arrow in our
NOTE Confidence: 0.97621727

00:37:29.034 --> 00:37:29.930 little graphic here.
NOTE Confidence: 0.97621727

00:37:29.930 --> 00:37:31.315 Then we should respond to
NOTE Confidence: 0.97621727

00:37:31.315 --> 00:37:32.146 those specific concerns.
NOTE Confidence: 0.97621727

00:37:32.150 --> 00:37:34.138 We should do our best to mitigate
NOTE Confidence: 0.97621727

00:37:34.138 --> 00:37:35.762 the experiences that are distressing
NOTE Confidence: 0.97621727

00:37:35.762 --> 00:37:37.552 or troublesome pain and symptom
NOTE Confidence: 0.97621727

00:37:37.552 --> 00:37:39.309 management should be deployed and
NOTE Confidence: 0.97621727

00:37:39.309 --> 00:37:40.884 as you know as sophisticated,
NOTE Confidence: 0.97621727

00:37:40.890 --> 00:37:43.165 as sophisticated away as we are able.
NOTE Confidence: 0.97621727

00:37:43.170 --> 00:37:45.126 Should call in specialists.
NOTE Confidence: 0.97621727

00:37:45.126 --> 00:37:48.623 Palliative care obviously can be a real
NOTE Confidence: 0.97621727

00:37:48.623 --> 00:37:51.527 help and resource in these situations.
NOTE Confidence: 0.97621727

00:37:51.530 --> 00:37:54.186 How how ought to we to respond though?

NOTE Confidence: 0.97621727

00:37:54.190 --> 00:37:55.590 So this is sort of focused more

NOTE Confidence: 0.97621727

00:37:55.590 --> 00:37:57.169 on the pain aspect of suffering,

NOTE Confidence: 0.97621727

00:37:57.170 --> 00:37:58.698 the physical symptom aspect

NOTE Confidence: 0.97621727

00:37:58.698 --> 00:37:59.844 aspect of suffering.

NOTE Confidence: 0.97621727

00:37:59.850 --> 00:38:02.420 But what should we do where we suspect that a

NOTE Confidence: 0.97621727

00:38:02.477 --> 00:38:04.987 child is experiencing existential suffering?

NOTE Confidence: 0.97621727

00:38:04.990 --> 00:38:05.574 And again,

NOTE Confidence: 0.97621727

00:38:05.574 --> 00:38:06.450 as a reminder,

NOTE Confidence: 0.97621727

00:38:06.450 --> 00:38:08.274 many of you really related definitions

NOTE Confidence: 0.97621727

00:38:08.274 --> 00:38:10.416 to us today that had a little

NOTE Confidence: 0.97621727

00:38:10.416 --> 00:38:12.150 more to do with the psychological,

NOTE Confidence: 0.97621727

00:38:12.150 --> 00:38:14.158 emotional or existential component

NOTE Confidence: 0.97621727

00:38:14.158 --> 00:38:15.664 of this concept.

NOTE Confidence: 0.97621727

00:38:15.670 --> 00:38:17.797 And we worry about that that

NOTE Confidence: 0.97621727

00:38:17.797 --> 00:38:19.279 sort of experience on behalf of

NOTE Confidence: 0.97621727

00:38:19.279 --> 00:38:20.619 the children that we hear for.

NOTE Confidence: 0.97621727

00:38:20.620 --> 00:38:22.010 And this is very difficult.

NOTE Confidence: 0.97621727

00:38:22.010 --> 00:38:23.720 Perhaps one of the hardest parts

NOTE Confidence: 0.97621727

00:38:23.720 --> 00:38:24.860 of our jobs is

NOTE Confidence: 0.901445405

00:38:24.928 --> 00:38:27.609 knowing how to respond to the possible

NOTE Confidence: 0.901445405

00:38:27.609 --> 00:38:29.610 existential suffering of our patients.

NOTE Confidence: 0.901445405

00:38:29.610 --> 00:38:32.900 What I'll suggest to you as potentially

NOTE Confidence: 0.901445405

00:38:32.900 --> 00:38:35.874 a powerful response is also perhaps

NOTE Confidence: 0.901445405

00:38:35.874 --> 00:38:38.379 the simplest response that you'll hear,

NOTE Confidence: 0.901445405

00:38:38.379 --> 00:38:40.437 which is we respond to suffering

NOTE Confidence: 0.901445405

00:38:40.437 --> 00:38:42.929 by being present with the sufferer.

NOTE Confidence: 0.901445405

00:38:42.930 --> 00:38:44.904 So I draw here from the

NOTE Confidence: 0.901445405

00:38:44.904 --> 00:38:46.650 work of Stanley Howard Wass,

NOTE Confidence: 0.901445405

00:38:46.650 --> 00:38:48.762 who's a Christian theologian who's written

NOTE Confidence: 0.901445405

00:38:48.762 --> 00:38:50.730 extensively on responses to suffering,

NOTE Confidence: 0.901445405

00:38:50.730 --> 00:38:53.514 and the term he offers is

NOTE Confidence: 0.901445405

00:38:53.514 --> 00:38:54.906 deemed suffering presence.

NOTE Confidence: 0.901445405

00:38:54.910 --> 00:38:58.406 So this is for him a wise and

NOTE Confidence: 0.901445405

00:38:58.406 --> 00:38:59.280 possible response.

NOTE Confidence: 0.901445405

00:38:59.280 --> 00:39:01.200 He urges us, with this concept,

NOTE Confidence: 0.901445405

00:39:01.200 --> 00:39:03.069 not to fall prey to the desire

NOTE Confidence: 0.901445405

00:39:03.069 --> 00:39:04.530 to prevent all suffering.

NOTE Confidence: 0.901445405

00:39:04.530 --> 00:39:06.378 We we simply can't do that,

NOTE Confidence: 0.901445405

00:39:06.380 --> 00:39:09.308 and that impulse would be mistaken.

NOTE Confidence: 0.901445405

00:39:09.310 --> 00:39:12.195 And as deeply and necessarily

NOTE Confidence: 0.901445405

00:39:12.195 --> 00:39:13.349 interdependent creatures,

NOTE Confidence: 0.901445405

00:39:13.350 --> 00:39:15.570 existential suffering calls us not only

NOTE Confidence: 0.901445405

00:39:15.570 --> 00:39:18.189 to Rage Against the suffering itself,

NOTE Confidence: 0.901445405

00:39:18.190 --> 00:39:18.952 but instead,

NOTE Confidence: 0.901445405

00:39:18.952 --> 00:39:21.238 and indeed in addition to draw

NOTE Confidence: 0.901445405

00:39:21.238 --> 00:39:23.029 close to the sufferer.

NOTE Confidence: 0.901445405

00:39:23.030 --> 00:39:25.081 He says that by attributing our own
NOTE Confidence: 0.901445405

00:39:25.081 --> 00:39:27.197 suffering to the patients we care for,
NOTE Confidence: 0.901445405

00:39:27.200 --> 00:39:29.468 in some cases we lack imagination,
NOTE Confidence: 0.901445405

00:39:29.470 --> 00:39:31.468 and in trying to avoid the
NOTE Confidence: 0.901445405

00:39:31.468 --> 00:39:33.230 boundaries of our compassion and
NOTE Confidence: 0.901445405

00:39:33.230 --> 00:39:35.045 perhaps again our own suffering,
NOTE Confidence: 0.901445405

00:39:35.050 --> 00:39:37.175 we might avoid the presence
NOTE Confidence: 0.901445405

00:39:37.175 --> 00:39:38.450 of those patients.
NOTE Confidence: 0.901445405

00:39:38.450 --> 00:39:40.046 So we respond to claims of.
NOTE Confidence: 0.901445405

00:39:40.050 --> 00:39:41.895 Residential suffering of
NOTE Confidence: 0.901445405

00:39:41.895 --> 00:39:44.355 children first by ourselves,
NOTE Confidence: 0.901445405

00:39:44.360 --> 00:39:45.840 drawing near to those children.
NOTE Confidence: 0.901445405

00:39:45.840 --> 00:39:47.916 We spend more time with them, not less.
NOTE Confidence: 0.901445405

00:39:47.916 --> 00:39:50.700 When they tolerate and respond to our touch,
NOTE Confidence: 0.901445405

00:39:50.700 --> 00:39:53.374 our embrace, we touch and we embrace.
NOTE Confidence: 0.901445405

00:39:53.380 --> 00:39:55.054 When our touch and or embrace

NOTE Confidence: 0.901445405

00:39:55.054 --> 00:39:56.500 seems to only agitate them,

NOTE Confidence: 0.901445405

00:39:56.500 --> 00:39:57.960 which it sometimes does.

NOTE Confidence: 0.901445405

00:39:57.960 --> 00:40:00.116 We sit nearby, we speak to them,

NOTE Confidence: 0.901445405

00:40:00.116 --> 00:40:02.068 sing to them, we stay near,

NOTE Confidence: 0.901445405

00:40:02.068 --> 00:40:05.579 and 2nd we encourage parents to do the same.

NOTE Confidence: 0.901445405

00:40:05.580 --> 00:40:08.100 Parents are often very deeply

NOTE Confidence: 0.901445405

00:40:08.100 --> 00:40:10.116 troubled by their powerlessness.

NOTE Confidence: 0.901445405

00:40:10.120 --> 00:40:11.860 To prevent or remove their

NOTE Confidence: 0.901445405

00:40:11.860 --> 00:40:12.556 children suffering.

NOTE Confidence: 0.901445405

00:40:12.560 --> 00:40:15.409 This is perhaps one of the most

NOTE Confidence: 0.901445405

00:40:15.410 --> 00:40:17.564 profound threats that a parent will

NOTE Confidence: 0.901445405

00:40:17.564 --> 00:40:19.000 experience during the hospitalization

NOTE Confidence: 0.901445405

00:40:19.054 --> 00:40:20.902 or illness of their child is a threat

NOTE Confidence: 0.901445405

00:40:20.902 --> 00:40:22.924 to really what they consider to be one

NOTE Confidence: 0.901445405

00:40:22.924 --> 00:40:24.761 of their primary roles as a parent,

NOTE Confidence: 0.901445405

00:40:24.761 --> 00:40:26.146 which is to protect their
NOTE Confidence: 0.901445405

00:40:26.146 --> 00:40:27.330 child from suffering.
NOTE Confidence: 0.901445405

00:40:27.330 --> 00:40:30.030 So providing parents with opportunities
NOTE Confidence: 0.901445405

00:40:30.030 --> 00:40:32.190 for active caregiving reaffirms
NOTE Confidence: 0.901445405

00:40:32.190 --> 00:40:34.938 this role as parent and in many
NOTE Confidence: 0.901445405

00:40:34.938 --> 00:40:36.946 cases can actually help alleviate
NOTE Confidence: 0.901445405

00:40:36.946 --> 00:40:39.286 some of their own distress.
NOTE Confidence: 0.901445405

00:40:39.290 --> 00:40:41.908 And then finally up here we have
NOTE Confidence: 0.901445405

00:40:41.910 --> 00:40:43.520 the suggestion that we should
NOTE Confidence: 0.901445405

00:40:43.520 --> 00:40:45.130 care better for our caregivers.
NOTE Confidence: 0.901445405

00:40:45.130 --> 00:40:48.358 When we do see evidence of
NOTE Confidence: 0.901445405

00:40:48.358 --> 00:40:50.510 caregiver suffering or distress,
NOTE Confidence: 0.901445405

00:40:50.510 --> 00:40:52.370 we should attend to that.
NOTE Confidence: 0.901445405

00:40:52.370 --> 00:40:52.788 Again,
NOTE Confidence: 0.901445405

00:40:52.788 --> 00:40:55.296 the the opportunities available to us
NOTE Confidence: 0.901445405

00:40:55.296 --> 00:40:57.930 here are largely conversation based.

NOTE Confidence: 0.901445405
00:40:57.930 --> 00:40:58.258 Again,
NOTE Confidence: 0.901445405
00:40:58.258 --> 00:41:00.308 I'd love to explore any solutions
NOTE Confidence: 0.901445405
00:41:00.308 --> 00:41:02.891 or sort of creative fora in which
NOTE Confidence: 0.901445405
00:41:02.891 --> 00:41:04.849 you've invited caregivers to
NOTE Confidence: 0.901445405
00:41:04.849 --> 00:41:07.379 discuss their own experiences of
NOTE Confidence: 0.901445405
00:41:07.379 --> 00:41:09.279 potential suffering or distress.
NOTE Confidence: 0.901445405
00:41:09.280 --> 00:41:11.583 But we acknowledge this suffering and we
NOTE Confidence: 0.901445405
00:41:11.583 --> 00:41:13.918 provide avenues to express and discuss it,
NOTE Confidence: 0.901445405
00:41:13.920 --> 00:41:15.560 often through things like
NOTE Confidence: 0.901445405
00:41:15.560 --> 00:41:16.380 interdisciplinary conversation,
NOTE Confidence: 0.901445405
00:41:16.380 --> 00:41:17.476 debriefings, counseling,
NOTE Confidence: 0.901445405
00:41:17.476 --> 00:41:21.050 peer-to-peer support groups, etcetera.
NOTE Confidence: 0.901445405
00:41:21.050 --> 00:41:21.971 So in conclusion,
NOTE Confidence: 0.901445405
00:41:21.971 --> 00:41:24.558 just sort of to to share with you
NOTE Confidence: 0.901445405
00:41:24.558 --> 00:41:26.408 maybe some take away thoughts.
NOTE Confidence: 0.901445405

00:41:26.410 --> 00:41:29.282 I'd like to argue that all claims of
NOTE Confidence: 0.901445405

00:41:29.282 --> 00:41:31.727 patient suffering do deserve our attention,
NOTE Confidence: 0.901445405

00:41:31.730 --> 00:41:34.603 but they perhaps do not require
NOTE Confidence: 0.901445405

00:41:34.603 --> 00:41:36.175 the dramatic decision making
NOTE Confidence: 0.901445405

00:41:36.175 --> 00:41:38.390 response that we think they do.
NOTE Confidence: 0.901445405

00:41:38.390 --> 00:41:40.430 Suffering should be specified and
NOTE Confidence: 0.901445405

00:41:40.430 --> 00:41:42.470 situated in the larger context
NOTE Confidence: 0.835616344583333

00:41:42.537 --> 00:41:44.607 of the decision making process
NOTE Confidence: 0.835616344583333

00:41:44.607 --> 00:41:46.263 and instead when secondhand
NOTE Confidence: 0.835616344583333

00:41:46.263 --> 00:41:48.467 claims of patient suffering occur,
NOTE Confidence: 0.835616344583333

00:41:48.470 --> 00:41:50.305 what they require us require
NOTE Confidence: 0.835616344583333

00:41:50.305 --> 00:41:52.140 of us is to investigate.
NOTE Confidence: 0.835616344583333

00:41:52.140 --> 00:41:55.094 To listen, to, engage and draw ever
NOTE Confidence: 0.835616344583333

00:41:55.094 --> 00:41:57.940 nearer to those who are suffering.
NOTE Confidence: 0.835616344583333

00:41:57.940 --> 00:42:01.900 And that is my presentation and I'm
NOTE Confidence: 0.835616344583333

00:42:01.900 --> 00:42:04.280 very eager to hear your thoughts,

NOTE Confidence: 0.835616344583333
00:42:04.280 --> 00:42:06.576 comments or questions and I will stop
NOTE Confidence: 0.835616344583333
00:42:06.576 --> 00:42:08.869 my screen share and let that happen.
NOTE Confidence: 0.881433568571429
00:42:10.940 --> 00:42:11.750 That's fantastic.
NOTE Confidence: 0.881433568571429
00:42:11.750 --> 00:42:13.775 Thank you so much Erica.
NOTE Confidence: 0.881433568571429
00:42:13.780 --> 00:42:17.002 That was a very interesting and
NOTE Confidence: 0.881433568571429
00:42:17.002 --> 00:42:20.890 thought provoking conversation.
NOTE Confidence: 0.881433568571429
00:42:20.890 --> 00:42:22.500 Well, again, I invite everyone
NOTE Confidence: 0.881433568571429
00:42:22.500 --> 00:42:24.110 to submit any questions or
NOTE Confidence: 0.881433568571429
00:42:24.168 --> 00:42:26.088 comments through the Q&A function,
NOTE Confidence: 0.881433568571429
00:42:26.090 --> 00:42:28.114 and I'll be reading them to Doctor Salter.
NOTE Confidence: 0.881433568571429
00:42:28.120 --> 00:42:30.160 In the meantime, I, you know,
NOTE Confidence: 0.881433568571429
00:42:30.160 --> 00:42:32.720 this is a place near and dear to my heart.
NOTE Confidence: 0.881433568571429
00:42:32.720 --> 00:42:34.970 First, I just. I just.
NOTE Confidence: 0.881433568571429
00:42:34.970 --> 00:42:37.346 I think in in the in the Ben
NOTE Confidence: 0.881433568571429
00:42:37.350 --> 00:42:40.332 Wilfong's chapter on trisomy 18 and
NOTE Confidence: 0.881433568571429

00:42:40.332 --> 00:42:42.447 that I think part of his point was
NOTE Confidence: 0.881433568571429

00:42:42.447 --> 00:42:44.719 and I think part of your point was
NOTE Confidence: 0.881433568571429

00:42:44.719 --> 00:42:46.584 also that perhaps the clinician in
NOTE Confidence: 0.881433568571429

00:42:46.584 --> 00:42:48.006 that scenario was overselling it
NOTE Confidence: 0.881433568571429

00:42:48.006 --> 00:42:50.310 a bit over selling it in terms of
NOTE Confidence: 0.881433568571429

00:42:50.370 --> 00:42:52.350 the lethality of the condition of
NOTE Confidence: 0.881433568571429

00:42:52.350 --> 00:42:54.330 trisomy 18 because of course we'll
NOTE Confidence: 0.881433568571429

00:42:54.330 --> 00:42:56.430 find has written about how we use
NOTE Confidence: 0.881433568571429

00:42:56.430 --> 00:42:59.760 the well known about lethal lethal
NOTE Confidence: 0.881433568571429

00:42:59.760 --> 00:43:01.654 language that we have to be very
NOTE Confidence: 0.881433568571429

00:43:01.654 --> 00:43:03.319 careful what we call lethal which is
NOTE Confidence: 0.881433568571429

00:43:03.319 --> 00:43:05.090 a bit of a self fulfilling prophecy.
NOTE Confidence: 0.881433568571429

00:43:05.090 --> 00:43:06.480 Just when we then don't,
NOTE Confidence: 0.881433568571429

00:43:06.480 --> 00:43:09.595 then don't treat people with these disorders,
NOTE Confidence: 0.881433568571429

00:43:09.600 --> 00:43:12.680 but that we use suffering.
NOTE Confidence: 0.881433568571429

00:43:12.680 --> 00:43:14.456 You know, there are certain buzzwords.

NOTE Confidence: 0.881433568571429

00:43:14.460 --> 00:43:15.516 It strikes me.

NOTE Confidence: 0.881433568571429

00:43:15.516 --> 00:43:17.276 And, and now for me,

NOTE Confidence: 0.881433568571429

00:43:17.280 --> 00:43:18.464 after hearing you talk,

NOTE Confidence: 0.881433568571429

00:43:18.464 --> 00:43:20.240 I I fear that suffering is

NOTE Confidence: 0.881433568571429

00:43:20.299 --> 00:43:21.719 on my list of buzzwords,

NOTE Confidence: 0.881433568571429

00:43:21.720 --> 00:43:23.995 which are words people use not to

NOTE Confidence: 0.881433568571429

00:43:23.995 --> 00:43:27.250 open up conversation, but to close it.

NOTE Confidence: 0.881433568571429

00:43:27.250 --> 00:43:29.690 And I mean another well known one or

NOTE Confidence: 0.881433568571429

00:43:29.690 --> 00:43:32.184 as is is a futile futility, right?

NOTE Confidence: 0.881433568571429

00:43:32.184 --> 00:43:33.828 And another I think is heroic.

NOTE Confidence: 0.881433568571429

00:43:33.830 --> 00:43:35.282 Just as you said that suffering

NOTE Confidence: 0.881433568571429

00:43:35.282 --> 00:43:36.843 is used often to stop therapy

NOTE Confidence: 0.881433568571429

00:43:36.843 --> 00:43:38.469 as opposed to to do something,

NOTE Confidence: 0.881433568571429

00:43:38.470 --> 00:43:40.210 it says to stop doing things.

NOTE Confidence: 0.881433568571429

00:43:40.210 --> 00:43:42.514 I find that people refer to a treatment

NOTE Confidence: 0.881433568571429

00:43:42.514 --> 00:43:45.213 as heroic only when they don't want to do it.

NOTE Confidence: 0.881433568571429

00:43:45.220 --> 00:43:47.656 And for perhaps for justifiable reasons,

NOTE Confidence: 0.881433568571429

00:43:47.660 --> 00:43:48.360 perhaps not.

NOTE Confidence: 0.881433568571429

00:43:48.360 --> 00:43:50.110 But but in like fashion,

NOTE Confidence: 0.881433568571429

00:43:50.110 --> 00:43:51.590 I worry that we do use the suffering.

NOTE Confidence: 0.881433568571429

00:43:51.590 --> 00:43:53.186 So a quick question before I then

NOTE Confidence: 0.881433568571429

00:43:53.186 --> 00:43:54.649 start looking at these questions.

NOTE Confidence: 0.881433568571429

00:43:54.650 --> 00:43:56.920 So would Cassells say?

NOTE Confidence: 0.881433568571429

00:43:56.920 --> 00:43:59.080 That and this I ask you,

NOTE Confidence: 0.881433568571429

00:43:59.080 --> 00:44:01.060 this is a neonatologist because I

NOTE Confidence: 0.881433568571429

00:44:01.060 --> 00:44:02.775 don't equate newborns with animals

NOTE Confidence: 0.881433568571429

00:44:02.775 --> 00:44:04.450 but there are some similarities

NOTE Confidence: 0.881433568571429

00:44:04.450 --> 00:44:06.350 in terms of cognition etcetera.

NOTE Confidence: 0.881433568571429

00:44:06.350 --> 00:44:08.138 So with Cassells say based on

NOTE Confidence: 0.881433568571429

00:44:08.138 --> 00:44:09.330 his definition it's impossible

NOTE Confidence: 0.881433568571429

00:44:09.385 --> 00:44:10.530 for an animal to suffer

NOTE Confidence: 0.83878157875

00:44:11.080 --> 00:44:13.056 I believe. So I believe it's sort of,

NOTE Confidence: 0.83878157875

00:44:13.060 --> 00:44:14.916 I mean even though I think he would

NOTE Confidence: 0.83878157875

00:44:14.916 --> 00:44:16.459 acknowledge that there are many animals,

NOTE Confidence: 0.83878157875

00:44:16.460 --> 00:44:17.616 primates for for example,

NOTE Confidence: 0.83878157875

00:44:17.616 --> 00:44:19.350 that do have sort of some

NOTE Confidence: 0.83878157875

00:44:19.411 --> 00:44:21.340 sophisticated cognitive abilities.

NOTE Confidence: 0.83878157875

00:44:21.340 --> 00:44:23.995 But for him it is about this sort of

NOTE Confidence: 0.83878157875

00:44:23.995 --> 00:44:26.028 narrative construction of ones life.

NOTE Confidence: 0.83878157875

00:44:26.030 --> 00:44:28.550 So I mean I it's actually an interesting.

NOTE Confidence: 0.83878157875

00:44:28.550 --> 00:44:29.456 Because zoological question,

NOTE Confidence: 0.83878157875

00:44:29.456 --> 00:44:31.911 I don't actually know if we can sort

NOTE Confidence: 0.83878157875

00:44:31.911 --> 00:44:33.386 of understand how, for example,

NOTE Confidence: 0.83878157875

00:44:33.386 --> 00:44:35.204 like a chimpanzee sort of understands

NOTE Confidence: 0.83878157875

00:44:35.204 --> 00:44:36.459 their existence in the world.

NOTE Confidence: 0.83878157875

00:44:36.460 --> 00:44:38.773 So for him, he hinges it on that type

NOTE Confidence: 0.83878157875

00:44:38.773 --> 00:44:41.098 of understanding of an experience,
NOTE Confidence: 0.83878157875

00:44:41.100 --> 00:44:43.326 so a threat to one's kind of
NOTE Confidence: 0.83878157875

00:44:43.326 --> 00:44:44.740 narrative intactness and perhaps
NOTE Confidence: 0.83878157875

00:44:44.740 --> 00:44:46.740 some animals could fulfill that.
NOTE Confidence: 0.83878157875

00:44:46.740 --> 00:44:48.354 But I think in general he
NOTE Confidence: 0.83878157875

00:44:48.354 --> 00:44:49.840 would argue that they can't.
NOTE Confidence: 0.83878157875

00:44:49.840 --> 00:44:50.418 And Mark,
NOTE Confidence: 0.83878157875

00:44:50.418 --> 00:44:53.117 thanks so much for bringing up a sort of
NOTE Confidence: 0.83878157875

00:44:53.117 --> 00:44:55.348 Ben Ben Wilson's position on this topic.
NOTE Confidence: 0.83878157875

00:44:55.348 --> 00:44:56.004 I agree.
NOTE Confidence: 0.83878157875

00:44:56.004 --> 00:44:58.560 I think he would largely agree with us.
NOTE Confidence: 0.83878157875

00:44:58.560 --> 00:45:00.331 And what you've said today and what
NOTE Confidence: 0.83878157875

00:45:00.331 --> 00:45:02.015 I've said today is the case that
NOTE Confidence: 0.83878157875

00:45:02.015 --> 00:45:03.904 they used in that chapter I think is
NOTE Confidence: 0.83878157875

00:45:03.904 --> 00:45:05.482 to illustrate some of the problems
NOTE Confidence: 0.83878157875

00:45:05.482 --> 00:45:07.162 with this sort of decision making.

NOTE Confidence: 0.83878157875

00:45:07.162 --> 00:45:09.471 And and he would very much as you

NOTE Confidence: 0.83878157875

00:45:09.471 --> 00:45:11.291 mentioned advocate for a a sort of

NOTE Confidence: 0.83878157875

00:45:11.291 --> 00:45:13.169 more careful look at what actually is

NOTE Confidence: 0.83878157875

00:45:13.169 --> 00:45:15.790 going on in a trisomy 13 or 18 case.

NOTE Confidence: 0.8413882

00:45:17.830 --> 00:45:22.726 Could you help me out a little bit with

NOTE Confidence: 0.822060362941176

00:45:22.730 --> 00:45:24.314 a term that gets used often and I

NOTE Confidence: 0.822060362941176

00:45:24.314 --> 00:45:26.201 wonder if we all have different

NOTE Confidence: 0.822060362941176

00:45:26.201 --> 00:45:27.284 understandings or understandings,

NOTE Confidence: 0.822060362941176

00:45:27.290 --> 00:45:30.160 existential suffering or existential pain?

NOTE Confidence: 0.90431433

00:45:32.390 --> 00:45:33.926 Yeah. No, that's a great question.

NOTE Confidence: 0.90431433

00:45:33.930 --> 00:45:36.060 So what we're dealing here with

NOTE Confidence: 0.90431433

00:45:36.060 --> 00:45:38.609 is sort of a a dimensions,

NOTE Confidence: 0.90431433

00:45:38.610 --> 00:45:40.850 kind of a combination dimension

NOTE Confidence: 0.90431433

00:45:40.850 --> 00:45:42.642 of emotional and psychological,

NOTE Confidence: 0.90431433

00:45:42.650 --> 00:45:44.848 like having to do with our specific

NOTE Confidence: 0.90431433

00:45:44.848 --> 00:45:46.874 identity in the world and what
NOTE Confidence: 0.90431433

00:45:46.874 --> 00:45:48.569 that means for our existence.
NOTE Confidence: 0.90431433

00:45:48.570 --> 00:45:49.555 I mean, I think probably
NOTE Confidence: 0.90431433

00:45:49.555 --> 00:45:50.343 there are many other,
NOTE Confidence: 0.90431433

00:45:50.350 --> 00:45:52.510 there's many definitions of existential,
NOTE Confidence: 0.90431433

00:45:52.510 --> 00:45:54.175 but it sort of is kind of, again,
NOTE Confidence: 0.90431433

00:45:54.175 --> 00:45:56.005 we're kind of moving up levels
NOTE Confidence: 0.90431433

00:45:56.005 --> 00:45:57.781 of experience here from maybe
NOTE Confidence: 0.90431433

00:45:57.781 --> 00:45:58.990 physical to psychological,
NOTE Confidence: 0.90431433

00:45:58.990 --> 00:46:00.850 emotional to spiritual to existential.
NOTE Confidence: 0.808895592

00:46:04.420 --> 00:46:07.048 The, the, the, the baby doe
NOTE Confidence: 0.808895592

00:46:07.048 --> 00:46:08.800 rules that you referenced.
NOTE Confidence: 0.808895592

00:46:08.800 --> 00:46:11.355 So they, they the, the the regulations
NOTE Confidence: 0.808895592

00:46:11.355 --> 00:46:13.120 again that's the baby doe.
NOTE Confidence: 0.808895592

00:46:13.120 --> 00:46:15.556 As I understand this is not law
NOTE Confidence: 0.808895592

00:46:15.556 --> 00:46:17.368 but rather federal regulation and

NOTE Confidence: 0.808895592

00:46:17.368 --> 00:46:19.804 it's so we can't use suffering as

NOTE Confidence: 0.808895592

00:46:19.804 --> 00:46:22.520 a justification to withhold life

NOTE Confidence: 0.808895592

00:46:22.520 --> 00:46:24.816 sustaining medical treatment right?

NOTE Confidence: 0.808895592

00:46:24.820 --> 00:46:26.492 So if if that's.

NOTE Confidence: 0.808895592

00:46:26.492 --> 00:46:28.582 I guess I would ask,

NOTE Confidence: 0.808895592

00:46:28.590 --> 00:46:30.494 do you agree with that and is

NOTE Confidence: 0.808895592

00:46:30.494 --> 00:46:32.083 that consistent with the practice

NOTE Confidence: 0.808895592

00:46:32.083 --> 00:46:33.160 at Cardinal Glennon?

NOTE Confidence: 0.84231848

00:46:34.650 --> 00:46:35.778 Yeah, this is a great question.

NOTE Confidence: 0.84231848

00:46:35.780 --> 00:46:37.772 You know, the sort of status

NOTE Confidence: 0.84231848

00:46:37.772 --> 00:46:39.100 of baby DOE regulations,

NOTE Confidence: 0.84231848

00:46:39.100 --> 00:46:40.750 my understanding is that so because

NOTE Confidence: 0.84231848

00:46:40.750 --> 00:46:42.280 they're tied to federal funding,

NOTE Confidence: 0.84231848

00:46:42.280 --> 00:46:44.464 so it's my understanding of the regulations

NOTE Confidence: 0.84231848

00:46:44.464 --> 00:46:47.074 is that if institutions are found to be

NOTE Confidence: 0.84231848

00:46:47.074 --> 00:46:49.620 violent in violation of the baby DOE rules,
NOTE Confidence: 0.84231848

00:46:49.620 --> 00:46:54.460 they would risk removal of federal
NOTE Confidence: 0.84231848

00:46:54.460 --> 00:46:56.700 funding through certain mechanisms.
NOTE Confidence: 0.84231848

00:46:56.700 --> 00:46:58.986 My understanding is this has actually
NOTE Confidence: 0.84231848

00:46:58.986 --> 00:47:01.451 never happened and and I think it's
NOTE Confidence: 0.84231848

00:47:01.451 --> 00:47:03.495 sort of interesting to to see the
NOTE Confidence: 0.84231848

00:47:03.561 --> 00:47:05.337 effects of that legislation.
NOTE Confidence: 0.84231848

00:47:05.340 --> 00:47:06.678 Today, I don't know that they
NOTE Confidence: 0.84231848

00:47:06.678 --> 00:47:07.347 are very widespread,
NOTE Confidence: 0.84231848

00:47:07.350 --> 00:47:09.149 but your question I think is more
NOTE Confidence: 0.84231848

00:47:09.149 --> 00:47:10.599 about whether it is suitable.
NOTE Confidence: 0.84231848

00:47:10.600 --> 00:47:11.710 Well, ask it again, Mark.
NOTE Confidence: 0.84231848

00:47:11.710 --> 00:47:12.682 Is it, is it,
NOTE Confidence: 0.84231848

00:47:12.682 --> 00:47:14.140 is it appropriate to set aside
NOTE Confidence: 0.84231848

00:47:14.195 --> 00:47:16.125 quality of life considerations when
NOTE Confidence: 0.84231848

00:47:16.125 --> 00:47:18.055 making treatment decisions for for

NOTE Confidence: 0.686770754

00:47:18.210 --> 00:47:19.040 so much quality of life.

NOTE Confidence: 0.686770754

00:47:19.040 --> 00:47:21.105 But of course quality of life and

NOTE Confidence: 0.686770754

00:47:21.105 --> 00:47:22.698 suffering are obviously these are

NOTE Confidence: 0.686770754

00:47:22.698 --> 00:47:24.328 overlapping ideas because oftentimes we

NOTE Confidence: 0.686770754

00:47:24.328 --> 00:47:26.527 say that it's justifiable to withhold

NOTE Confidence: 0.686770754

00:47:26.527 --> 00:47:28.467 or withdraw life sustaining medical

NOTE Confidence: 0.686770754

00:47:28.467 --> 00:47:30.758 treatment based on quality of life

NOTE Confidence: 0.686770754

00:47:30.758 --> 00:47:33.450 considerations that mean as as you know,

NOTE Confidence: 0.686770754

00:47:33.450 --> 00:47:35.347 I'm sure better than I do that.

NOTE Confidence: 0.686770754

00:47:35.350 --> 00:47:37.015 That that's that's dangerous territory

NOTE Confidence: 0.686770754

00:47:37.015 --> 00:47:39.018 when we start making judgment about

NOTE Confidence: 0.686770754

00:47:39.018 --> 00:47:40.740 the quality of someone else's life.

NOTE Confidence: 0.686770754

00:47:40.740 --> 00:47:42.556 When we do try to make an assessment

NOTE Confidence: 0.686770754

00:47:42.556 --> 00:47:43.822 about their suffering, however,

NOTE Confidence: 0.686770754

00:47:43.822 --> 00:47:45.514 it's not exactly the same thing.

NOTE Confidence: 0.686770754

00:47:45.520 --> 00:47:48.004 But as I understand that the that the baby

NOTE Confidence: 0.686770754

00:47:48.004 --> 00:47:50.215 doll regulation said specifically that we

NOTE Confidence: 0.686770754

00:47:50.215 --> 00:47:52.980 can't use suffering as that consideration.

NOTE Confidence: 0.686770754

00:47:52.980 --> 00:47:53.856 So, for example,

NOTE Confidence: 0.686770754

00:47:53.856 --> 00:47:55.316 the folks in the Netherlands

NOTE Confidence: 0.686770754

00:47:55.316 --> 00:47:56.757 would say that if it was,

NOTE Confidence: 0.686770754

00:47:56.760 --> 00:47:57.446 you know,

NOTE Confidence: 0.686770754

00:47:57.446 --> 00:47:58.818 severe and intractable suffering

NOTE Confidence: 0.686770754

00:47:58.818 --> 00:48:01.234 that that would be a justification

NOTE Confidence: 0.686770754

00:48:01.234 --> 00:48:02.716 potentially for youthanasia.

NOTE Confidence: 0.686770754

00:48:02.720 --> 00:48:04.617 We wouldn't say that here in the

NOTE Confidence: 0.686770754

00:48:04.617 --> 00:48:05.430 legal context yet.

NOTE Confidence: 0.686770754

00:48:05.430 --> 00:48:07.118 But we might say and and I'll go

NOTE Confidence: 0.686770754

00:48:07.118 --> 00:48:09.066 out on a limb and say that that I,

NOTE Confidence: 0.686770754

00:48:09.070 --> 00:48:11.002 I am quite sure that there are

NOTE Confidence: 0.686770754

00:48:11.002 --> 00:48:12.569 hospitals where this occurs when if

NOTE Confidence: 0.686770754

00:48:12.569 --> 00:48:14.490 we think that a child is in pain,

NOTE Confidence: 0.686770754

00:48:14.490 --> 00:48:17.122 in severe pain and there is little

NOTE Confidence: 0.686770754

00:48:17.122 --> 00:48:20.716 or no hope of ever getting out of

NOTE Confidence: 0.686770754

00:48:20.716 --> 00:48:22.585 the hospital that we tend to give

NOTE Confidence: 0.686770754

00:48:22.585 --> 00:48:24.140 parents a fair amount of latitude.

NOTE Confidence: 0.739502066153846

00:48:24.240 --> 00:48:25.125 Yeah, yeah, absolutely.

NOTE Confidence: 0.739502066153846

00:48:25.125 --> 00:48:26.600 That is certainly the practice

NOTE Confidence: 0.739502066153846

00:48:26.600 --> 00:48:28.008 here at Glennon as well.

NOTE Confidence: 0.739502066153846

00:48:28.010 --> 00:48:29.754 It does deviate a little bit from the

NOTE Confidence: 0.739502066153846

00:48:29.754 --> 00:48:31.270 requirements of the baby DOE regulations,

NOTE Confidence: 0.739502066153846

00:48:31.270 --> 00:48:33.230 which is why I sort of question how,

NOTE Confidence: 0.739502066153846

00:48:33.230 --> 00:48:34.498 you know, how influential

NOTE Confidence: 0.739502066153846

00:48:34.498 --> 00:48:35.449 those regulations are.

NOTE Confidence: 0.739502066153846

00:48:35.450 --> 00:48:37.530 Today, because I think actual

NOTE Confidence: 0.739502066153846

00:48:37.530 --> 00:48:39.610 clinical decision making in pediatric

NOTE Confidence: 0.739502066153846

00:48:39.672 --> 00:48:41.336 institutions today more represents
NOTE Confidence: 0.739502066153846

00:48:41.336 --> 00:48:43.786 this sort of kind of an empowered
NOTE Confidence: 0.739502066153846

00:48:43.786 --> 00:48:45.998 parent approach to to make a more
NOTE Confidence: 0.739502066153846

00:48:45.998 --> 00:48:47.768 holistic decision about what is
NOTE Confidence: 0.739502066153846

00:48:47.768 --> 00:48:49.979 helpful or hurtful to their child.
NOTE Confidence: 0.739502066153846

00:48:49.980 --> 00:48:51.324 The point of the baby don't
NOTE Confidence: 0.739502066153846

00:48:51.324 --> 00:48:52.617 regulations is mainly about making
NOTE Confidence: 0.739502066153846

00:48:52.617 --> 00:48:53.658 decisions about disability.
NOTE Confidence: 0.739502066153846

00:48:53.660 --> 00:48:55.298 It was you know they were they
NOTE Confidence: 0.739502066153846

00:48:55.298 --> 00:48:56.983 came out of a couple cases
NOTE Confidence: 0.739502066153846

00:48:56.983 --> 00:48:58.518 of babies with Down syndrome,
NOTE Confidence: 0.739502066153846

00:48:58.520 --> 00:49:00.956 Down syndrome with very easily correctable,
NOTE Confidence: 0.739502066153846

00:49:00.960 --> 00:49:03.060 surgically correctable like a
NOTE Confidence: 0.739502066153846

00:49:03.060 --> 00:49:04.635 tracheal esophageal fistula,
NOTE Confidence: 0.739502066153846

00:49:04.640 --> 00:49:05.564 which actually was.
NOTE Confidence: 0.739502066153846

00:49:05.564 --> 00:49:08.077 One of the features of the case that

NOTE Confidence: 0.739502066153846

00:49:08.077 --> 00:49:10.397 we discussed today and and the idea is

NOTE Confidence: 0.739502066153846

00:49:10.397 --> 00:49:12.866 that we shouldn't deny that sort of Umm,

NOTE Confidence: 0.739502066153846

00:49:12.870 --> 00:49:14.965 surgical intervention based on the

NOTE Confidence: 0.739502066153846

00:49:14.965 --> 00:49:17.060 idea that their disability affects

NOTE Confidence: 0.739502066153846

00:49:17.123 --> 00:49:18.963 their life in such a way as to

NOTE Confidence: 0.739502066153846

00:49:18.963 --> 00:49:20.889 make it unbearable or low cost,

NOTE Confidence: 0.739502066153846

00:49:20.890 --> 00:49:22.914 low quality of life.

NOTE Confidence: 0.739502066153846

00:49:22.914 --> 00:49:25.050 So yeah, I think it's a,

NOTE Confidence: 0.739502066153846

00:49:25.050 --> 00:49:26.730 it's an interesting question to ask,

NOTE Confidence: 0.739502066153846

00:49:26.730 --> 00:49:28.302 you know how much those specific

NOTE Confidence: 0.739502066153846

00:49:28.302 --> 00:49:29.350 regulations do actually affect

NOTE Confidence: 0.739502066153846

00:49:29.397 --> 00:49:30.228 our decision making.

NOTE Confidence: 0.739502066153846

00:49:30.230 --> 00:49:32.090 I suspect not very much,

NOTE Confidence: 0.739502066153846

00:49:32.090 --> 00:49:34.358 although some of the some of the

NOTE Confidence: 0.739502066153846

00:49:34.358 --> 00:49:35.880 kind of philosophical content.

NOTE Confidence: 0.739502066153846

00:49:35.880 --> 00:49:39.230 There I think has. Existed.
NOTE Confidence: 0.836747015714286

00:49:40.460 --> 00:49:42.548 Yeah, I think that that I mean in my
NOTE Confidence: 0.836747015714286

00:49:42.548 --> 00:49:43.917 experience there's been you know,
NOTE Confidence: 0.836747015714286

00:49:43.920 --> 00:49:45.999 over the years there was a great
NOTE Confidence: 0.836747015714286

00:49:45.999 --> 00:49:47.753 deal of unhappiness on the part
NOTE Confidence: 0.836747015714286

00:49:47.753 --> 00:49:49.361 of the of the Pediatrics world
NOTE Confidence: 0.836747015714286

00:49:49.361 --> 00:49:51.119 with the baby DOE regulations.
NOTE Confidence: 0.836747015714286

00:49:51.120 --> 00:49:52.976 And yet looking back at the notion that
NOTE Confidence: 0.836747015714286

00:49:52.976 --> 00:49:54.948 that one shouldn't try to save a child,
NOTE Confidence: 0.836747015714286

00:49:54.950 --> 00:49:55.938 which drives me 21,
NOTE Confidence: 0.836747015714286

00:49:55.938 --> 00:49:58.099 they look back and say that what at
NOTE Confidence: 0.836747015714286

00:49:58.099 --> 00:49:59.649 least where those regulations came
NOTE Confidence: 0.836747015714286

00:49:59.649 --> 00:50:01.638 from seemed like a reasonable place.
NOTE Confidence: 0.836747015714286

00:50:01.640 --> 00:50:02.520 But where they go,
NOTE Confidence: 0.836747015714286

00:50:02.520 --> 00:50:04.432 where they take us may not be reasonable
NOTE Confidence: 0.836747015714286

00:50:04.432 --> 00:50:06.315 and they made too restricting in terms

NOTE Confidence: 0.836747015714286

00:50:06.315 --> 00:50:08.500 of latitude that we like to give parents.

NOTE Confidence: 0.836747015714286

00:50:08.500 --> 00:50:10.000 Yeah, absolutely. Yeah.

NOTE Confidence: 0.836747015714286

00:50:10.000 --> 00:50:11.010 Let me, let me read.

NOTE Confidence: 0.836747015714286

00:50:11.010 --> 00:50:13.117 I've got a couple of questions here.

NOTE Confidence: 0.836747015714286

00:50:13.120 --> 00:50:15.038 Thank you for this really excellent talk.

NOTE Confidence: 0.836747015714286

00:50:15.040 --> 00:50:16.942 I'm a nurse scientist with a

NOTE Confidence: 0.836747015714286

00:50:16.942 --> 00:50:19.091 pick you background and my work

NOTE Confidence: 0.836747015714286

00:50:19.091 --> 00:50:20.719 focuses on parental bereavement.

NOTE Confidence: 0.836747015714286

00:50:20.720 --> 00:50:22.988 We see time and time again that

NOTE Confidence: 0.836747015714286

00:50:22.988 --> 00:50:24.742 bereaved parents perceive a lot of

NOTE Confidence: 0.836747015714286

00:50:24.742 --> 00:50:26.760 suffering at the end of a child's life.

NOTE Confidence: 0.836747015714286

00:50:26.760 --> 00:50:29.329 How do you think about second hand

NOTE Confidence: 0.836747015714286

00:50:29.329 --> 00:50:31.389 accounts of suffering in the context

NOTE Confidence: 0.836747015714286

00:50:31.389 --> 00:50:33.454 of end of life care and grief?

NOTE Confidence: 0.819220284

00:50:35.180 --> 00:50:35.934 Oh goodness.

NOTE Confidence: 0.819220284

00:50:35.934 --> 00:50:38.950 I mean, so I would say first this,
NOTE Confidence: 0.819220284

00:50:38.950 --> 00:50:40.290 as this commenter mentions,
NOTE Confidence: 0.819220284

00:50:40.290 --> 00:50:43.580 I think this is a very common experience.
NOTE Confidence: 0.819220284

00:50:43.580 --> 00:50:45.908 I mean, it's it, I think.
NOTE Confidence: 0.819220284

00:50:45.910 --> 00:50:47.262 If we think phenomenologically
NOTE Confidence: 0.819220284

00:50:47.262 --> 00:50:48.952 about the experience of of
NOTE Confidence: 0.819220284

00:50:48.952 --> 00:50:50.608 having to watch your child die,
NOTE Confidence: 0.819220284

00:50:50.610 --> 00:50:52.300 it's a very unnatural experience.
NOTE Confidence: 0.819220284

00:50:52.300 --> 00:50:54.586 Again, it in many ways subverts
NOTE Confidence: 0.819220284

00:50:54.586 --> 00:50:57.127 many of the roles that a parent
NOTE Confidence: 0.819220284

00:50:57.127 --> 00:50:59.161 feels as being kind of closest
NOTE Confidence: 0.819220284

00:50:59.161 --> 00:51:01.517 to their identity as a parent.
NOTE Confidence: 0.819220284

00:51:01.520 --> 00:51:04.400 And the death of one child,
NOTE Confidence: 0.819220284

00:51:04.400 --> 00:51:06.356 or it's just experiencing what happens
NOTE Confidence: 0.819220284

00:51:06.356 --> 00:51:09.236 at the end of life of one child again,
NOTE Confidence: 0.819220284

00:51:09.240 --> 00:51:11.568 can can cause a lot of

NOTE Confidence: 0.819220284

00:51:11.568 --> 00:51:13.120 suffering in the parents.

NOTE Confidence: 0.819220284

00:51:13.120 --> 00:51:15.059 I think many of the same sort

NOTE Confidence: 0.819220284

00:51:15.059 --> 00:51:16.500 of conclusions would hold here.

NOTE Confidence: 0.819220284

00:51:16.500 --> 00:51:18.733 And my guess is that this commenter

NOTE Confidence: 0.819220284

00:51:18.733 --> 00:51:21.351 would agree that we need to do an

NOTE Confidence: 0.819220284

00:51:21.351 --> 00:51:22.946 even better job supporting bereaved

NOTE Confidence: 0.819220284

00:51:23.013 --> 00:51:25.038 parents and recognize that again,

NOTE Confidence: 0.819220284

00:51:25.040 --> 00:51:27.000 their child may be suffering,

NOTE Confidence: 0.819220284

00:51:27.000 --> 00:51:28.176 may or may not be suffering,

NOTE Confidence: 0.819220284

00:51:28.180 --> 00:51:30.238 but it's almost certain that they are.

NOTE Confidence: 0.819220284

00:51:30.240 --> 00:51:31.620 The parent is suffering again.

NOTE Confidence: 0.819220284

00:51:31.620 --> 00:51:33.525 Because of the nature of

NOTE Confidence: 0.819220284

00:51:33.525 --> 00:51:35.332 this sort of experience and,

NOTE Confidence: 0.819220284

00:51:35.332 --> 00:51:35.896 you know,

NOTE Confidence: 0.819220284

00:51:35.896 --> 00:51:37.306 caring well for that patient

NOTE Confidence: 0.819220284

00:51:37.306 --> 00:51:39.099 might also include caring well for
NOTE Confidence: 0.819220284

00:51:39.099 --> 00:51:40.857 that parent in a more supportive
NOTE Confidence: 0.819220284

00:51:40.909 --> 00:51:42.415 fashion as they as they grieve
NOTE Confidence: 0.819220284

00:51:42.415 --> 00:51:43.770 the loss of their child.
NOTE Confidence: 0.880764528333333

00:51:45.030 --> 00:51:47.820 You know I was. I was.
NOTE Confidence: 0.880764528333333

00:51:47.820 --> 00:51:49.764 I was touched by the third
NOTE Confidence: 0.880764528333333

00:51:49.764 --> 00:51:51.060 of their three paintings.
NOTE Confidence: 0.880764528333333

00:51:51.060 --> 00:51:53.160 I think it was the Munch painting.
NOTE Confidence: 0.880764528333333

00:51:53.160 --> 00:51:53.772 We're in that painting.
NOTE Confidence: 0.880764528333333

00:51:53.772 --> 00:51:55.309 It struck me it was one that was inspired,
NOTE Confidence: 0.880764528333333

00:51:55.310 --> 00:51:56.787 I guess, by a death from tuberculosis.
NOTE Confidence: 0.880764528333333

00:51:56.790 --> 00:51:58.900 You had said that that,
NOTE Confidence: 0.880764528333333

00:51:58.900 --> 00:52:00.412 and I got a quick look at it only,
NOTE Confidence: 0.880764528333333

00:52:00.420 --> 00:52:01.524 but it didn't look to me
NOTE Confidence: 0.880764528333333

00:52:01.524 --> 00:52:02.740 like the child was suffering,
NOTE Confidence: 0.880764528333333

00:52:02.740 --> 00:52:04.115 but it looked like the

NOTE Confidence: 0.880764528333333
00:52:04.115 --> 00:52:05.215 parent was surely suffering.
NOTE Confidence: 0.880764528333333
00:52:05.220 --> 00:52:06.924 And that's that's so much of what we
NOTE Confidence: 0.880764528333333
00:52:06.924 --> 00:52:08.598 see in the intensive care setting
NOTE Confidence: 0.880764528333333
00:52:08.598 --> 00:52:10.088 is so much parental suffering
NOTE Confidence: 0.880764528333333
00:52:10.088 --> 00:52:11.548 and a lot of suffering, frankly,
NOTE Confidence: 0.880764528333333
00:52:11.548 --> 00:52:13.640 on the part of the staff, too.
NOTE Confidence: 0.880764528333333
00:52:13.640 --> 00:52:15.725 Yeah. Here's a question,
NOTE Confidence: 0.880764528333333
00:52:15.725 --> 00:52:17.735 and perhaps this is a phrase.
NOTE Confidence: 0.880764528333333
00:52:17.740 --> 00:52:19.524 That that you'll understand better than I do.
NOTE Confidence: 0.880764528333333
00:52:19.530 --> 00:52:20.766 But someone asks,
NOTE Confidence: 0.880764528333333
00:52:20.766 --> 00:52:22.826 and I encourage everyone else.
NOTE Confidence: 0.880764528333333
00:52:22.830 --> 00:52:25.068 If you have questions or comments,
NOTE Confidence: 0.880764528333333
00:52:25.070 --> 00:52:28.268 by all means send them in
NOTE Confidence: 0.880764528333333
00:52:28.270 --> 00:52:29.410 through the Q&A portion.
NOTE Confidence: 0.880764528333333
00:52:29.410 --> 00:52:30.550 But here's a question.
NOTE Confidence: 0.880764528333333

00:52:30.550 --> 00:52:33.430 Where does the idea of total
NOTE Confidence: 0.8807645283333333

00:52:33.430 --> 00:52:34.978 pain fit into this paradigm?
NOTE Confidence: 0.8807645283333333

00:52:34.978 --> 00:52:36.313 The idea of total pain,
NOTE Confidence: 0.757392728

00:52:36.750 --> 00:52:37.850 yeah, that's a great question.
NOTE Confidence: 0.757392728

00:52:37.850 --> 00:52:40.554 This is sort of maybe a newer concept.
NOTE Confidence: 0.757392728

00:52:40.560 --> 00:52:42.000 My understanding is that the
NOTE Confidence: 0.757392728

00:52:42.000 --> 00:52:44.143 idea of total pain is that there
NOTE Confidence: 0.757392728

00:52:44.143 --> 00:52:45.748 are many dimensions to pain.
NOTE Confidence: 0.757392728

00:52:45.750 --> 00:52:47.328 There's sort of the physical aspect,
NOTE Confidence: 0.757392728

00:52:47.330 --> 00:52:50.160 but also. Perhaps spiritual pain,
NOTE Confidence: 0.757392728

00:52:50.160 --> 00:52:51.768 social pain, psychological pain
NOTE Confidence: 0.757392728

00:52:51.768 --> 00:52:54.692 and that these all are sort of
NOTE Confidence: 0.757392728

00:52:54.692 --> 00:52:56.436 interactive with one another.
NOTE Confidence: 0.757392728

00:52:56.440 --> 00:52:58.274 I think the idea of total pain
NOTE Confidence: 0.757392728

00:52:58.274 --> 00:52:59.622 actually captures quite well some
NOTE Confidence: 0.757392728

00:52:59.622 --> 00:53:01.393 of the suspicions that we might have

NOTE Confidence: 0.757392728

00:53:01.393 --> 00:53:03.055 about the phenomenon of pain and

NOTE Confidence: 0.757392728

00:53:03.055 --> 00:53:04.823 suffering like that these are sort

NOTE Confidence: 0.757392728

00:53:04.823 --> 00:53:06.838 of again not identical concepts,

NOTE Confidence: 0.757392728

00:53:06.840 --> 00:53:09.590 but often Co occurring experiences

NOTE Confidence: 0.757392728

00:53:09.590 --> 00:53:11.240 and they're interrelated.

NOTE Confidence: 0.757392728

00:53:11.240 --> 00:53:12.281 Again, you know,

NOTE Confidence: 0.757392728

00:53:12.281 --> 00:53:14.740 I gave some examples of ways in which,

NOTE Confidence: 0.757392728

00:53:14.740 --> 00:53:15.220 you know,

NOTE Confidence: 0.757392728

00:53:15.220 --> 00:53:16.356 we experience physical pain

NOTE Confidence: 0.757392728

00:53:16.356 --> 00:53:18.450 and that may or may not cause.

NOTE Confidence: 0.757392728

00:53:18.450 --> 00:53:20.925 Suffering or in the in the total pain model,

NOTE Confidence: 0.757392728

00:53:20.930 --> 00:53:21.470 a physical,

NOTE Confidence: 0.757392728

00:53:21.470 --> 00:53:23.090 physical pain may or may not

NOTE Confidence: 0.757392728

00:53:23.090 --> 00:53:24.816 cause or contribute to social

NOTE Confidence: 0.757392728

00:53:24.816 --> 00:53:26.324 pain or psychological pain.

NOTE Confidence: 0.757392728

00:53:26.330 --> 00:53:28.208 But in many cases it does.

NOTE Confidence: 0.757392728

00:53:28.210 --> 00:53:31.080 And I think a model like total

NOTE Confidence: 0.757392728

00:53:31.080 --> 00:53:33.492 pain allows us to attend in a more

NOTE Confidence: 0.757392728

00:53:33.492 --> 00:53:35.658 specific way to what the patient

NOTE Confidence: 0.757392728

00:53:35.658 --> 00:53:37.723 or person is actually experiencing.

NOTE Confidence: 0.757392728

00:53:37.730 --> 00:53:38.594 Because you know,

NOTE Confidence: 0.757392728

00:53:38.594 --> 00:53:40.322 what we deploy like our solutions

NOTE Confidence: 0.757392728

00:53:40.322 --> 00:53:42.461 to that problem might look different

NOTE Confidence: 0.757392728

00:53:42.461 --> 00:53:44.251 if what we're actually addressing

NOTE Confidence: 0.757392728

00:53:44.308 --> 00:53:45.109 is social pain.

NOTE Confidence: 0.757392728

00:53:45.110 --> 00:53:47.850 So, for example, like isolation,

NOTE Confidence: 0.757392728

00:53:47.850 --> 00:53:48.942 it may, you know.

NOTE Confidence: 0.757392728

00:53:48.942 --> 00:53:50.580 Maybe manifesting in a physical manner,

NOTE Confidence: 0.757392728

00:53:50.580 --> 00:53:52.860 but the physical symptoms alone may

NOTE Confidence: 0.757392728

00:53:52.860 --> 00:53:55.539 not describe the the full experience.

NOTE Confidence: 0.757392728

00:53:55.540 --> 00:53:57.689 So I don't know if that answers

NOTE Confidence: 0.757392728

00:53:57.689 --> 00:53:59.639 the the question that was asked,

NOTE Confidence: 0.757392728

00:53:59.640 --> 00:54:01.900 but it it's a it's a a good and sort

NOTE Confidence: 0.757392728

00:54:01.970 --> 00:54:04.502 of interesting more kind of holistic

NOTE Confidence: 0.757392728

00:54:04.502 --> 00:54:06.190 concept that's being utilized.

NOTE Confidence: 0.867353964

00:54:07.100 --> 00:54:08.682 And so the next question seems to

NOTE Confidence: 0.867353964

00:54:08.682 --> 00:54:10.380 follow on the heels of that a bit,

NOTE Confidence: 0.867353964

00:54:10.380 --> 00:54:12.644 which is how do you deal with the

NOTE Confidence: 0.867353964

00:54:12.644 --> 00:54:14.458 spiritual aspect of pain or suffering?

NOTE Confidence: 0.867353964

00:54:14.460 --> 00:54:16.190 For example, an older person

NOTE Confidence: 0.867353964

00:54:16.190 --> 00:54:17.996 offering up their pain on this

NOTE Confidence: 0.867353964

00:54:17.996 --> 00:54:19.036 is a phrase that's interesting,

NOTE Confidence: 0.867353964

00:54:19.040 --> 00:54:20.570 offering up something we were

NOTE Confidence: 0.867353964

00:54:20.570 --> 00:54:22.100 talking about before we went,

NOTE Confidence: 0.867353964

00:54:22.100 --> 00:54:24.668 went live here, offering up their

NOTE Confidence: 0.867353964

00:54:24.668 --> 00:54:27.319 pain for the interest of another.

NOTE Confidence: 0.867353964

00:54:27.320 --> 00:54:29.894 What would be considered an unacceptable
NOTE Confidence: 0.867353964

00:54:29.894 --> 00:54:32.862 life status to one person may be
NOTE Confidence: 0.867353964

00:54:32.862 --> 00:54:37.320 considered just how they live for another.
NOTE Confidence: 0.867353964

00:54:37.320 --> 00:54:39.496 So the spiritual aspect of pain and suffering
NOTE Confidence: 0.867353964

00:54:39.496 --> 00:54:41.217 is something you've touched on a bit,
NOTE Confidence: 0.867353964

00:54:41.220 --> 00:54:43.479 but could you talk perhaps a bit more about,
NOTE Confidence: 0.867353964

00:54:43.480 --> 00:54:45.288 about approaches to that?
NOTE Confidence: 0.887569045

00:54:45.360 --> 00:54:46.818 Yeah. No, it's a great question.
NOTE Confidence: 0.887569045

00:54:46.820 --> 00:54:48.636 And I think it's one that often is
NOTE Confidence: 0.887569045

00:54:48.636 --> 00:54:50.718 sort of mystifying for practitioners.
NOTE Confidence: 0.887569045

00:54:50.720 --> 00:54:52.645 It's not really the domain or the
NOTE Confidence: 0.887569045

00:54:52.645 --> 00:54:54.518 language that we're most familiar with,
NOTE Confidence: 0.887569045

00:54:54.520 --> 00:54:56.130 but it's good to remember that there
NOTE Confidence: 0.887569045

00:54:56.130 --> 00:54:57.696 are people in our institutions that
NOTE Confidence: 0.887569045

00:54:57.696 --> 00:54:59.628 for whom that is their primary domain,
NOTE Confidence: 0.887569045

00:54:59.630 --> 00:55:03.368 you know, chaplaincy or pastoral care.

NOTE Confidence: 0.887569045

00:55:03.370 --> 00:55:07.732 If a if a patient or family is sort of

NOTE Confidence: 0.887569045

00:55:07.732 --> 00:55:09.437 making claims about religious beliefs

NOTE Confidence: 0.887569045

00:55:09.437 --> 00:55:11.512 or spiritual beliefs that are really

NOTE Confidence: 0.887569045

00:55:11.512 --> 00:55:13.510 affecting their experience of the illness,

NOTE Confidence: 0.887569045

00:55:13.510 --> 00:55:15.364 I think it's very appropriate to

NOTE Confidence: 0.887569045

00:55:15.364 --> 00:55:17.353 look at possible ways of mediating

NOTE Confidence: 0.887569045

00:55:17.353 --> 00:55:18.729 some of that suffering,

NOTE Confidence: 0.887569045

00:55:18.730 --> 00:55:20.462 utilizing the resources not,

NOTE Confidence: 0.887569045

00:55:20.462 --> 00:55:22.548 you know, not medical resources,

NOTE Confidence: 0.887569045

00:55:22.548 --> 00:55:24.172 but chaplaincy resources or

NOTE Confidence: 0.887569045

00:55:24.172 --> 00:55:25.390 pastoral care resources,

NOTE Confidence: 0.887569045

00:55:25.390 --> 00:55:26.527 or, you know,

NOTE Confidence: 0.887569045

00:55:26.527 --> 00:55:28.422 psychology resources or even resources

NOTE Confidence: 0.887569045

00:55:28.422 --> 00:55:30.795 from the local community or perhaps

NOTE Confidence: 0.887569045

00:55:30.795 --> 00:55:32.730 their local place of worship.

NOTE Confidence: 0.887569045

00:55:32.730 --> 00:55:34.584 And I think just the acknowledgement
NOTE Confidence: 0.887569045

00:55:34.584 --> 00:55:37.021 that that might be happening is a step
NOTE Confidence: 0.887569045

00:55:37.021 --> 00:55:39.080 in the right direction that you know,
NOTE Confidence: 0.887569045

00:55:39.080 --> 00:55:40.862 there are there are experiences in
NOTE Confidence: 0.887569045

00:55:40.862 --> 00:55:43.128 front of us that can't necessarily be
NOTE Confidence: 0.887569045

00:55:43.128 --> 00:55:45.494 reduced down to just the physical and
NOTE Confidence: 0.887569045

00:55:45.556 --> 00:55:47.887 that those deserve attending to as well.
NOTE Confidence: 0.902669525555555

00:55:49.080 --> 00:55:52.644 And perhaps when we think about some of the.
NOTE Confidence: 0.902669525555555

00:55:52.650 --> 00:55:53.995 Some of the worst suffering
NOTE Confidence: 0.902669525555555

00:55:53.995 --> 00:55:55.760 that we do in our lives.
NOTE Confidence: 0.902669525555555

00:55:55.760 --> 00:55:58.294 I mean, there's certainly so many folks
NOTE Confidence: 0.902669525555555

00:55:58.294 --> 00:56:00.878 have suffered just horrible physical pain.
NOTE Confidence: 0.902669525555555

00:56:00.880 --> 00:56:02.188 But the suffering associated
NOTE Confidence: 0.902669525555555

00:56:02.188 --> 00:56:04.340 with the loss of a loved 1,
NOTE Confidence: 0.902669525555555

00:56:04.340 --> 00:56:06.808 the suffering associated with
NOTE Confidence: 0.902669525555555

00:56:06.808 --> 00:56:09.893 isolation and loneliness is colossal.

NOTE Confidence: 0.902669525555555
00:56:09.900 --> 00:56:10.770 And you know,
NOTE Confidence: 0.902669525555555
00:56:10.770 --> 00:56:12.220 you mentioned about the chaplains,
NOTE Confidence: 0.902669525555555
00:56:12.220 --> 00:56:14.872 etcetera, one thing that's always impressed
NOTE Confidence: 0.902669525555555
00:56:14.872 --> 00:56:18.528 me about my profession in general.
NOTE Confidence: 0.902669525555555
00:56:18.530 --> 00:56:21.211 Is that there is a sense that
NOTE Confidence: 0.902669525555555
00:56:21.211 --> 00:56:22.360 physicians in particular,
NOTE Confidence: 0.902669525555555
00:56:22.360 --> 00:56:24.117 and I don't know if nurses suffer
NOTE Confidence: 0.902669525555555
00:56:24.117 --> 00:56:25.766 from this same delusion as much
NOTE Confidence: 0.902669525555555
00:56:25.766 --> 00:56:27.434 as we physicians do this notion
NOTE Confidence: 0.902669525555555
00:56:27.434 --> 00:56:29.076 that we really are supposed to
NOTE Confidence: 0.902669525555555
00:56:29.076 --> 00:56:30.718 be able to do everything related
NOTE Confidence: 0.902669525555555
00:56:30.718 --> 00:56:32.686 to taking care of sick people.
NOTE Confidence: 0.902669525555555
00:56:32.690 --> 00:56:35.610 And and there's really not much else that
NOTE Confidence: 0.902669525555555
00:56:35.610 --> 00:56:38.369 someone else has to offer that I can't do.
NOTE Confidence: 0.902669525555555
00:56:38.370 --> 00:56:40.586 And I mean this, this comes to light
NOTE Confidence: 0.902669525555555

00:56:40.590 --> 00:56:42.650 with regard to ethics committees.
NOTE Confidence: 0.902669525555555

00:56:42.650 --> 00:56:43.850 There was a, you know,
NOTE Confidence: 0.902669525555555

00:56:43.850 --> 00:56:45.215 there have been physician leaders in the
NOTE Confidence: 0.902669525555555

00:56:45.215 --> 00:56:46.850 past have said, you know what if you,
NOTE Confidence: 0.902669525555555

00:56:46.850 --> 00:56:48.690 if you get an ethics counsel that shows
NOTE Confidence: 0.902669525555555

00:56:48.690 --> 00:56:50.647 that you've basically failed as a physician.
NOTE Confidence: 0.902669525555555

00:56:50.650 --> 00:56:52.096 And I think that that in
NOTE Confidence: 0.902669525555555

00:56:52.096 --> 00:56:52.819 dealing with suffering,
NOTE Confidence: 0.902669525555555

00:56:52.820 --> 00:56:54.988 there's some of that too that we think,
NOTE Confidence: 0.902669525555555

00:56:54.990 --> 00:56:56.106 you know, what do you mean?
NOTE Confidence: 0.902669525555555

00:56:56.110 --> 00:56:56.730 I know how to do.
NOTE Confidence: 0.902669525555555

00:56:56.730 --> 00:56:58.608 I know the dose of morphine.
NOTE Confidence: 0.902669525555555

00:56:58.610 --> 00:56:59.536 That's it.
NOTE Confidence: 0.902669525555555

00:56:59.536 --> 00:57:01.388 I got that covered.
NOTE Confidence: 0.902669525555555

00:57:01.390 --> 00:57:02.815 There's so many aspects and
NOTE Confidence: 0.902669525555555

00:57:02.815 --> 00:57:04.450 there's so many people around us.

NOTE Confidence: 0.902669525555555
00:57:04.450 --> 00:57:05.338 And the Ethics Committee,
NOTE Confidence: 0.902669525555555
00:57:05.338 --> 00:57:06.226 I mean I'm impressed.
NOTE Confidence: 0.902669525555555
00:57:06.230 --> 00:57:07.406 I'm on the Ethics Committee here.
NOTE Confidence: 0.902669525555555
00:57:07.410 --> 00:57:08.510 I've been for many years.
NOTE Confidence: 0.902669525555555
00:57:08.510 --> 00:57:10.498 With with various members
NOTE Confidence: 0.902669525555555
00:57:10.498 --> 00:57:13.480 of that committee who are so
NOTE Confidence: 0.902669525555555
00:57:13.580 --> 00:57:16.530 insightful and so attentive and.
NOTE Confidence: 0.902669525555555
00:57:16.530 --> 00:57:18.504 And so sensitive to the suffering
NOTE Confidence: 0.902669525555555
00:57:18.504 --> 00:57:20.236 of of various people involved
NOTE Confidence: 0.902669525555555
00:57:20.236 --> 00:57:22.324 in the dramas that unfold here,
NOTE Confidence: 0.902669525555555
00:57:22.330 --> 00:57:23.720 but also the chaplains and
NOTE Confidence: 0.902669525555555
00:57:23.720 --> 00:57:25.110 and so many other folks,
NOTE Confidence: 0.902669525555555
00:57:25.110 --> 00:57:27.312 the folks on the palliative care
NOTE Confidence: 0.902669525555555
00:57:27.312 --> 00:57:29.688 service on the adult side and and
NOTE Confidence: 0.902669525555555
00:57:29.690 --> 00:57:31.458 and in the new one in our newborn
NOTE Confidence: 0.902669525555555

00:57:31.458 --> 00:57:32.994 here we're still in the process
NOTE Confidence: 0.902669525555555

00:57:32.994 --> 00:57:34.560 of really building as robust of
NOTE Confidence: 0.902669525555555

00:57:34.612 --> 00:57:36.267 palliative care services we want.
NOTE Confidence: 0.902669525555555

00:57:36.270 --> 00:57:38.358 But in the in the hospital now there
NOTE Confidence: 0.902669525555555

00:57:38.358 --> 00:57:40.114 are individuals and certainly in the
NOTE Confidence: 0.902669525555555

00:57:40.114 --> 00:57:41.594 newborn ICU there are individuals
NOTE Confidence: 0.902669525555555

00:57:41.594 --> 00:57:43.622 with a lot of insight and a lot of
NOTE Confidence: 0.902669525555555

00:57:43.622 --> 00:57:45.094 knowledge in these things and yet
NOTE Confidence: 0.902669525555555

00:57:45.094 --> 00:57:46.972 somehow we always have to kind of
NOTE Confidence: 0.902669525555555

00:57:46.972 --> 00:57:48.508 be nudged and reminded you know.
NOTE Confidence: 0.902669525555555

00:57:48.510 --> 00:57:49.590 Because what you're what are you
NOTE Confidence: 0.902669525555555

00:57:49.590 --> 00:57:51.020 saying that I'm an insensitive person?
NOTE Confidence: 0.902669525555555

00:57:51.020 --> 00:57:52.460 No, no, no one's saying that.
NOTE Confidence: 0.902669525555555

00:57:52.460 --> 00:57:53.595 We're saying that somebody else
NOTE Confidence: 0.902669525555555

00:57:53.595 --> 00:57:55.352 may have an angle on this that
NOTE Confidence: 0.902669525555555

00:57:55.352 --> 00:57:56.792 you haven't considered that could

NOTE Confidence: 0.902669525555555
00:57:56.792 --> 00:57:57.984 actually help somebody suffering
NOTE Confidence: 0.902669525555555
00:57:57.984 --> 00:57:59.664 that's beyond the dose of morphine.
NOTE Confidence: 0.830659322857143
00:58:00.120 --> 00:58:01.146 Yeah, absolutely. That's.
NOTE Confidence: 0.830659322857143
00:58:01.146 --> 00:58:02.860 Yeah, very well said, Mark.
NOTE Confidence: 0.830659322857143
00:58:02.860 --> 00:58:04.560 And it does, you know,
NOTE Confidence: 0.830659322857143
00:58:04.560 --> 00:58:06.624 invite me to consider even just
NOTE Confidence: 0.830659322857143
00:58:06.624 --> 00:58:08.435 sort of the professional impacts
NOTE Confidence: 0.830659322857143
00:58:08.435 --> 00:58:10.280 of some of these situations.
NOTE Confidence: 0.830659322857143
00:58:10.280 --> 00:58:11.660 I think in many ways, you know,
NOTE Confidence: 0.830659322857143
00:58:11.660 --> 00:58:13.580 we've come a long way in medical education,
NOTE Confidence: 0.830659322857143
00:58:13.580 --> 00:58:14.324 but as you mentioned,
NOTE Confidence: 0.830659322857143
00:58:14.324 --> 00:58:15.254 you already mentioned this word.
NOTE Confidence: 0.830659322857143
00:58:15.260 --> 00:58:17.234 I think it's appropriate in many ways.
NOTE Confidence: 0.830659322857143
00:58:17.240 --> 00:58:18.315 We see the death and
NOTE Confidence: 0.830659322857143
00:58:18.315 --> 00:58:19.175 suffering of our patients.
NOTE Confidence: 0.830659322857143

00:58:19.180 --> 00:58:21.588 As a failure, as a professional failure,
NOTE Confidence: 0.830659322857143

00:58:21.590 --> 00:58:23.606 you know, I have failed as a physician.
NOTE Confidence: 0.830659322857143

00:58:23.610 --> 00:58:24.242 I'm not a physician.
NOTE Confidence: 0.830659322857143

00:58:24.242 --> 00:58:25.748 But if I were a physician that's sort of,
NOTE Confidence: 0.830659322857143

00:58:25.750 --> 00:58:27.430 you know, how I would maybe
NOTE Confidence: 0.830659322857143

00:58:27.430 --> 00:58:28.550 think about that experience.
NOTE Confidence: 0.830659322857143

00:58:28.550 --> 00:58:29.370 And again,
NOTE Confidence: 0.830659322857143

00:58:29.370 --> 00:58:31.830 that experience in and of itself
NOTE Confidence: 0.830659322857143

00:58:31.830 --> 00:58:34.037 might actually cause some suffering
NOTE Confidence: 0.830659322857143

00:58:34.037 --> 00:58:36.665 because of its inability to be
NOTE Confidence: 0.830659322857143

00:58:36.665 --> 00:58:38.688 integrated with their understanding
NOTE Confidence: 0.830659322857143

00:58:38.688 --> 00:58:41.203 of themselves as a professional.
NOTE Confidence: 0.830659322857143

00:58:41.210 --> 00:58:42.594 So utilizing the resources
NOTE Confidence: 0.830659322857143

00:58:42.594 --> 00:58:44.324 that are available to us,
NOTE Confidence: 0.830659322857143

00:58:44.330 --> 00:58:45.296 as you mentioned,
NOTE Confidence: 0.830659322857143

00:58:45.296 --> 00:58:47.228 there are often far more resources

NOTE Confidence: 0.830659322857143

00:58:47.228 --> 00:58:49.188 than we remember available to us.

NOTE Confidence: 0.830659322857143

00:58:49.190 --> 00:58:50.810 Many people with expertise that

NOTE Confidence: 0.830659322857143

00:58:50.810 --> 00:58:53.336 go far beyond ours and also just

NOTE Confidence: 0.830659322857143

00:58:53.336 --> 00:58:55.016 acknowledging our own suffering,

NOTE Confidence: 0.830659322857143

00:58:55.020 --> 00:58:58.215 like sort of noticing when it is that we

NOTE Confidence: 0.830659322857143

00:58:58.215 --> 00:59:01.339 feel we feel overwhelmed or distressed,

NOTE Confidence: 0.830659322857143

00:59:01.340 --> 00:59:04.637 stressed out and reaching out for help,

NOTE Confidence: 0.830659322857143

00:59:04.640 --> 00:59:05.495 even for ourselves,

NOTE Confidence: 0.830659322857143

00:59:05.495 --> 00:59:06.635 when when that's appropriate.

NOTE Confidence: 0.872890064615385

00:59:07.910 --> 00:59:10.686 Thank you. Do you agree that the US

NOTE Confidence: 0.872890064615385

00:59:10.686 --> 00:59:13.541 government should have the right to directly

NOTE Confidence: 0.872890064615385

00:59:13.541 --> 00:59:15.636 intervene and set medical regulations

NOTE Confidence: 0.872890064615385

00:59:15.703 --> 00:59:17.929 such as the baby don't regulation?

NOTE Confidence: 0.872890064615385

00:59:17.930 --> 00:59:19.729 Or do you think that those decisions

NOTE Confidence: 0.872890064615385

00:59:19.729 --> 00:59:21.182 should be left to healthcare

NOTE Confidence: 0.872890064615385

00:59:21.182 --> 00:59:23.380 professionals or left up to each hospital?

NOTE Confidence: 0.891140656

00:59:24.590 --> 00:59:26.020 Wow, that's a big question.

NOTE Confidence: 0.770325570666667

00:59:26.850 --> 00:59:28.656 And yes, we are recording here.

NOTE Confidence: 0.800466295714286

00:59:30.940 --> 00:59:33.908 Be careful who we share this with.

NOTE Confidence: 0.800466295714286

00:59:33.910 --> 00:59:35.090 Yeah, I mean it's interesting.

NOTE Confidence: 0.800466295714286

00:59:35.090 --> 00:59:37.400 I think the the so in especially

NOTE Confidence: 0.800466295714286

00:59:37.400 --> 00:59:39.489 in the realm of Pediatrics,

NOTE Confidence: 0.800466295714286

00:59:39.490 --> 00:59:41.415 the government does have I think a

NOTE Confidence: 0.800466295714286

00:59:41.415 --> 00:59:43.310 more robust role because of what's

NOTE Confidence: 0.800466295714286

00:59:43.310 --> 00:59:45.326 known as the parents patriae doctrine.

NOTE Confidence: 0.800466295714286

00:59:45.330 --> 00:59:47.381 So this is a doctrine that it's

NOTE Confidence: 0.800466295714286

00:59:47.381 --> 00:59:48.929 essentially parent of the nation.

NOTE Confidence: 0.800466295714286

00:59:48.930 --> 00:59:51.730 The idea here is that the government itself

NOTE Confidence: 0.800466295714286

00:59:51.730 --> 00:59:55.096 or the states may need to serve a role

NOTE Confidence: 0.800466295714286

00:59:55.096 --> 00:59:57.140 to protect vulnerable patients or vote,

NOTE Confidence: 0.800466295714286

00:59:57.140 --> 00:59:58.420 excuse me, but vulnerable persons,

NOTE Confidence: 0.800466295714286
00:59:58.420 --> 00:59:59.462 vulnerable populations,
NOTE Confidence: 0.800466295714286
00:59:59.462 --> 01:00:02.240 there are certain populations that just sort
NOTE Confidence: 0.800466295714286
01:00:02.240 --> 01:00:04.419 of by virtue of their state in the world.
NOTE Confidence: 0.800466295714286
01:00:04.420 --> 01:00:06.255 Require extra protection and that
NOTE Confidence: 0.800466295714286
01:00:06.255 --> 01:00:08.580 perhaps it is the the government's job
NOTE Confidence: 0.800466295714286
01:00:08.580 --> 01:00:10.295 to step in and provide that protection.
NOTE Confidence: 0.800466295714286
01:00:10.300 --> 01:00:12.876 I think baby DOE regulations are an
NOTE Confidence: 0.800466295714286
01:00:12.876 --> 01:00:16.053 example perhaps of a way in which the
NOTE Confidence: 0.800466295714286
01:00:16.053 --> 01:00:17.657 federal government was envisioning
NOTE Confidence: 0.800466295714286
01:00:17.660 --> 01:00:20.740 sort of enacting a parents patria type
NOTE Confidence: 0.800466295714286
01:00:20.740 --> 01:00:23.720 of role for parents or for children,
NOTE Confidence: 0.800466295714286
01:00:23.720 --> 01:00:25.388 specifically children with disabilities.
NOTE Confidence: 0.800466295714286
01:00:25.388 --> 01:00:27.890 And certainly I mean just in
NOTE Confidence: 0.800466295714286
01:00:27.953 --> 01:00:29.673 general pediatric practice there
NOTE Confidence: 0.800466295714286
01:00:29.673 --> 01:00:33.770 are protections in place to.
NOTE Confidence: 0.800466295714286

01:00:33.770 --> 01:00:34.574 You know,
NOTE Confidence: 0.800466295714286

01:00:34.574 --> 01:00:36.986 in situations where parents might be
NOTE Confidence: 0.800466295714286

01:00:36.986 --> 01:00:38.987 making decisions that we consider to
NOTE Confidence: 0.800466295714286

01:00:38.987 --> 01:00:41.590 be unacceptably harmful to a child,
NOTE Confidence: 0.800466295714286

01:00:41.590 --> 01:00:43.108 typically we like to give parents
NOTE Confidence: 0.800466295714286

01:00:43.108 --> 01:00:44.700 the ability to make, you know,
NOTE Confidence: 0.800466295714286

01:00:44.700 --> 01:00:46.150 have pretty wide discretion and
NOTE Confidence: 0.800466295714286

01:00:46.150 --> 01:00:47.979 make kind of a wide latitude
NOTE Confidence: 0.800466295714286

01:00:47.979 --> 01:00:49.489 of decisions for their child.
NOTE Confidence: 0.800466295714286

01:00:49.490 --> 01:00:50.786 But there are limits to that.
NOTE Confidence: 0.800466295714286

01:00:50.790 --> 01:00:51.570 And I think,
NOTE Confidence: 0.800466295714286

01:00:51.570 --> 01:00:52.090 you know,
NOTE Confidence: 0.800466295714286

01:00:52.090 --> 01:00:53.668 the government has sort of depending
NOTE Confidence: 0.800466295714286

01:00:53.668 --> 01:00:54.910 on the state you're in,
NOTE Confidence: 0.800466295714286

01:00:54.910 --> 01:00:56.838 specified sort of what that might look like.
NOTE Confidence: 0.800466295714286

01:00:56.840 --> 01:00:58.779 That's often the role of judges or

NOTE Confidence: 0.800466295714286
01:00:58.779 --> 01:01:00.966 courts to make a decision about when
NOTE Confidence: 0.800466295714286
01:01:00.966 --> 01:01:03.245 those decisions are so harmful that we
NOTE Confidence: 0.800466295714286
01:01:03.245 --> 01:01:05.226 should step in and protect the child.
NOTE Confidence: 0.800466295714286
01:01:05.230 --> 01:01:05.508 So.
NOTE Confidence: 0.800466295714286
01:01:05.508 --> 01:01:08.010 My sort of answer or non answer is I
NOTE Confidence: 0.800466295714286
01:01:08.089 --> 01:01:10.817 do think there is some role for the
NOTE Confidence: 0.800466295714286
01:01:10.817 --> 01:01:12.899 government to protect vulnerable,
NOTE Confidence: 0.800466295714286
01:01:12.900 --> 01:01:14.484 vulnerable persons and populations.
NOTE Confidence: 0.800466295714286
01:01:14.484 --> 01:01:17.450 I think children qualify in that category.
NOTE Confidence: 0.800466295714286
01:01:17.450 --> 01:01:19.606 I think probably where we'd get into
NOTE Confidence: 0.800466295714286
01:01:19.606 --> 01:01:21.517 much more debate and controversy is
NOTE Confidence: 0.800466295714286
01:01:21.517 --> 01:01:23.673 like the exact nature of when it's
NOTE Confidence: 0.800466295714286
01:01:23.736 --> 01:01:25.794 appropriate to step in and intervene
NOTE Confidence: 0.800466295714286
01:01:25.794 --> 01:01:29.201 on parent decisions or even, you know,
NOTE Confidence: 0.800466295714286
01:01:29.201 --> 01:01:31.909 provider discretion or decisions.
NOTE Confidence: 0.800466295714286

01:01:31.910 --> 01:01:34.520 But that's a good hard question
NOTE Confidence: 0.7651748025

01:01:34.940 --> 01:01:36.508 and I think that was a thoughtful answer.
NOTE Confidence: 0.7651748025

01:01:36.510 --> 01:01:38.726 I mean perhaps an analogy can be drawn
NOTE Confidence: 0.7651748025

01:01:38.726 --> 01:01:41.472 if we say that that we think that parents
NOTE Confidence: 0.7651748025

01:01:41.472 --> 01:01:43.768 should be in charge of their kids,
NOTE Confidence: 0.7651748025

01:01:43.770 --> 01:01:46.392 but we as healthcare professionals recognize
NOTE Confidence: 0.7651748025

01:01:46.392 --> 01:01:49.186 that in certain settings we've got an
NOTE Confidence: 0.7651748025

01:01:49.186 --> 01:01:52.218 obligation to the child to seek to overrule.
NOTE Confidence: 0.7651748025

01:01:52.218 --> 01:01:54.810 A parents choice doesn't happen often,
NOTE Confidence: 0.7651748025

01:01:54.810 --> 01:01:56.553 but it may happen and that's that's
NOTE Confidence: 0.7651748025

01:01:56.553 --> 01:01:58.305 based on our perception of the
NOTE Confidence: 0.7651748025

01:01:58.305 --> 01:02:00.207 child's rights and of our obligation.
NOTE Confidence: 0.7651748025

01:02:00.210 --> 01:02:02.994 And an analogy might be drawn to say
NOTE Confidence: 0.7651748025

01:02:02.994 --> 01:02:05.105 that that perhaps the government should
NOTE Confidence: 0.7651748025

01:02:05.105 --> 01:02:06.860 be giving parents and physicians.
NOTE Confidence: 0.7651748025

01:02:06.860 --> 01:02:09.800 Wide latitude but not not complete control.

NOTE Confidence: 0.7651748025

01:02:09.800 --> 01:02:10.640 One can imagine,

NOTE Confidence: 0.7651748025

01:02:10.640 --> 01:02:12.600 again if you think of extreme cases,

NOTE Confidence: 0.7651748025

01:02:12.600 --> 01:02:14.931 if a hospital decided we're going to

NOTE Confidence: 0.7651748025

01:02:14.931 --> 01:02:17.261 make it legal to youthanize children

NOTE Confidence: 0.7651748025

01:02:17.261 --> 01:02:18.937 born with trisomy 21.

NOTE Confidence: 0.7651748025

01:02:18.940 --> 01:02:20.320 If a hospital said, you know,

NOTE Confidence: 0.7651748025

01:02:20.320 --> 01:02:22.154 we're going to say this is acceptable,

NOTE Confidence: 0.7651748025

01:02:22.160 --> 01:02:23.582 that it would no longer seem

NOTE Confidence: 0.7651748025

01:02:23.582 --> 01:02:25.135 unreasonable to us to think, well,

NOTE Confidence: 0.7651748025

01:02:25.135 --> 01:02:26.990 it's it's that it's OK for the

NOTE Confidence: 0.7651748025

01:02:26.990 --> 01:02:28.518 government still to draw the bounds.

NOTE Confidence: 0.7651748025

01:02:28.520 --> 01:02:30.230 That indeed we think that we're

NOTE Confidence: 0.7651748025

01:02:30.230 --> 01:02:32.120 the ones who decide that we're

NOTE Confidence: 0.7651748025

01:02:32.120 --> 01:02:33.840 going to enforce certain things.

NOTE Confidence: 0.7651748025

01:02:33.840 --> 01:02:35.150 But really in the emergency

NOTE Confidence: 0.7651748025

01:02:35.150 --> 01:02:36.198 setting we often do.
NOTE Confidence: 0.7651748025

01:02:36.200 --> 01:02:37.750 But in a non-emergency setting.
NOTE Confidence: 0.7651748025

01:02:37.750 --> 01:02:38.962 That actually falls to the government
NOTE Confidence: 0.7651748025

01:02:38.962 --> 01:02:40.430 in the form of a probate judge,
NOTE Confidence: 0.7651748025

01:02:40.430 --> 01:02:42.677 right, in certain settings and so that
NOTE Confidence: 0.7651748025

01:02:42.677 --> 01:02:45.858 that I I think that your answer was
NOTE Confidence: 0.7651748025

01:02:45.858 --> 01:02:48.008 thoughtful and reasonable that yeah.
NOTE Confidence: 0.7651748025

01:02:48.010 --> 01:02:50.224 But the hard part gets down to the detail.
NOTE Confidence: 0.7651748025

01:02:50.230 --> 01:02:50.590 Exactly.
NOTE Confidence: 0.7651748025

01:02:50.590 --> 01:02:52.850 It always does, yeah.
NOTE Confidence: 0.7651748025

01:02:52.850 --> 01:02:53.710 Well,
NOTE Confidence: 0.864113922857143

01:02:53.720 --> 01:02:54.959 and I do want to mention Mark,
NOTE Confidence: 0.864113922857143

01:02:54.960 --> 01:02:56.608 you just sort of mentioned kind of the
NOTE Confidence: 0.864113922857143

01:02:56.608 --> 01:02:58.220 parent role and then the clinician role.
NOTE Confidence: 0.864113922857143

01:02:58.220 --> 01:03:00.776 And I do want to sort of emphasize that
NOTE Confidence: 0.864113922857143

01:03:00.776 --> 01:03:02.798 clinicians do have play a very sort of

NOTE Confidence: 0.864113922857143
01:03:02.798 --> 01:03:05.167 robust role in the decision making process.
NOTE Confidence: 0.864113922857143
01:03:05.170 --> 01:03:07.034 I mean we sort of now are using
NOTE Confidence: 0.864113922857143
01:03:07.034 --> 01:03:08.779 words like shared decision making
NOTE Confidence: 0.864113922857143
01:03:08.780 --> 01:03:10.810 but of course physicians you know in
NOTE Confidence: 0.864113922857143
01:03:10.810 --> 01:03:12.742 deploying their own kind of competency
NOTE Confidence: 0.864113922857143
01:03:12.742 --> 01:03:14.422 and professional integrity do have
NOTE Confidence: 0.864113922857143
01:03:14.422 --> 01:03:16.524 some rights to kind of define the
NOTE Confidence: 0.864113922857143
01:03:16.524 --> 01:03:18.170 boundaries of what's offered to parents.
NOTE Confidence: 0.864113922857143
01:03:18.170 --> 01:03:20.060 You know that is a pretty robust
NOTE Confidence: 0.864113922857143
01:03:20.060 --> 01:03:21.225 right or obligation depending
NOTE Confidence: 0.864113922857143
01:03:21.225 --> 01:03:23.473 on how you see it that is that.
NOTE Confidence: 0.864113922857143
01:03:23.480 --> 01:03:24.380 That's given them,
NOTE Confidence: 0.864113922857143
01:03:24.380 --> 01:03:26.180 that's given to the medical profession.
NOTE Confidence: 0.864113922857143
01:03:26.180 --> 01:03:28.130 We don't let parents just sort
NOTE Confidence: 0.864113922857143
01:03:28.130 --> 01:03:30.723 of choose off of an infinite menu
NOTE Confidence: 0.864113922857143

01:03:30.723 --> 01:03:32.753 of options for their children.
NOTE Confidence: 0.864113922857143

01:03:32.760 --> 01:03:34.716 We usually sort of specify a
NOTE Confidence: 0.864113922857143

01:03:34.716 --> 01:03:36.020 reasonable reign of option,
NOTE Confidence: 0.864113922857143

01:03:36.020 --> 01:03:37.128 a range of options.
NOTE Confidence: 0.864113922857143

01:03:37.128 --> 01:03:38.866 But of course the, you know,
NOTE Confidence: 0.864113922857143

01:03:38.866 --> 01:03:40.431 the reason they're pediatric ethicists
NOTE Confidence: 0.864113922857143

01:03:40.431 --> 01:03:42.659 like you and me is because sometimes,
NOTE Confidence: 0.864113922857143

01:03:42.660 --> 01:03:43.740 you know, there are options on
NOTE Confidence: 0.864113922857143

01:03:43.740 --> 01:03:44.600 that list that shouldn't be,
NOTE Confidence: 0.864113922857143

01:03:44.600 --> 01:03:46.076 or sometimes there are options not
NOTE Confidence: 0.864113922857143

01:03:46.076 --> 01:03:47.960 on that list that perhaps should be.
NOTE Confidence: 0.864113922857143

01:03:47.960 --> 01:03:48.752 And there's some,
NOTE Confidence: 0.864113922857143

01:03:48.752 --> 01:03:49.280 you know,
NOTE Confidence: 0.864113922857143

01:03:49.280 --> 01:03:50.356 interesting conversation we could
NOTE Confidence: 0.864113922857143

01:03:50.356 --> 01:03:52.310 have about what what what does belong,
NOTE Confidence: 0.864113922857143

01:03:52.310 --> 01:03:53.078 what doesn't belong.

NOTE Confidence: 0.818739711

01:03:53.940 --> 01:03:55.830 Yeah. And I and I think that it it

NOTE Confidence: 0.818739711

01:03:55.830 --> 01:03:57.682 that obligation is is to my lights

NOTE Confidence: 0.818739711

01:03:57.682 --> 01:03:59.852 the right word that that we have not

NOTE Confidence: 0.818739711

01:03:59.852 --> 01:04:01.814 just the right but an obligation when

NOTE Confidence: 0.818739711

01:04:01.814 --> 01:04:04.058 parents making a choice that's clearly

NOTE Confidence: 0.818739711

01:04:04.058 --> 01:04:06.720 opposed to a child's best interest.

NOTE Confidence: 0.818739711

01:04:06.720 --> 01:04:08.309 I'm I'm among those who like to

NOTE Confidence: 0.818739711

01:04:08.309 --> 01:04:09.731 give parents wide latitude but not

NOTE Confidence: 0.818739711

01:04:09.731 --> 01:04:11.348 complete latitude and I I guess I

NOTE Confidence: 0.818739711

01:04:11.401 --> 01:04:12.920 would want the same from the state

NOTE Confidence: 0.818739711

01:04:12.920 --> 01:04:14.875 I would want them to give us wide

NOTE Confidence: 0.818739711

01:04:14.875 --> 01:04:16.170 latitude but can't think reasonably

NOTE Confidence: 0.818739711

01:04:16.218 --> 01:04:17.658 that they would give us complete

NOTE Confidence: 0.818739711

01:04:17.658 --> 01:04:19.550 latitude and how we manage these cases.

NOTE Confidence: 0.818739711

01:04:19.550 --> 01:04:20.998 Yeah that seems reasonable.

NOTE Confidence: 0.818739711

01:04:21.000 --> 01:04:22.940 Another question.
NOTE Confidence: 0.818739711

01:04:22.940 --> 01:04:24.326 OK, I'm going to this is all,
NOTE Confidence: 0.818739711

01:04:24.330 --> 01:04:25.458 this is a long one here.
NOTE Confidence: 0.818739711

01:04:25.460 --> 01:04:27.126 So let me let me read because
NOTE Confidence: 0.818739711

01:04:27.126 --> 01:04:28.660 this is not simple stuff.
NOTE Confidence: 0.818739711

01:04:28.660 --> 01:04:30.530 So what about when we,
NOTE Confidence: 0.818739711

01:04:30.530 --> 01:04:31.244 the speaker,
NOTE Confidence: 0.818739711

01:04:31.244 --> 01:04:33.386 are distressed because we fear the
NOTE Confidence: 0.818739711

01:04:33.386 --> 01:04:35.557 act of giving medical treatment
NOTE Confidence: 0.818739711

01:04:35.557 --> 01:04:37.409 is causing emotional suffering
NOTE Confidence: 0.818739711

01:04:37.409 --> 01:04:39.790 at the expense of addressing?
NOTE Confidence: 0.818739711

01:04:39.790 --> 01:04:42.086 Physical suffering, for example,
NOTE Confidence: 0.818739711

01:04:42.086 --> 01:04:45.530 providing quality and standard of care.
NOTE Confidence: 0.818739711

01:04:45.530 --> 01:04:47.530 Pain management during terminal illness.
NOTE Confidence: 0.818739711

01:04:47.530 --> 01:04:49.259 But it keeps the patients in the
NOTE Confidence: 0.818739711

01:04:49.259 --> 01:04:51.119 hospital and away from home where it

NOTE Confidence: 0.818739711

01:04:51.119 --> 01:04:52.721 seems they will be more comfortable

NOTE Confidence: 0.818739711

01:04:52.770 --> 01:04:54.546 and better surrounded by loved ones.

NOTE Confidence: 0.818739711

01:04:54.550 --> 01:04:55.420 For example,

NOTE Confidence: 0.818739711

01:04:55.420 --> 01:04:58.030 COVID policies during end of life.

NOTE Confidence: 0.818739711

01:04:58.030 --> 01:05:00.067 What if we're a student without power

NOTE Confidence: 0.818739711

01:05:00.067 --> 01:05:02.378 but have the luxury of time and can

NOTE Confidence: 0.818739711

01:05:02.378 --> 01:05:04.783 draw near to the patient and be more

NOTE Confidence: 0.818739711

01:05:04.783 --> 01:05:06.727 in tune with the emotional experience?

NOTE Confidence: 0.818739711

01:05:06.730 --> 01:05:08.101 In these cases,

NOTE Confidence: 0.818739711

01:05:08.101 --> 01:05:09.929 the physician is satisfied.

NOTE Confidence: 0.818739711

01:05:09.930 --> 01:05:11.856 With the addressing the physical suffering,

NOTE Confidence: 0.818739711

01:05:11.860 --> 01:05:14.878 but refuses to significantly weigh the

NOTE Confidence: 0.818739711

01:05:14.878 --> 01:05:16.890 possible emotional suffering because

NOTE Confidence: 0.818739711

01:05:16.966 --> 01:05:19.248 they lack the time to perceive it.

NOTE Confidence: 0.698712556666667

01:05:19.760 --> 01:05:22.040 Wow, yeah, that's a great question.

NOTE Confidence: 0.698712556666667

01:05:22.040 --> 01:05:23.320 I really appreciate the examples.
NOTE Confidence: 0.698712556666667

01:05:23.320 --> 01:05:25.240 Actually that was helpful to understand
NOTE Confidence: 0.698712556666667

01:05:25.240 --> 01:05:27.209 where this speaker is coming from.
NOTE Confidence: 0.698712556666667

01:05:27.210 --> 01:05:29.594 So the first case or example was you
NOTE Confidence: 0.698712556666667

01:05:29.594 --> 01:05:32.149 know whether we keep a patient in the
NOTE Confidence: 0.698712556666667

01:05:32.149 --> 01:05:34.220 hospital to provide certain maybe like
NOTE Confidence: 0.698712556666667

01:05:34.220 --> 01:05:36.446 the most advanced palliative care services
NOTE Confidence: 0.698712556666667

01:05:36.446 --> 01:05:38.845 that we can versus discharging a patient
NOTE Confidence: 0.698712556666667

01:05:38.845 --> 01:05:40.911 home where we think perhaps they'll
NOTE Confidence: 0.698712556666667

01:05:40.911 --> 01:05:43.347 be more comfortable or again maybe the
NOTE Confidence: 0.698712556666667

01:05:43.347 --> 01:05:45.557 home environment is more amenable to
NOTE Confidence: 0.698712556666667

01:05:45.557 --> 01:05:47.013 flourishing socially and relationally
NOTE Confidence: 0.698712556666667

01:05:47.013 --> 01:05:50.630 or maybe even just sort of comfort wise.
NOTE Confidence: 0.698712556666667

01:05:50.630 --> 01:05:51.614 I think it is,
NOTE Confidence: 0.698712556666667

01:05:51.614 --> 01:05:53.510 you know I'll use the word obligation
NOTE Confidence: 0.698712556666667

01:05:53.510 --> 01:05:56.030 again it is the obligation of care

NOTE Confidence: 0.698712556666667
01:05:56.030 --> 01:05:58.370 providers when presenting these sorts of.
NOTE Confidence: 0.698712556666667
01:05:58.370 --> 01:05:59.858 Decisions to patients,
NOTE Confidence: 0.698712556666667
01:05:59.858 --> 01:06:02.338 families and parents to think
NOTE Confidence: 0.698712556666667
01:06:02.338 --> 01:06:05.277 through not only the physical risks,
NOTE Confidence: 0.698712556666667
01:06:05.280 --> 01:06:08.820 benefits, burdens, but the emotional,
NOTE Confidence: 0.698712556666667
01:06:08.820 --> 01:06:10.170 psychological, relational risks,
NOTE Confidence: 0.698712556666667
01:06:10.170 --> 01:06:11.520 benefits and burdens.
NOTE Confidence: 0.698712556666667
01:06:11.520 --> 01:06:14.208 And I think the example that this questioner
NOTE Confidence: 0.698712556666667
01:06:14.208 --> 01:06:16.440 provided is a great example of where,
NOTE Confidence: 0.698712556666667
01:06:16.440 --> 01:06:16.974 you know,
NOTE Confidence: 0.698712556666667
01:06:16.974 --> 01:06:19.110 if we don't talk about the fact that
NOTE Confidence: 0.698712556666667
01:06:19.168 --> 01:06:21.118 this patient may be more comfortable
NOTE Confidence: 0.698712556666667
01:06:21.118 --> 01:06:22.940 in these other ways at home,
NOTE Confidence: 0.698712556666667
01:06:22.940 --> 01:06:24.325 maybe they're not actually making
NOTE Confidence: 0.698712556666667
01:06:24.325 --> 01:06:25.710 a real informed choice about
NOTE Confidence: 0.698712556666667

01:06:25.764 --> 01:06:26.840 staying in the hospital.
NOTE Confidence: 0.698712556666667

01:06:26.840 --> 01:06:29.270 So, you know, I think.
NOTE Confidence: 0.698712556666667

01:06:29.270 --> 01:06:31.342 I think the question was phrased as what
NOTE Confidence: 0.698712556666667

01:06:31.342 --> 01:06:33.379 what should we do when the speaker is
NOTE Confidence: 0.698712556666667

01:06:33.379 --> 01:06:35.010 perceiving this sort of discrepancy?
NOTE Confidence: 0.698712556666667

01:06:35.010 --> 01:06:35.902 And I would say,
NOTE Confidence: 0.698712556666667

01:06:35.902 --> 01:06:36.348 you know,
NOTE Confidence: 0.698712556666667

01:06:36.350 --> 01:06:37.562 I would acknowledge that.
NOTE Confidence: 0.698712556666667

01:06:37.562 --> 01:06:39.714 I would sort of articulate the concerns
NOTE Confidence: 0.698712556666667

01:06:39.714 --> 01:06:41.922 that you might have and again sort of
NOTE Confidence: 0.698712556666667

01:06:41.930 --> 01:06:44.247 present what you consider to be some
NOTE Confidence: 0.698712556666667

01:06:44.247 --> 01:06:47.270 of the maybe relevant but neglected risks,
NOTE Confidence: 0.698712556666667

01:06:47.270 --> 01:06:49.448 benefits and burdens that fall less
NOTE Confidence: 0.698712556666667

01:06:49.448 --> 01:06:51.778 on the physical side of things and
NOTE Confidence: 0.698712556666667

01:06:51.778 --> 01:06:53.165 more on the spiritual,
NOTE Confidence: 0.698712556666667

01:06:53.165 --> 01:06:53.740 emotional,

NOTE Confidence: 0.698712556666667
01:06:53.740 --> 01:06:56.040 relational side of things.
NOTE Confidence: 0.698712556666667
01:06:56.040 --> 01:06:58.007 And I've I've already forgotten the speaker
NOTE Confidence: 0.698712556666667
01:06:58.007 --> 01:06:59.670 asked another part of that question.
NOTE Confidence: 0.698712556666667
01:06:59.670 --> 01:07:01.910 That was with the student,
NOTE Confidence: 0.644321815454545
01:07:02.280 --> 01:07:04.518 right. So. So if a student
NOTE Confidence: 0.644321815454545
01:07:04.518 --> 01:07:06.540 used the phrase without power,
NOTE Confidence: 0.644321815454545
01:07:06.540 --> 01:07:08.852 but the luxury of time and can in
NOTE Confidence: 0.644321815454545
01:07:08.852 --> 01:07:10.790 quotes draw near to the patient,
NOTE Confidence: 0.644321815454545
01:07:10.790 --> 01:07:12.430 you're more in tune with
NOTE Confidence: 0.644321815454545
01:07:12.430 --> 01:07:13.414 the emotional experience.
NOTE Confidence: 0.644321815454545
01:07:13.420 --> 01:07:15.200 So the physician here, presumably.
NOTE Confidence: 0.644321815454545
01:07:15.200 --> 01:07:16.832 So we'll say that the attending
NOTE Confidence: 0.644321815454545
01:07:16.832 --> 01:07:18.290 is satisfied that we're taking
NOTE Confidence: 0.644321815454545
01:07:18.290 --> 01:07:19.860 care of the physical suffering,
NOTE Confidence: 0.644321815454545
01:07:19.860 --> 01:07:21.735 but refuses to significantly weigh
NOTE Confidence: 0.644321815454545

01:07:21.735 --> 01:07:23.235 the possible emotional suffering.

NOTE Confidence: 0.644321815454545

01:07:23.240 --> 01:07:24.980 So students are in a tough

NOTE Confidence: 0.644321815454545

01:07:24.980 --> 01:07:25.980 spot in this situation.

NOTE Confidence: 0.644321815454545

01:07:25.980 --> 01:07:27.940 And they see things that

NOTE Confidence: 0.644321815454545

01:07:27.940 --> 01:07:29.508 perhaps they are busier,

NOTE Confidence: 0.644321815454545

01:07:29.510 --> 01:07:31.140 more senior physicians don't see.

NOTE Confidence: 0.862180662727273

01:07:31.230 --> 01:07:33.372 Yeah, it does seem like a sort of cruel

NOTE Confidence: 0.862180662727273

01:07:33.372 --> 01:07:35.162 irony that the that the more authority

NOTE Confidence: 0.862180662727273

01:07:35.162 --> 01:07:37.219 one has in the medical profession,

NOTE Confidence: 0.862180662727273

01:07:37.220 --> 01:07:38.630 the less time they have to

NOTE Confidence: 0.862180662727273

01:07:38.630 --> 01:07:40.150 sort of enact that authority.

NOTE Confidence: 0.862180662727273

01:07:40.150 --> 01:07:43.464 So I do think it's that experience

NOTE Confidence: 0.862180662727273

01:07:43.464 --> 01:07:45.549 I don't think is uncommon.

NOTE Confidence: 0.862180662727273

01:07:45.550 --> 01:07:47.827 And I will also maybe add to the list

NOTE Confidence: 0.862180662727273

01:07:47.827 --> 01:07:50.054 the experiences of our nursing staff

NOTE Confidence: 0.862180662727273

01:07:50.054 --> 01:07:52.368 who are bedside with patients more

NOTE Confidence: 0.862180662727273
01:07:52.368 --> 01:07:54.699 regularly and I think what our obligation
NOTE Confidence: 0.862180662727273
01:07:54.699 --> 01:07:56.298 or duty is in these situations.
NOTE Confidence: 0.862180662727273
01:07:56.298 --> 01:07:58.170 Is to listen to these people who are
NOTE Confidence: 0.862180662727273
01:07:58.170 --> 01:07:59.914 able to spend more time with the patient.
NOTE Confidence: 0.862180662727273
01:07:59.920 --> 01:08:02.416 If our goal is to understand in a
NOTE Confidence: 0.862180662727273
01:08:02.416 --> 01:08:05.325 more robust and accurate way what our
NOTE Confidence: 0.862180662727273
01:08:05.325 --> 01:08:07.097 patients are actually experiencing
NOTE Confidence: 0.862180662727273
01:08:07.097 --> 01:08:08.960 and how we can, you know,
NOTE Confidence: 0.862180662727273
01:08:08.960 --> 01:08:10.700 solve any problems that exist there,
NOTE Confidence: 0.862180662727273
01:08:10.700 --> 01:08:12.740 then we have to sort of be willing
NOTE Confidence: 0.862180662727273
01:08:12.740 --> 01:08:14.466 to take information from all
NOTE Confidence: 0.862180662727273
01:08:14.466 --> 01:08:16.560 those sources and it's, you know,
NOTE Confidence: 0.862180662727273
01:08:16.560 --> 01:08:17.960 it's interesting like what counts
NOTE Confidence: 0.862180662727273
01:08:17.960 --> 01:08:19.060 is relevant information here.
NOTE Confidence: 0.862180662727273
01:08:19.060 --> 01:08:21.055 Many physicians might say like you know,
NOTE Confidence: 0.862180662727273

01:08:21.060 --> 01:08:22.653 I have everything I need with the I have
NOTE Confidence: 0.862180662727273

01:08:22.653 --> 01:08:24.508 the lab values, I have the monitors,
NOTE Confidence: 0.862180662727273

01:08:24.508 --> 01:08:26.720 I can see the patients vital signs.
NOTE Confidence: 0.862180662727273

01:08:26.720 --> 01:08:27.644 You know, right in front of me.
NOTE Confidence: 0.862180662727273

01:08:27.650 --> 01:08:28.946 That's all I need to know.
NOTE Confidence: 0.862180662727273

01:08:28.950 --> 01:08:30.427 But I think the claim of this,
NOTE Confidence: 0.862180662727273

01:08:30.430 --> 01:08:32.358 the person who asked this question is like,
NOTE Confidence: 0.862180662727273

01:08:32.360 --> 01:08:33.116 you know, no,
NOTE Confidence: 0.862180662727273

01:08:33.116 --> 01:08:34.880 there's other things we should add to
NOTE Confidence: 0.862180662727273

01:08:34.933 --> 01:08:36.697 the list that actually you haven't been
NOTE Confidence: 0.862180662727273

01:08:36.697 --> 01:08:38.986 able to see because you haven't been here.
NOTE Confidence: 0.862180662727273

01:08:38.990 --> 01:08:39.572 So I mean,
NOTE Confidence: 0.862180662727273

01:08:39.572 --> 01:08:40.930 it's an easy solution to say we
NOTE Confidence: 0.862180662727273

01:08:40.985 --> 01:08:42.330 should listen to the student.
NOTE Confidence: 0.862180662727273

01:08:42.330 --> 01:08:42.966 Of course,
NOTE Confidence: 0.862180662727273

01:08:42.966 --> 01:08:44.874 it's much harder to sort of

NOTE Confidence: 0.862180662727273
01:08:44.874 --> 01:08:46.309 culturally fold that practice
NOTE Confidence: 0.862180662727273
01:08:46.309 --> 01:08:48.159 into how we practice medicine.
NOTE Confidence: 0.825483388333333
01:08:49.660 --> 01:08:51.202 Sure. But, but I I would
NOTE Confidence: 0.825483388333333
01:08:51.202 --> 01:08:52.800 just add that if I could.
NOTE Confidence: 0.825483388333333
01:08:52.800 --> 01:08:54.340 I don't mean to paint on your
NOTE Confidence: 0.825483388333333
01:08:54.340 --> 01:08:56.560 painting please if this is a local
NOTE Confidence: 0.825483388333333
01:08:56.560 --> 01:08:58.670 situation to say to the student that.
NOTE Confidence: 0.843030876
01:09:00.700 --> 01:09:02.810 That to give the attendings
NOTE Confidence: 0.843030876
01:09:02.810 --> 01:09:04.920 the benefit of the doubt,
NOTE Confidence: 0.843030876
01:09:04.920 --> 01:09:06.720 which is to say that I can't speak
NOTE Confidence: 0.843030876
01:09:06.720 --> 01:09:08.618 for for every attending physician,
NOTE Confidence: 0.843030876
01:09:08.620 --> 01:09:11.108 but I'd be willing to bet that most
NOTE Confidence: 0.843030876
01:09:11.108 --> 01:09:12.593 attending physicians in the hospital
NOTE Confidence: 0.843030876
01:09:12.593 --> 01:09:15.020 actually want to do right by the patients.
NOTE Confidence: 0.843030876
01:09:15.020 --> 01:09:16.636 And so that that it takes and it's
NOTE Confidence: 0.843030876

01:09:16.636 --> 01:09:18.301 easy for an old guy who's not going
NOTE Confidence: 0.843030876

01:09:18.301 --> 01:09:20.203 to apply for any more jobs and not
NOTE Confidence: 0.843030876

01:09:20.203 --> 01:09:21.508 working for any more promotions.
NOTE Confidence: 0.843030876

01:09:21.510 --> 01:09:23.330 So it's easy for me to say it and it's
NOTE Confidence: 0.843030876

01:09:23.378 --> 01:09:25.142 harder for you as a student to do it.
NOTE Confidence: 0.843030876

01:09:25.150 --> 01:09:27.425 But I would encourage you to to
NOTE Confidence: 0.843030876

01:09:27.425 --> 01:09:29.580 bring this forward to the attending.
NOTE Confidence: 0.843030876

01:09:29.580 --> 01:09:32.286 Because the vast majority of attendings,
NOTE Confidence: 0.843030876

01:09:32.290 --> 01:09:34.746 even if at first they they get they,
NOTE Confidence: 0.843030876

01:09:34.750 --> 01:09:36.850 they are unhappy with the notion that
NOTE Confidence: 0.843030876

01:09:36.850 --> 01:09:39.149 they didn't keep their eye on everything.
NOTE Confidence: 0.843030876

01:09:39.150 --> 01:09:41.075 That in fact they'll appreciate
NOTE Confidence: 0.843030876

01:09:41.075 --> 01:09:42.456 the insight and you know,
NOTE Confidence: 0.843030876

01:09:42.456 --> 01:09:43.668 and if you really think that
NOTE Confidence: 0.843030876

01:09:43.668 --> 01:09:45.169 a patient's suffering is not.
NOTE Confidence: 0.843030876

01:09:45.170 --> 01:09:47.192 Being addressed and you really feel

NOTE Confidence: 0.843030876

01:09:47.192 --> 01:09:49.845 you can't take it to the attending

NOTE Confidence: 0.843030876

01:09:49.845 --> 01:09:52.115 physician then I would say you need to

NOTE Confidence: 0.843030876

01:09:52.115 --> 01:09:53.900 find someone else you trust who you

NOTE Confidence: 0.843030876

01:09:53.900 --> 01:09:56.636 can take it to and you know and and one

NOTE Confidence: 0.843030876

01:09:56.636 --> 01:09:58.574 possible example is the chief resident.

NOTE Confidence: 0.843030876

01:09:58.580 --> 01:10:00.556 But if if you really feel a patient

NOTE Confidence: 0.843030876

01:10:00.556 --> 01:10:02.597 suffering is not being properly addressed.

NOTE Confidence: 0.843030876

01:10:02.600 --> 01:10:04.480 I would hope that you could take it

NOTE Confidence: 0.843030876

01:10:04.480 --> 01:10:06.660 to the attending but I won't presume

NOTE Confidence: 0.843030876

01:10:06.660 --> 01:10:08.548 that that's always easy but I I think

NOTE Confidence: 0.843030876

01:10:08.548 --> 01:10:09.825 that it's takes a lot of courage more

NOTE Confidence: 0.843030876

01:10:09.825 --> 01:10:11.162 courage than I'm going to have to

NOTE Confidence: 0.843030876

01:10:11.162 --> 01:10:12.703 show because it's easy as I say it's

NOTE Confidence: 0.843030876

01:10:12.703 --> 01:10:14.104 easier once you're old and senior.

NOTE Confidence: 0.843030876

01:10:14.104 --> 01:10:16.948 Just say this. It takes some courage.

NOTE Confidence: 0.843030876

01:10:16.948 --> 01:10:18.401 But that's, you know,
NOTE Confidence: 0.843030876

01:10:18.401 --> 01:10:20.303 that's part of the job too.
NOTE Confidence: 0.843030876

01:10:20.310 --> 01:10:20.519 And,
NOTE Confidence: 0.843030876

01:10:20.519 --> 01:10:22.191 and I would say to find somebody you
NOTE Confidence: 0.843030876

01:10:22.191 --> 01:10:24.085 can trust to say that this is what
NOTE Confidence: 0.843030876

01:10:24.085 --> 01:10:25.655 I'm worried because it might just
NOTE Confidence: 0.843030876

01:10:25.655 --> 01:10:27.030 be the attendings actually seeing
NOTE Confidence: 0.843030876

01:10:27.030 --> 01:10:28.786 things that the student isn't.
NOTE Confidence: 0.843030876

01:10:28.786 --> 01:10:29.590 But no,
NOTE Confidence: 0.843030876

01:10:29.590 --> 01:10:30.886 we're not going to find any of that
NOTE Confidence: 0.843030876

01:10:30.886 --> 01:10:32.366 stuff out of the dialogue doesn't happen.
NOTE Confidence: 0.843030876

01:10:32.370 --> 01:10:33.720 So yeah.
NOTE Confidence: 0.843030876

01:10:33.720 --> 01:10:34.970 So I appreciate the question,
NOTE Confidence: 0.843030876

01:10:34.970 --> 01:10:36.206 appreciate the spirit of the student
NOTE Confidence: 0.843030876

01:10:36.206 --> 01:10:37.370 trying real hard to address.
NOTE Confidence: 0.843030876

01:10:37.370 --> 01:10:39.210 And I also don't want to assume that

NOTE Confidence: 0.843030876

01:10:39.210 --> 01:10:40.603 every attending always wants to do

NOTE Confidence: 0.843030876

01:10:40.603 --> 01:10:42.692 the right thing, no matter what.

NOTE Confidence: 0.843030876

01:10:42.692 --> 01:10:44.588 We get tired too.

NOTE Confidence: 0.843030876

01:10:44.590 --> 01:10:46.529 But I very much appreciate the question.

NOTE Confidence: 0.843030876

01:10:46.530 --> 01:10:48.084 And I have another question for you,

NOTE Confidence: 0.843030876

01:10:48.090 --> 01:10:50.260 my friend. Great.

NOTE Confidence: 0.843030876

01:10:50.260 --> 01:10:51.667 This is from a chaplain who knows.

NOTE Confidence: 0.843030876

01:10:51.670 --> 01:10:53.660 As a pediatric chaplain myself,

NOTE Confidence: 0.843030876

01:10:53.660 --> 01:10:56.060 I have to consistently and gently

NOTE Confidence: 0.843030876

01:10:56.060 --> 01:10:57.660 remind providers that chaplains

NOTE Confidence: 0.843030876

01:10:57.722 --> 01:10:59.917 are attuned to existential and

NOTE Confidence: 0.843030876

01:10:59.917 --> 01:11:00.795 spiritual concerns.

NOTE Confidence: 0.843030876

01:11:00.800 --> 01:11:03.620 Not only quote religious End Quote,

NOTE Confidence: 0.843030876

01:11:03.620 --> 01:11:05.732 we're skilled listeners who are often

NOTE Confidence: 0.843030876

01:11:05.732 --> 01:11:07.864 able to connect with patients and

NOTE Confidence: 0.843030876

01:11:07.864 --> 01:11:10.174 families on a deep level as persons,
NOTE Confidence: 0.843030876

01:11:10.180 --> 01:11:12.772 and who have done a lot of work to
NOTE Confidence: 0.843030876

01:11:12.772 --> 01:11:15.110 understand our own responses to suffering.
NOTE Confidence: 0.843030876

01:11:15.110 --> 01:11:17.410 And integrate them into our
NOTE Confidence: 0.843030876

01:11:17.410 --> 01:11:18.330 everyday practice.
NOTE Confidence: 0.843030876

01:11:18.330 --> 01:11:20.135 I think you're wonderful talk
NOTE Confidence: 0.843030876

01:11:20.135 --> 01:11:21.940 points of the importance of
NOTE Confidence: 0.843030876

01:11:22.010 --> 01:11:24.620 understanding ourselves as caregivers.
NOTE Confidence: 0.760432288

01:11:26.060 --> 01:11:28.280 Beautiful reflection and I'm I'm.
NOTE Confidence: 0.760432288

01:11:28.280 --> 01:11:30.422 I hope those skills are being valued
NOTE Confidence: 0.760432288

01:11:30.422 --> 01:11:32.221 for this particular chaplain and and
NOTE Confidence: 0.760432288

01:11:32.221 --> 01:11:34.132 all those in in our present site.
NOTE Confidence: 0.760432288

01:11:34.140 --> 01:11:35.995 It's it is there is a temptation.
NOTE Confidence: 0.760432288

01:11:36.000 --> 01:11:37.827 I worry at times for some of
NOTE Confidence: 0.760432288

01:11:37.827 --> 01:11:39.770 those quote UN quote soft skills,
NOTE Confidence: 0.760432288

01:11:39.770 --> 01:11:42.212 the more sort of interpersonal or

NOTE Confidence: 0.760432288

01:11:42.212 --> 01:11:44.598 communication based or sort of emotional

NOTE Confidence: 0.760432288

01:11:44.598 --> 01:11:47.326 skills to be devalued in favor of more

NOTE Confidence: 0.760432288

01:11:47.393 --> 01:11:49.799 sort of technical or medical skills.

NOTE Confidence: 0.760432288

01:11:49.800 --> 01:11:51.248 When in fact in many cases at least

NOTE Confidence: 0.760432288

01:11:51.248 --> 01:11:52.798 in I don't know about you mark

NOTE Confidence: 0.760432288

01:11:52.798 --> 01:11:54.523 but in the vast majority of ethics

NOTE Confidence: 0.760432288

01:11:54.523 --> 01:11:56.155 councils tonight that I'm involved in.

NOTE Confidence: 0.760432288

01:11:56.160 --> 01:11:58.210 Where things get really sticky,

NOTE Confidence: 0.760432288

01:11:58.210 --> 01:11:59.698 it's really the communication

NOTE Confidence: 0.760432288

01:11:59.698 --> 01:12:01.558 interpersonal skills that that are

NOTE Confidence: 0.760432288

01:12:01.558 --> 01:12:03.092 most central to the resolution

NOTE Confidence: 0.760432288

01:12:03.092 --> 01:12:05.089 of a case and that's when things

NOTE Confidence: 0.760432288

01:12:05.089 --> 01:12:06.529 go wrong on those fronts.

NOTE Confidence: 0.760432288

01:12:06.530 --> 01:12:07.715 It really doesn't matter how

NOTE Confidence: 0.760432288

01:12:07.715 --> 01:12:08.663 well you practice medicine.

NOTE Confidence: 0.760432288

01:12:08.670 --> 01:12:10.588 Things are just going to get hard.
NOTE Confidence: 0.760432288

01:12:10.590 --> 01:12:11.188 So yeah,
NOTE Confidence: 0.760432288

01:12:11.188 --> 01:12:13.281 beautifully said and I I hope that
NOTE Confidence: 0.760432288

01:12:13.281 --> 01:12:15.106 that Chaplain feels appreciated
NOTE Confidence: 0.760432288

01:12:15.106 --> 01:12:16.570 by their colleagues.
NOTE Confidence: 0.760432288

01:12:16.570 --> 01:12:16.840 I
NOTE Confidence: 0.897347490909091

01:12:16.850 --> 01:12:18.950 hope so too is I can tell you that this job,
NOTE Confidence: 0.897347490909091

01:12:18.950 --> 01:12:20.350 I don't say the names of the question
NOTE Confidence: 0.897347490909091

01:12:20.350 --> 01:12:21.510 is because we're being recorded.
NOTE Confidence: 0.897347490909091

01:12:21.510 --> 01:12:24.018 This particular chaplain is very skilled
NOTE Confidence: 0.897347490909091

01:12:24.018 --> 01:12:27.438 at this and is very much appreciated.
NOTE Confidence: 0.897347490909091

01:12:27.440 --> 01:12:29.426 I think that's it for questions.
NOTE Confidence: 0.897347490909091

01:12:29.430 --> 01:12:32.460 So I'm going to wrap this up in a minute.
NOTE Confidence: 0.897347490909091

01:12:32.460 --> 01:12:34.760 But before I do, Erica,
NOTE Confidence: 0.897347490909091

01:12:34.760 --> 01:12:36.332 based on the conversation that that
NOTE Confidence: 0.897347490909091

01:12:36.332 --> 01:12:38.469 we've had here in the many interesting

NOTE Confidence: 0.897347490909091
01:12:38.469 --> 01:12:40.199 questions and you're terrific talk,
NOTE Confidence: 0.897347490909091
01:12:40.200 --> 01:12:42.612 I wonder if you have any final thoughts or
NOTE Confidence: 0.897347490909091
01:12:42.612 --> 01:12:44.316 suggestions you'd like to leave us with?
NOTE Confidence: 0.885059549130435
01:12:45.180 --> 01:12:47.007 Yeah, you know, I mean this is a really
NOTE Confidence: 0.885059549130435
01:12:47.007 --> 01:12:48.745 nice offer to sort of get to close
NOTE Confidence: 0.885059549130435
01:12:48.745 --> 01:12:50.359 the session with some final thoughts.
NOTE Confidence: 0.885059549130435
01:12:50.360 --> 01:12:51.440 And I think actually my,
NOTE Confidence: 0.885059549130435
01:12:51.440 --> 01:12:53.414 my final thoughts are a little more
NOTE Confidence: 0.885059549130435
01:12:53.414 --> 01:12:55.237 general than the talk that I gave.
NOTE Confidence: 0.885059549130435
01:12:55.240 --> 01:12:56.836 You know, I, I'm an academic.
NOTE Confidence: 0.885059549130435
01:12:56.840 --> 01:12:58.048 I'm not a practitioner.
NOTE Confidence: 0.885059549130435
01:12:58.048 --> 01:12:59.256 I'm not a clinician.
NOTE Confidence: 0.885059549130435
01:12:59.260 --> 01:13:02.522 And so I have the sort of liberty and
NOTE Confidence: 0.885059549130435
01:13:02.522 --> 01:13:05.810 privilege to and luxury to sort of from,
NOTE Confidence: 0.885059549130435
01:13:05.810 --> 01:13:07.442 you know, my cozy academic office
NOTE Confidence: 0.885059549130435

01:13:07.442 --> 01:13:09.078 to think about these questions and

NOTE Confidence: 0.885059549130435

01:13:09.078 --> 01:13:11.054 sort of give advice to those of you

NOTE Confidence: 0.885059549130435

01:13:11.105 --> 01:13:12.820 on the ground doing the hard work.

NOTE Confidence: 0.885059549130435

01:13:12.820 --> 01:13:14.206 And I just want to acknowledge

NOTE Confidence: 0.885059549130435

01:13:14.206 --> 01:13:16.020 that the work is really hard work.

NOTE Confidence: 0.885059549130435

01:13:16.020 --> 01:13:17.917 You know, like the topic that we're

NOTE Confidence: 0.885059549130435

01:13:17.917 --> 01:13:19.665 engaging with today is what do you

NOTE Confidence: 0.885059549130435

01:13:19.665 --> 01:13:20.991 do when you're in the presence

NOTE Confidence: 0.885059549130435

01:13:21.049 --> 01:13:22.429 of a child who is suffering?

NOTE Confidence: 0.885059549130435

01:13:22.430 --> 01:13:24.370 And that's something you experience

NOTE Confidence: 0.885059549130435

01:13:24.370 --> 01:13:26.310 potentially on a daily basis.

NOTE Confidence: 0.885059549130435

01:13:26.310 --> 01:13:28.962 And I just want to affirm

NOTE Confidence: 0.885059549130435

01:13:28.962 --> 01:13:31.290 the importance of that work.

NOTE Confidence: 0.885059549130435

01:13:31.290 --> 01:13:33.218 I hope all of you that do this

NOTE Confidence: 0.885059549130435

01:13:33.218 --> 01:13:34.969 hard work do feel appreciated.

NOTE Confidence: 0.885059549130435

01:13:34.970 --> 01:13:37.328 I, and I also hope you,

NOTE Confidence: 0.885059549130435
01:13:37.330 --> 01:13:38.674 you have resources available to you
NOTE Confidence: 0.885059549130435
01:13:38.674 --> 01:13:40.434 and you can sort of self identify
NOTE Confidence: 0.885059549130435
01:13:40.434 --> 01:13:42.066 when you might need those additional
NOTE Confidence: 0.885059549130435
01:13:42.066 --> 01:13:43.522 resources to make sure that you're
NOTE Confidence: 0.885059549130435
01:13:43.522 --> 01:13:45.322 taking good care of yourself as well.
NOTE Confidence: 0.885059549130435
01:13:45.322 --> 01:13:46.300 I think COVID.
NOTE Confidence: 0.885059549130435
01:13:46.300 --> 01:13:50.578 Sort of expose this real deficit
NOTE Confidence: 0.885059549130435
01:13:50.578 --> 01:13:54.303 in good support models for medical
NOTE Confidence: 0.885059549130435
01:13:54.303 --> 01:13:55.009 nursing professions,
NOTE Confidence: 0.885059549130435
01:13:55.009 --> 01:13:56.421 other ancillary care professionals
NOTE Confidence: 0.885059549130435
01:13:56.421 --> 01:13:58.448 on the ground doing the hard work.
NOTE Confidence: 0.885059549130435
01:13:58.450 --> 01:14:01.213 So my final word is just thank you for
NOTE Confidence: 0.885059549130435
01:14:01.213 --> 01:14:04.458 the job that you do and you're appreciated.
NOTE Confidence: 0.857289813125
01:14:06.050 --> 01:14:07.964 Erica, thank you so much for
NOTE Confidence: 0.857289813125
01:14:07.964 --> 01:14:09.650 for the insightful talk and
NOTE Confidence: 0.857289813125

01:14:09.650 --> 01:14:11.385 for the conversation for your,
NOTE Confidence: 0.857289813125

01:14:11.390 --> 01:14:13.470 your responses to the question.
NOTE Confidence: 0.857289813125

01:14:13.470 --> 01:14:15.906 This has been a wonderful evening.
NOTE Confidence: 0.857289813125

01:14:15.910 --> 01:14:17.198 I look forward to hosting you in New
NOTE Confidence: 0.857289813125

01:14:17.198 --> 01:14:19.258 Haven in person, somewhere down the road.
NOTE Confidence: 0.857289813125

01:14:19.258 --> 01:14:21.998 In the meantime, there's a Yale baseball
NOTE Confidence: 0.857289813125

01:14:21.998 --> 01:14:25.246 cap in your future and we will be in touch.
NOTE Confidence: 0.857289813125

01:14:25.250 --> 01:14:27.248 And I thank you so much for coming here.
NOTE Confidence: 0.857289813125

01:14:27.250 --> 01:14:28.648 I thank you folks very much.
NOTE Confidence: 0.857289813125

01:14:28.650 --> 01:14:31.594 We'll be back in another week with our
NOTE Confidence: 0.857289813125

01:14:31.594 --> 01:14:33.914 next seminar which we'll which you'll
NOTE Confidence: 0.857289813125

01:14:33.914 --> 01:14:36.290 get a mailing about again tomorrow.
NOTE Confidence: 0.857289813125

01:14:36.290 --> 01:14:37.325 But for tonight,
NOTE Confidence: 0.857289813125

01:14:37.325 --> 01:14:39.395 this has been a terrific evening.
NOTE Confidence: 0.857289813125

01:14:39.400 --> 01:14:40.213 Doctor Erica Salter,
NOTE Confidence: 0.857289813125

01:14:40.213 --> 01:14:42.430 thank you very much and have a great

NOTE Confidence: 0.968593888

01:14:42.440 --> 01:14:46.000 evening. Thank you so much. Thanks folks.